The *Olmstead* Decision and Long-Term Care in California: Lessons on Services, Access, and Costs from Colorado, Washington, and Wisconsin

December 2003

Prepared for the California HealthCare Foundation by

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ISBN 1-932064-59-1

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Executive Summary

California's long-term care system has distinct strong points but even more glaring problems. Areas of strength—most notably, universal access to mental retardation or developmental disabilities (MR/DD) services and a large and generous entitlement to personal assistance provided through the In-Home Supportive Services (IHSS) program—deserve national recognition. But areas of weakness—including the paucity of alternatives to nursing homes for people who need more than part-time unskilled personal assistance, poor intensive community mental health services in much of the state, administrative fragmentation, and the unnecessary and ad hoc reliance on nursing homes as sites of care for relatively highly functioning people—are dramatic and long-festering.

More specifically, the most pressing long-term care policy problems in California are the following:

- ***Lack of Intensive Community Services and Residential Options for Frail Elders and People with Serious Physical Disabilities.*** With the exception of a small case management program run by the California Department of Aging and two miniscule programs run by the California Department of Health Services, Californians with intense physical assistance and related needs have a choice between the In-Home Supportive Services program and the nursing home. However, there is a crucial middle range of more intensive home and community-based services that are not currently available through IHSS—a program that funds unskilled personal assistance. *IHSS is not a realistic alternative to the nursing home for many people who could potentially live in the community at modest cost—it lacks the skilled in-home care, training and therapeutic services, professional service coordinators, and availability of assisted living and other homelike residential alternatives that many disabled people with more intensive needs require to stay out of nursing homes.* Given California's current fiscal circumstances, tighter screening of nursing home admissions should be at the foundation of a reformed long-term care system. Freeing up some of the resources currently spent on nursing homes would make a more comprehensive home and community-based service (HCBS) system possible. California could learn from other states

how to use its existing resources to fund the more expansive service package needed to provide real alternatives to nursing home services.

- ***Lack of Intensive Outpatient and Community Mental Illness Treatment.*** California's county-run mental health system has sharply reduced utilization of state psychiatric hospitals in recent years. But, as alternatives to mental hospitals, most areas of California have either nursing homes or nursing home-based facilities, many of which are outside the county-run behavioral managed care system, or group homes with limited mental illness treatment. *Most of the state lacks the short-term crisis treatment and long-term intensive mobile treatment teams that have proven effective in other states.* Discharges from psychiatric hospitalizations in much of California are likely to lead to spells in homeless shelters, nursing homes, or jails rather than to a set of outpatient services and supports or an affordable housing arrangement. With the growth of integrated adult and child system-of-care programs and the pilot of an assertive mental illness treatment program for homeless individuals, California is working toward a stronger mental health system; but, these still-modest steps have barely survived the state's fiscal crisis and will continue to be at risk.
- ***Lack of a Substantial Housing Component to Disabilities Services.*** Stakeholders in California's administration, legislature, and advocacy community all emphasize the central importance of adding housing to the mix of supports and services offered to individuals with severe mental illnesses. The housing problem is a major driver of California's and other states' reliance on group homes and other congregate facilities as sites of care for the mentally ill. Whether or not they offer strong mental illness services, these facilities offer relatively low cost housing. Colorado has demonstrated another means of achieving the goal of integrating housing supports with mental illness services using federal housing vouchers. Senior mental health administrators in California have expressed skepticism about using this approach to serve people with mental illness, noting that landlords do not want tenants who are difficult to deal with; yet, Colorado has overcome this obstacle. One senior administrator in Colorado noted that an appropriately structured program can surmount the particular challenges of placing people with mental illness. The Colorado program works with a variety of special housing types—including group homes, single room occupancy (SRO) facilities, live-in aide and rent-from-relative arrangements—and it allows people with mental or cognitive impairments to fail in one or more apartments and remain in the program. A pilot program in California that similarly linked rental assistance to services was eliminated in 2002.
- ***Fragmented State Administrative Structure.*** Long-term care programs in California, particularly those programs directed at people who need physical assistance, are divided among multiple state departments. Most long-term care programs are run by one of the departments California's huge Health and Human Services Agency (CHHSA). California has stand-alone departments for developmental disabilities services and mental illness services—a set-up common in other states. (Wisconsin is the only state that has integrated various long-term care departments into one department, called the "Division of Supportive Living.") But California's fragmentation of departments, with its various programs delivering or coordinating physical assistance services, is particularly striking. Most states have not gone as far as the most aggressive integrators (including Wisconsin, Washington, and Colorado), which have placed nursing home and HCBS administration into one department. But California, in allowing its largest HCBS program, IHSS, to remain separate

from other long-term care programs in other agencies, has allowed a particularly significant level of administrative balkanization to persist.

California has some wonderful home and community-based care programs in place. Yet, California has for too long accepted the administrative fragmentation at the state level; misconceived incentives placed on county and regional agencies; failure to link housing policy to disabilities services; and, most importantly, gaps in intensive services for mental illness and for personal assistance. In most cases, the state could address these problems by redirecting resources currently spent on institutional care or by drawing down federal Medicaid dollars more effectively, rather than by increasing state spending.

I. Introduction

A. Context: The *Olmstead* Decision

On June 22, 1999, the U.S. Supreme Court decided in *Olmstead v. L.C.* that confining persons with disabilities in institutions without adequate medical reasons is a form of discrimination that violates the Americans with Disabilities Act (ADA) of 1990. The court held that states are required to make reasonable modifications to their programs and policies to avoid unnecessary institutionalization.

The case dealt directly with two individuals with mental illness and mental retardation. But, in holding that institutionalization can be a form of illegal discrimination against persons with disabilities, the court actually addressed the care of millions of Americans with physical and mental disabilities both in and out institutions, including large numbers of elderly people with age-related disabilities. In *Olmstead*, the Supreme Court held that states cannot make institutionalization a condition for publicly funded health coverage unless it is clinically mandated. Instead, states must direct their health programs for persons with disabilities to provide community-based care, with institutionalization requiring a burden of proof on states to show why community care is not appropriate.

While the remedy that the court mandated in *Olmstead* is unclear in its scope, subsequent litigation is making clearer what states are legally bound to do. A recent lower court decision in Maryland is the most important test of what federal courts will actually require of states under *Olmstead*. The state of Maryland was found to meet *Olmstead*'s requirements because it is making steady, incremental progress in expanding home and community-based long-term care services and because its process for allocating those services is relatively fair and transparent.

In pushing states to shift resources out of institutions and nursing homes and into home care and smaller, community-based residential sites of care, the *Olmstead* decision will not force a complete change in direction for state policy. Rather, it is likely to require accelerated change in a direction that most states have been moving. The *Olmstead* decision will require California and other states to expand their home and community service programs for people with disabilities, especially for people with more intensive needs than community-based services have provided for in the past.

B. Purpose and Methods

This report seeks to analyze critical issues for California in responding to the U.S. Supreme Court's mandate to expand home and community-based services in the *Olmstead* decision. By examining best practices, innovations, and barriers to providing high-quality, cost-effective community services to persons with disabilities in California and three other states with particularly innovative long-term care systems (Colorado, Washington, and Wisconsin), issue areas were identified. These issues are representative of the similar problems being confronted by California and many other states as they determine how to structure disability services in reaction to the *Olmstead* decision. The states were chosen for study for two reasons: (1) because of their demonstrated success in limiting institutionalization; and (2) because they appeared to operate their home and community-based programs in ways that are likely to have important lessons for California. For example, Colorado and Washington have effectively reduced institutionalization and shifted resources into home and community-based services while holding down growth in overall long-term care expenditures.[1] Wisconsin was of particular interest because of its intensive community-based mental health system, which is administered through a state-county partnership. All three states also provide a mix of residential options and supportive services in addition to personal assistance for people with physical disabilities—a model that is different from California's.

Findings were derived from three sources: (1) extensive documentary research; (2) on-site interviews with dozens of state officials, advocates, academic experts, and consumers in each of the four states; and (3) interviews with national experts on long-term care policy and services provided to people with disabilities.

While rich and comprehensive sources of both quantitative and qualitative information were found on California's existing long-term care programs, almost no hard data was uncovered that explained levels of unmet need in California. As a result, many of the judgments made in this report about the impact of the gaps in California long-term care are, of necessity, based on inference rather than on direct data gathering. As an important first step in *Olmstead* planning, California should identify the gaps in community resources with a comprehensive needs assessment. According to experts in disabilities law, the notion that such a needs assessment poses legal risks is largely a myth. Moreover, policymakers in many states knowingly hide behind this belief as a way to avoid the politically powerful revelations such a needs assessment might produce.

Thus far, California's formal process to develop a response to the *Olmstead* decision has avoided both quantitative analysis and detailed policy recommendations. Following on a mandate from the California Legislature for the state to write an Olmstead Plan by April 2003, *Olmstead* planning became the responsibility of California's Long Term Care Council—a body within the Health and Human Services Agency that includes the directors of nine different state departments. The council convened a series of public forums and workgroup meetings that drew consumers, care workers, advocates, and other stakeholders. However, the comments received at these forums are a source of qualitative and anecdotal information rather than a substitute for a more rigorous needs assessment. Indeed, the state Olmstead Plan that was released in May 2003 committed California to a more data-driven quantitative analysis.[2] This was one of the few

concrete commitments made in the California Olmstead Plan; the remainder of the plan is almost entirely composed of promises to conduct further reviews and to write more planning documents.

C. Categorizing People with Disabilities

The analysis for this report has been divided according to three broad categories of people with disabilities: (1) frail elders and people with physical disabilities; (2) people with mental illnesses; and (3) people with mental retardation or developmental disabilities. The categories of frail elderly/physically disabled, mentally ill, and mentally retarded/developmentally disabled (MR/DD) are used in this report for their policy relevance rather than for their descriptive value. (Among other descriptive limitations, the first category includes two dramatically different subgroups.) As detailed below, the policy agenda in long-term care for each of these populations is distinctive and generally implicates separate state bureaucracies, different types of long-term care providers, and a particular set of choices between service types.

II. The Policy Context for Home and Community-Based Services

A. People with Physical Disabilities and the Frail Elderly

Policy debates about home care and other community-based long-term care for the elderly and physically disabled often center on alternatives to nursing homes. Nursing homes are enormously expensive for Medicaid programs, and they are often dreaded by seniors and strongly resisted by younger people in need of physical assistance. These realities make the prospect of offering alternative care at home or in a homelike environment appealing both financially and morally. However, providing large-scale substitutes for nursing home care has proven difficult. Particularly challenging are efforts to provide home or community care for people with dementia or with incontinence, as these individuals need virtually 24-hour care and/or supervision.

Rigorous efforts to see if established state home and community-based care programs reduce nursing home utilization have had confusing results. Controlled studies repeatedly show no substantial reductions, while several recent real-world programs show positive results—at least when operated in specific ways.[3] (Research for this report in Colorado and Washington confirms the positive real-world studies.) There has also been increasing debate over whether cost savings is the right criterion for evaluating the effectiveness of home and community-based services—a debate that has taken different forms for younger people with physical disabilities and for the elderly. Rather than seeing home and community-based services for the elderly as an alternative to nursing homes that performs a similar function of assisting with basic life activities and maintaining function, some are calling for an understanding of HCBS for the elderly as a parallel system to nursing homes that provides different goods. They argue that HCBS is promoting the fullest possible participation in society and ensuring a high quality of life, despite physical or cognitive disabilities.[4] In contrast, this understanding of home and community-based services as a system that provides different goods has already been established in disability policy for the nonelderly with physical or cognitive impairments.[5]

While nursing homes remain ubiquitous and still dominate long-term care for the elderly in most states, the importance of institutional care for people with mental retardation and mental illness has been drastically reduced since the 1970s. Censuses at state mental institutions and MR/DD institutions have dropped by multiple orders of magnitude. But the outcomes of deinstitutionalization have been starkly different for the mentally ill and mentally retarded.

B. People with Severe Mental Illnesses

The central policy problem for people with severe mental illnesses is the lack of intensive community services in most of the United States. This is partly the result of Medicaid rules, as Medicaid has emerged as the primary vehicle for delivering publicly funded long-term care. Medicaid is similarly the largest source of funding for treating mental illness.[6] Yet, Medicaid has always excluded coverage for those aged 22 to 64 in psychiatric institutions, with the intent of allowing those facilities to remain a state responsibility and encouraging the treatment of the mentally ill in the community. This coverage exclusion has the consequence of making it difficult to create flexible Medicaid waivers for adults with mental illness. Yet, as this report will discuss, this problem is not insurmountable. For example, Wisconsin has created an effective, flexible Medicaid mental illness system without such a waiver.

The goal of moving the treatment of mental illness out of state mental institutions has clearly been achieved. The last 40 years have seen a massive and continuing deinstitutionalization of people with mental illnesses. Nationally, the number of people in state psychiatric hospitals went from 559,000 in 1955 to 71,000 in 1994 to fewer than 60,000 in 1999—a tiny percentage of those with mental illnesses.[7] But this drop in the number of people in psychiatric hospitals is only part of the story. Congregate care of the mentally ill has shifted to a major extent into Medicaid-eligible nursing homes or small, private community homes—such as board and care facilities and group homes—for long stays, and into psychiatric units of general hospitals for short stays. The number of inpatient admissions to small, private psychiatric homes quadrupled between 1970 and 1992, and the number of hospital psychiatric units grew two and half times in the same period.[8]

These facilities may have trouble treating those with the most serious mental illnesses—people who need a high degree of

Medicaid Home and Community-Based Waivers

Under Section 1915(c) of the Social Security Act, which was first enacted in 1981, states have the option of supplying a broad range of home and community-based services to beneficiaries who would otherwise require institutional care in a hospital, nursing home, or intermediate care facility for the mentally retarded. In addition to those services customarily covered under Medicaid, states may, under Home and Community-Based Service Waivers, cover case management, homemaker/home health aide assistance, personal care, habilitation, respite care, partial hospitalization, and a range of other services. States operating HCBS Waivers are permitted to limit enrollment, eligibility, and geographic coverage in ways that are not normally permissible under Medicaid rules.

By regulation, the federal government has always required that total Medicaid costs for beneficiaries enrolled in any particular HCBS Waiver not exceed the costs of institutional care for a comparable population. However, such "budget neutrality" is defined in the aggregate on an annual basis, rather than on a case-by-case level.

Nationally, roughly 500,000 Medicaid beneficiaries are receiving HCBS Waiver services at any given time. While 1915(c) was originally intended to focus largely on the elderly, the mentally retarded/developmentally disabled constitute a substantial majority of all recipients of waiver services both nationally and in most states.

supervision to keep themselves and others safe and to make pharmaceutical and other treatment effective. Behavioral managed care, both in and out of Medicaid, has exacerbated those difficulties by reducing hospital lengths of stay and excluding community support services.[9] Such individuals can bounce from the community to the hospital emergency room to day treatment or small board and care homes, as they are frequently dependent on the coverage limitations and decisions of their insurer (whether private, Medicaid, or a Medicaid managed care company). Lengths of stay are much shorter in community homes, hospitals, and nursing homes than they once were in mental institutions—a seemingly positive outcome and certainly one consistent with the *Olmstead* decision. But mentally ill individuals who would have once been confined to institutions are now ending up addicted to drugs, homeless, in prison, or victims of suicide. This reality is a visible and well-chronicled consequence of deinstitutionalization, particularly in California.[10]

C. People with Mental Retardation or Developmental Disabilities

Deinstitutionalization has been a considerably less ambiguous success story for people with mental retardation or developmental disabilities. As with state mental institutions, the number of large state institutions for the developmentally disabled has shrunk drastically. For example, in 1977, 54,000 people 21 and younger resided in such institutions nationally, while in 1998, that number was less than 3,000. In contrast with mental illness services, substantial and effective systems of community-based care for people with MR/DD have been established in many states, primarily using Medicaid HCBS Waivers. Notably, the MR/DD population tends to enter care younger and have much more effective advocates than the mentally ill population. Although both long-term care MR/DD programs and per-enrollee budgets within those programs tend to be strong relative to programs for other disabled populations, they also continue to be the object of relatively more intense lobbying and *Olmstead* litigation. Although the number of institutions for people with MR/DD has been shrinking, families of the remaining residents in large institutions have often objected to transferring their family members out; these family members have also been strong supporters of keeping the MR/DD institutions at their current capacity.

Many states, including California, have seen explosive growth in recent years in the demand and spending for long-term MR/DD services. This growth is somewhat mysterious, but is in part being driven by medical advances improving the survival rates of children born in clinical distress; it is also likely the result of the controversial but unquestionable increases in the prevalence of autism. A major policy agenda for many states, including California, is containing this growth and finding a way to allocate MR/DD services fairly and adequately without generating arbitrary decisions or waiting lists. This agenda is particularly pressing in California because the state gives residents a universal entitlement to MR/DD services, regardless of income—an entitlement that is unique in the United States.

III. California's Long-Term Care System: Description and Recommendations

A. Services for People with Physical Disabilities and the Frail Elderly

1. California's Programs and Services

California's long-term care system for both seniors and younger people who need physical assistance is almost totally dominated by nursing homes and an unskilled, consumer-directed home care program called In-Home Supportive Services.

a. In-Home Supportive Services

The In-Home Supportive Services program is the largest state home and community-based service program in the country, serving 250,000 people of all ages. Because IHSS is part of California's Medicaid "state plan"—that is, part of the regular package of Medicaid benefits rather than a separate HCBS Waiver program—it is an entitlement for people with Medicaid.[11] Many other states have enhanced home and community-based services that are available to only those enrolled in a waiver. These services may be capped at a certain number of enrollees, with a consequent waiting list, or controlled through the use of special eligibility rules. On the other hand, while most states do offer a Medicaid benefit with the same statutory title as IHSS ("personal care"), California's benefit is much more extensive, allowing up to 283 hours a month in personal assistance and averaging approximately 80 hours a month for each client. Other states offer a fraction of those hours in their state plan personal care benefit. In addition, California has been a pioneer in "consumer-directed services" through the IHSS program, allowing consumers to hire, train, direct, and fire their own assistants.

Nevertheless, IHSS is not a realistic alternative to the nursing home for many people who could potentially live in the community at modest cost. With some small exceptions, people with intense physical assistance and related needs in California can choose only between the IHSS program and a nursing home. This choice is a stark one. IHSS, for all its considerable merits, is a program that allows people to hire relatives, friends, or unskilled paraprofessionals to help them with daily activities with which they need assistance. IHSS does not provide any skilled in-home

care, training and therapeutic services, professional service coordinators, or assisted living and other homelike residential alternatives that many disabled people with more intensive needs require to stay out of nursing homes. Furthermore, IHSS is limited to part-time in-home care.[12] Services needed on more than a part-time basis—including those for people with dementia or with needs for assistance with toileting—generally require admission to a nursing home. States like Washington, Wisconsin, and Colorado offer other choices for people with more intensive needs, including small family-run homes and more sophisticated and creative in-home arrangements.

Disabilities advocates in California are also particularly concerned that IHSS does not provide Medi-Cal funding for case management. Counties either fund case management themselves or, much more frequently, do not fund it at all. IHSS clients receive funding allocations from county managers, who vary widely in their qualifications. In many counties, these allocations are set by nonprofessional county welfare staffers. Because IHSS is limited in what it provides, the lack of coordination of other services is even more important. Although targeted case management is a Medicaid state plan benefit in California, most services provided under that benefit are for developmentally disabled clients.

b. Multipurpose Senior Services Program

Currently, the way for IHSS clients to receive care management (and, in some cases, more hours of personal care than IHSS provides) is through an HCBS Waiver program for the elderly called the Multipurpose Senior Services Program (MSSP). MSSP is administered by the California Department of Aging (CDA) through a variety of local contractors and is effectively an enhanced program of grants to local nonprofit agencies, Area Agencies on Aging (AAA), or county social services departments for case management of frail elderly clients. The main service enhancement is a modest budget available to local contractors for purchasing services directly. Most clients are IHSS recipients, either before they get to MSSP or through the efforts of MSSP agencies. While case management dominates MSSP expenditures, MSSP purchases some services for clients when necessary, including respite services, broad and flexible gap-filling spending, and supplementary IHSS personal care services when counties limit IHSS clients to an inadequate number of hours per month. But, although the MSSP program has grown gradually over the last three years, it is not a large program. California allocates approximately 10,000 slots among 41 local sites throughout the state, and almost all sites operate some sort of a waiting list, with slots assigned according to need. Spending is relatively modest as well. The average per-client budget is approximately $3,800, but most contracted agencies supplement this amount with their own funds. About one-half to three-quarters of that budget goes to case management and administration, with the remainder available for purchase of services.

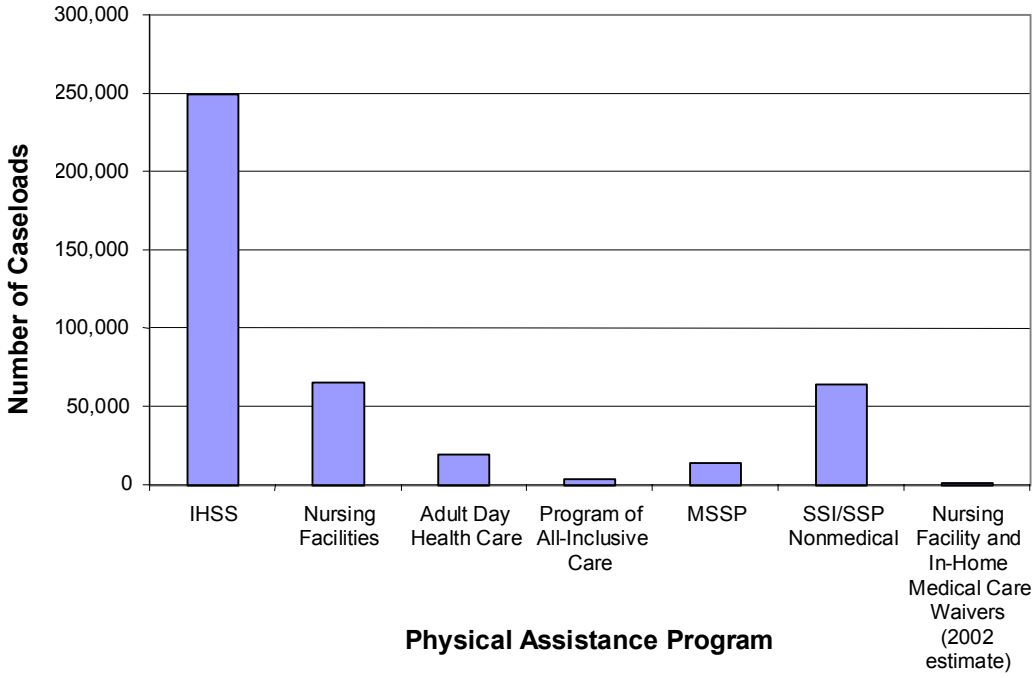
c. Other Home-Based Services

There are two existing options for Californians who need more skilled nursing and medical services in the home. The first option is California's Medicaid home health care benefit. The benefit has a relatively limited impact, with only 0.6 percent of elderly California Medi-Cal beneficiaries making use of the home health service. This represents one of the lowest percentages in the country, and costs per participant are unusually low as well. Even more

limited in their effect are three Medicaid HCBS Waivers operated by the California Department of Health Services (DHS): (1) the Nursing Facility Level A and B Waiver; (2) the Nursing Facility Subacute Waiver; and (3) the In-Home Medical Care Waiver. Each of the titles of these waivers corresponds to one of the four levels of nursing facility care and reimbursement in California. These facilities provide skilled nursing, including private duty nursing, and other medical services at home as alternatives to nursing homes. Waiver clients have intense neuromuscular impairment and medical needs, and more than half are on ventilators and/or have feeding tubes. Notably, however, these waivers were recently cut back to require each individual enrollee budget to be less than nursing facility costs, rather than merely requiring budget neutrality in aggregate waiver costs. State administrators expect this change to shift services from skilled nursing to more unskilled personal care. In addition, these waivers are very small—capped at 1,300 slots for beneficiaries combined. Approximately 1,000 clients were enrolled as of late 2002. Mainly because of their size, these waivers are niche programs and are not significant factors in California long-term care policy.

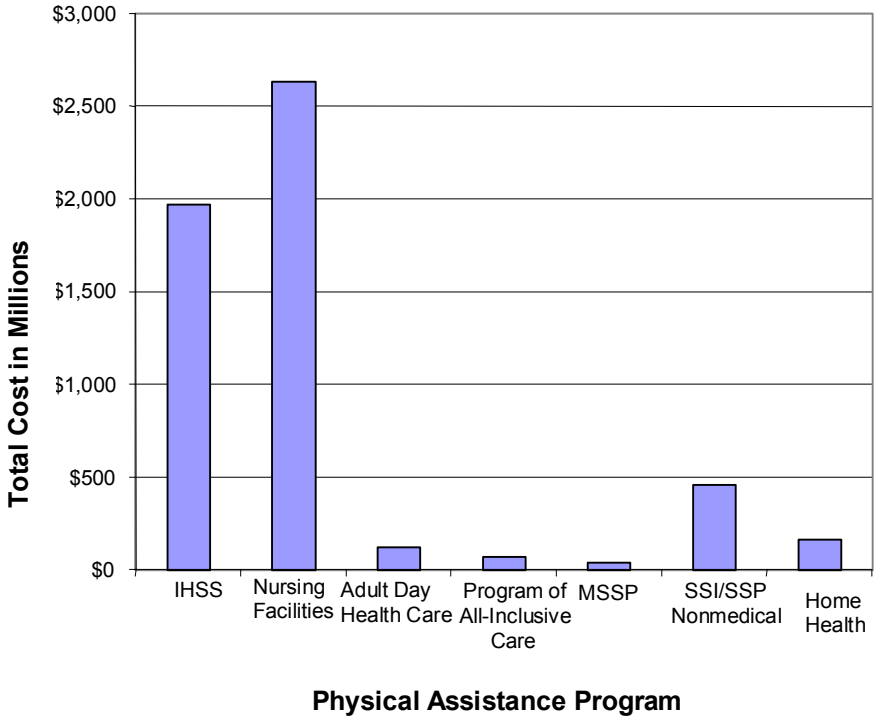
Indeed, knowledgeable nongovernmental observers see little or no impact from California's four HCBS Waivers for the elderly and physically disabled. In addition to the waivers' small size, these observers decry separate data systems for programs run by various departments, minimal outreach for the waivers, and a poorly defined and largely nonpublic enrollment and screening process.

Figure 1. Caseload for Physical Assistance Programs in California, 2000-01



Sources: California Legislative Analyst's Office, 2001-02 Analysis; California Department of Health Services.

Figure 2. Total Coast for Physical Assistance Programs in California, 2000-01



Sources: California Legislative Analyst's Office, 2001-02 Analysis; California Department of Health Services.

d. Residential Care Facilities and Assisted Living

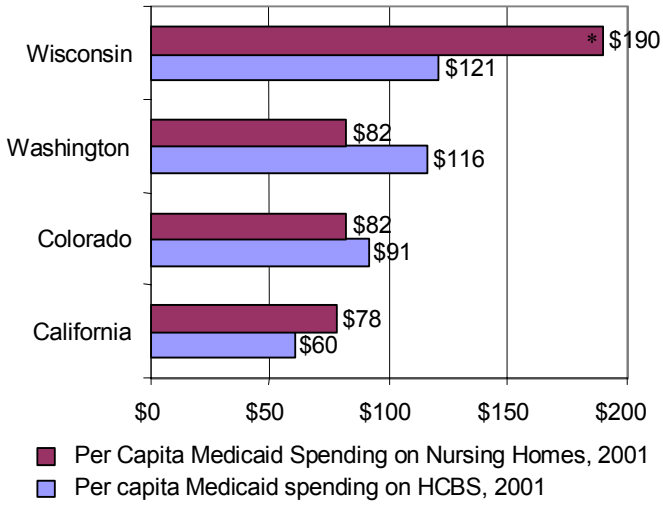
California has approximately 25,000 licensed residential care facilities of various types, with over 225,000 residents. While about one-quarter of these are designated "Residential Care Facilities for the Elderly," most facilities are without the private rooms and personal assistance that characterize assisted living. The only state payment to residential facilities comes through state supplements to SSI payments, used by some 64,000 Californians. While SSI supplementation is an important source of both income support and expanded Medicaid eligibility for many people with disabilities, the supplement cannot fund the level of residential services that can normally substitute for a nursing home. SSI and state supplementation combined amounts to approximately $10,000 annually, which is not enough in most of California to cover the cost of more than minimal services in a facility with relatively nonprivate living arrangements, often described as group homes. (The only exception is for individuals with developmental disabilities, who can and do receive both SSI supplementation and HCBS Waiver reimbursement for residential care in group homes and assisted living facilities. County mental health departments also make extensive use of a variety of group homes, but not generally through Medicaid.) Assisting living as such, according to knowledgeable observers, is a resource largely restricted to those paying privately. Assisted living is not a Medi-Cal-reimbursable service in California, unlike some other states. Furthermore, California licensing allows no medical care in residential facilities (including both group homes and assisted living facilities). As a result, people who need only minor medical management must go to nursing homes.

(California has applied for a small Medi-Cal residential facility pilot Medicaid waiver, and although it was not funded, the state plans to go forward with it.)

e. Nursing Homes

There were 65,000 Medi-Cal nursing home residents in the 2000-01 fiscal year.[13] This is not a particularly large number by national standards. As a percentage of people over 65, it is well below the national average and less than the nursing home populations in Colorado, Wisconsin, and Washington.[14] But, unlike Colorado and Washington, California still spends more, by a wide margin, on nursing homes than on home and community-based services for those who need physical assistance. Medi-Cal fee-for-service (FFS) nursing home costs were $2.6 billion in 2001 versus approximately $2 billion for IHSS and other programs for the aged and physically disabled.[15] As with Medi-Cal provider rates in general, nursing home rates are low in California, so greater nursing home spending in California is not simply a matter of higher reimbursement rates. IHSS and nursing homes dominate the long-term care landscape. The only other significant funding in 2001 for people with physical assistance needs was $450 million in SSI supplements for people in residential placements. IHSS and FFS nursing home payments comprise a majority of *all* California long-term care spending, including spending on MR/DD and mental illness services.

Figure 3. Per Capita Medicaid Spending on Nursing Homes Versus HCBS, 2001



Sources: California Senate Health and Human Services Committee, 2001-2002 Budget Analysis; Colorado Joint Budget Committee, Fiscal Year 2002-03 Appropriations Report; Washington Department of Social and Health Services, Aging and Adult Services Administration, "2001-2003 Biennium Funding", September 25, 2002; Wisconsin Legislative Fiscal Bureau, Community-Based Long-Term Care Programs, Informational Paper #49, January 2001.

California is not aggressive about screening for nursing home eligibility. According to knowledgeable observers, California currently fulfills the minimal federal regulatory requirement for nursing home screening, which is done by the county Medicaid offices, using a short and perfunctory form. California has performed the federally required PASSR screening for mental retardation and mental illness on admission to nursing homes, but only as a result of a lawsuit settlement.[16] Moreover, there has been little movement toward tighter nursing home screening or assessment of current nursing home residents for transfer to the community. What movement has

taken place has been small-scale, halting, and focused on pilots and demonstrations, rather than broader policy change.

2. Comparison to Colorado, Washington, and Wisconsin

As described in detail below, the lack of intensive community-based services in California represents a dramatic contrast from all three states examined for this report—Colorado, Washington, and Wisconsin. Washington has reduced nursing home utilization among both the nonelderly with disabilities and the elderly by substituting community services and diverting nursing home admissions. Colorado's service package offers less home care than California's but makes extensive and well-regarded use of assisted living. Colorado has held down nursing home utilization and restrained costs in its long-term care systems by providing an array of attractive alternative services in the community at very low cost. Wisconsin makes an extensive array of one-on-one services available in the home and elsewhere and has public funding available for homelike residential alternatives to nursing homes, including high-quality alternatives for people with dementia. Wisconsin effectively rations these services in most counties by operating waiting lists for its main HCBS Waiver and has provided these services in a context of high nursing home capacity and utilization.

a. Washington

Washington has liberal home care benefits, and more than half as many Washington Medicaid beneficiaries receive care in adult family homes and in group homes or assisted living centers as in nursing homes. Washington provides this array of options systematically through screening and enrollment at a variety of sites. Washington does not operate waiting lists for its HCBS Waivers (with the exception of its MR/DD Waiver). However, it holds per-enrollee costs relatively low. Home and community-based services provided to people with physical assistance needs currently average approximately $12,000 per year per client, or about 40 percent of nursing home costs. Washington has also explicitly diverted resources from nursing homes into the HCBS system. As a result, it has reduced institutionalization among both the nonelderly with disabilities and the elderly. Observers both in and out of government, including outspoken advocates for the independent living movement, confirm that substitution of home and community-based services for nursing homes is real in Washington. Washington has reduced institutionalization among both the nonelderly with disabilities and the elderly. Washington's nursing home population declined from 17,000 in 1993 to under 13,500 in 2001—a drop of more than 20 percent.[17] California's Medicaid nursing home census fell less than 5 percent in the same period.

In Washington, both home care and residential alternatives to nursing homes are part of a large HCBS Waiver called Community Options Entry System (COPES). There is also a smaller state plan personal care benefit, which includes more intensive services, more restrictive income eligibility (since it lacks the 300 percent of SSI income limit), and a less restrictive functional eligibility standard than the COPES or nursing facility requirements. Washington's home care, both through the COPES Waiver program and the state plan personal care benefit, is mostly consumer-directed, with case management provided by Area Agencies on Aging. Service limits in COPES are 112 hours per month for the more expensive agency providers and 184 hours a

month for independent providers, and nearly 40 percent of COPES clients use more than the 112 hour cap. Washington's personal care benefit has much higher service caps—up to 400 hours per month. The personal care benefit also places a greater emphasis on direct physical assistance, while COPES in-home care is more related to chore services and more instrumental activities. Although Washington's formal hours caps in COPES are lower than those in the IHSS program in California, average utilization appears to be higher. This may be at least in part due to the fact that Washington's home care services are less than half the size of California's, relative to population. Also, as an HCBS Waiver that includes a nursing home level of care requirement, they may serve a more intensive population.

Both Washington's in-home benefits and group residences provide for more intensive services than California's HCBS programs. Washington integrates skilled home nursing services into the COPES home care benefit and has allowed home care aides to perform medical services, such as delivering medications, inserting catheters, and the like, since 1999. The state administration is seeking to expand medicalized in-home services further, proposing to allow in-home nurse delegation at the extensive level permitted in group homes and in assisted living facilities. According to knowledgeable observers, this proposal reflects an increasing change in the medical intensity of home care clients as nursing home utilization is reduced.

Washington also has substantial assisted living, small home, and board and care home services as alternatives to nursing homes. These residential alternatives served nearly 8,000 Medicaid beneficiaries in late 2002, compared to the nearly 13,000 living in nursing homes. Particularly important are small adult family homes with one to six residents. These are homelike environments that, in some cases, are essentially arrangements to share a personal care worker among multiple roommates. State surveys confirm that adult family homes serve the most intensive-needs individuals of the three types of congregate community-based care, and they are widely regarded as a cheap alternative to nursing homes. Adult family homes are paid case-mix and regionally adjusted rates, which ranged from $44 to $78 a day in late 2002, or about 35 to 65 percent of nursing home costs including room and board. Notably, California’s only current funding for group homes, SSI supplementation, pays only about $28 a day. Adult family homes care for approximately 3,150 COPES beneficiaries in Washington.

Larger board and care facilities, averaging 60 residents, house and care for approximately 4,700 COPES beneficiaries. Boarding homes designated as “adult residential care” must be licensed by the state to receive Medicaid clients. However, these facilities have limited requirements in service levels or in living arrangements and may be, in the words of one advocate, serving as homeless shelters for people with mental illnesses. Approximately 1,300 individuals are served in more intensive assisted living arrangements, which are also licensed as boarding home facilities but required to have nursing support, private rooms, and 24-hour staffing. Assisted living facilities were receiving case-mix and regionally adjusted rates of $54 to $81 in late 2002, or 40 to 70 percent of nursing home costs and two to three times California’s SSI payment for residential facility clients.

Unlike the nursing home sector, both boarding homes and adult family homes are mostly private pay in Washington. Medicaid pays for approximately 30 percent of boarding home beds and 30 to 40 percent of adult family home beds, according to senior state administrators. Although there

have been well-documented quality problems both in adult family homes and in group homes, disabilities advocates in Washington feel strongly that they are an important Medicaid benefit and that they need to be reformed rather than eliminated.[18]

Washington does much more than California to divert avoidable nursing home admission, directly limiting nursing home utilization in three ways. First and most importantly, Washington provides options to potential nursing home clients on the front end through an eligibility screening and care planning process. Screening for all long-term care services is managed by local and regional offices throughout the state. Screenings take place both in potential clients' homes and in hospitals and post-acute facilities. Second, Washington has explicitly directed state caseworkers to relocate significant numbers of current nursing home residents to the community on an annual basis since 1995. Nursing home resident relocation is not a boutique program in Washington—it is an important mechanism for financing home and community-based care expansion. Third, the state uses an aggressive certificate of need program and incentives for nursing homes to close unused beds or convert to less congregate assisted living structures as direct inducements to reduce nursing home censuses.[19] As a result, as noted above, Washington's Medicaid nursing home census declined by more than 20 percent between 1993 and 2001.[20]

b. Colorado

Colorado spent 51 percent of its Medicaid long-term care budget on home and community-based services in 2001, while California spent approximately 40 percent.[21] Colorado's service package offers less home care than California's, but it makes extensive use of assisted living, especially for those who require medication oversight and assistance with meals and/or dressing. Assisted living appears to be well regarded by administrators, consumers, advocates, and case managers, and it is still predominantly a private pay industry. Medicaid allows charges of $1,595 a month; $450 is room and board costs covered by patient payments or SSI payments and the remaining amount is Medicaid reimbursable. Assisted living is thus an inexpensive option for Colorado Medicaid that allows the state to maintain below average costs in its HCBS Waiver for the elderly and physically disabled. Senior administrators describe assisted living as the primary service for preventing institutionalization in Colorado and note that, because many people resist assisted living, it self-screens for people at high risk of nursing home admission.

Colorado's eligibility screening for HCBS Waivers has received national attention, but there are major questions regarding the importance of the formal screen, operated by the same single entry point agencies that manage waiver benefits.[22] (These agencies are mostly private nonprofit organizations, county departments of health, or county nursing services.) Some of those who operate the screen downplay the significance of the screening protocol, noting that a capable case manager will work the screen to get someone he or she feels is an appropriate individual onto the waiver. This skepticism about the importance of the enrollment screen seems validated by the controversial phenomenon of individuals (mainly SSI beneficiaries) qualifying for Medicaid through the HCBS Waiver under the 300 percent of SSI income limit solely for the purpose of gaining Medicaid prescription drug coverage. (Colorado does not have Medically Needy eligibility.) Advocates argue that this is a marginal factor in waiver enrollment. Nevertheless, the credibility of this concern indicates that the waiver screen is not nearly as formidable in practice as its national reputation. Nursing homes are also not included in the single entry point system.

To the extent Colorado has restrained costs in its long-term care systems, then, it appears to have been accomplished by providing an array of attractive alternative services very inexpensively in the community, rather than by aggressively seeking to divert nursing home admissions.

c. Wisconsin

Wisconsin makes an unusually wide array of services available to those who need physical assistance in their homes and even in their workplaces or at leisure or recreational activities. Wisconsin also has public funding available for homelike residential alternatives to nursing homes, including high-quality alternatives for people with dementia. But Wisconsin effectively rations these services in most counties by operating waiting lists for its Community Options Program (COP) HCBS Waiver, with significantly skimpier services available to those on the waiting list through regular Medicaid benefits. Moreover, Wisconsin has provided these services in a context of high nursing home capacity and utilization; the services have not been truly tested as workable substitutes for nursing home care on a large scale.

Wisconsin's COP Waiver and its smaller counterpart, the Community Integration Program II (CIP II) Waiver, allow for flexible service packages. Multiple stakeholders interviewed for this report described county case managers as mandated to do "whatever it takes" to serve people in the community and improve their quality of life. Although personal care and case management are the largest items in their budgets, the COP and CIP II Waivers fund a variety of services that traditional personal care does not, including: personal assistance outside the home; in-home oversight and cueing of daily activities, rather than direct physical assistance; psycho-socially oriented services, such as adult day centers and skills training; and adaptive aids. Furthermore, waiver enrollees have better access than regular Medicaid participants to occupational, physical, and psychological therapy because counties generally pay better rates than FFS Medicaid.

The COP and CIP II Waivers also fund a variety of residential options, including adult family homes, group homes of eight beds or less (such as community-based residential facilities, or CBRFs), assisted living facilities, and specialized supported apartments with 24-hour supervision for people with dementia. Twenty-two percent of COP/CIP II participants are in out-of-home placements. Two-thirds of these out-of-home participants are in small group or family homes (such as CBRFs or adult family homes); the rest are in larger assisted living facilities, many of which were converted from nursing homes.[23] These facilities generally offer more intensive services than most licensed group homes in California. Wisconsin also has homelike alternatives for people with incontinence and people with dementia. These facilities are certified and monitored at the counties level. (Counties use contractors for criminal background checks on home operators.) Many people in and out of state government have described the facilities as an inexpensive way to provide intensive services. Group homes (community-based residential facilities) serve either a somewhat more medically intensive or cognitively compromised population. They are small (generally eight beds or less), licensed for 24-hour supervision, and many have some nursing services available. At the high end, the state funds a small number of assisted living facilities that specialize in elderly clients with dementia. These facilities, which can be more expensive than nursing homes, are well regarded even by observers who are otherwise skeptical of assisted living in general.

Advocates for people with disabilities generally see a positive role for these facilities, which are available to those who need more services than they can get at home, agreeing that they provide a higher quality of life than nursing homes and that they substitute for some inappropriate nursing home admissions. A knowledgeable advocate described group homes and larger assisted living facilities as critically important for people who need structured environments, particularly those with dementia or those who have been in institutions for a long time. It is believed that these facilities offer a more productive and more private environment than nursing homes but much better supervision and more programming than an overstretched home care arrangement. According to one county human services administrator, the smaller adult family homes are particularly suitable for people with incontinence, but they are used for that purpose in only some Wisconsin counties. Other roles for the smaller adult family homes include serving the mentally ill and the MR/DD populations. Nevertheless, as with other waiver services, public funding for assisted living and group home residence is rationed in most of Wisconsin through waiting lists. (The primary exception is those counties that have implemented a capitated long-term care pilot program.)

Wisconsin counties also have an almost totally flexible source of funding—state-only COP (COP-R) funds. These are limited in statute to "long-term care support services," but, in practice, the restriction is nominal and funds are notably more open-ended than in California's state-only IHSS funds. Counties use much of these open-ended funds for gap filling. This includes services that are not Medicaid reimbursable, including housing and energy costs and personal assistance by spouses or parents (11 percent of the funding); services to those who are not yet waiver-enrolled, such as those spending down to Medicaid eligibility or those on the wait list (37 percent of the funding); and supplements to state reimbursement rates for waiver services (12 percent of the funding).[24]

Despite all these services, nursing homes are the dominant service type for people who need physical assistance in Wisconsin. According to both advocates and state administrators, Wisconsin built up an unusually large nursing home capacity in the 1960s and 1970s, including a substantial county-owned sector, creating a powerful lobby as well as policy inertia. In fiscal year 2000, institutional costs were more than 62 percent of total long-term care costs. Looking only at programs for the frail elderly and physically disabled, many more people received publicly funded services in nursing homes than in community-based settings or at home in 2001.[25] Wisconsin has almost twice California's level of elderly nursing home residents as a percentage of the elderly population. In addition, in contrast to Wisconsin, there are approximately 68,000 Medicaid nursing facility residents in California, as compared to the 250,000 participants in the In-Home Supportive Services program alone. Wisconsin has been slowly reducing nursing home beds and utilization figures, but multiple stakeholders interviewed for this report noted strong obstacles to more aggressive targeting of nursing home admissions.

As with other HCBS programs in Wisconsin, waiting lists for COP services are extensive—more than 11,000 people were on waiting lists in 2001. The number of people on waiting lists for services went up dramatically during the 1990s, despite significant increases in the number of people receiving waiver services. COP and CIP II Waiver recipients increased from 8,000 in 1990 to more than 16,000 in 1999, while the county waiting lists went from 2,444 to 11,353 in

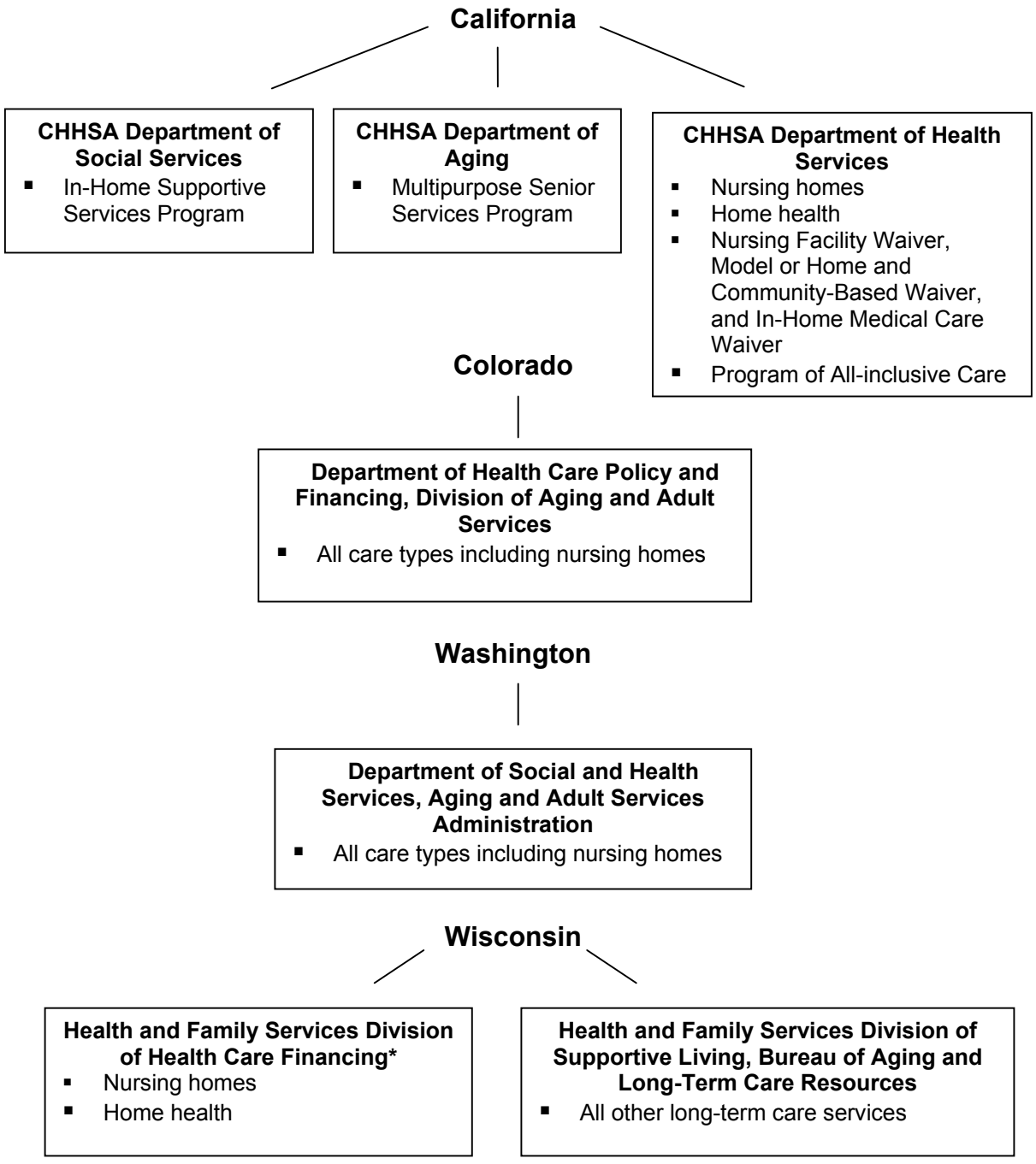
the same period.[26] Because the state maintains little information on these waiting lists and because county operation of them varies, it is hard to generalize about what happens to individuals while they are on waiting lists and how they are selected to move off the waiting lists to become eligible for waiver services. Some counties operate a first-on, first-off system with emergency exceptions, while others rank individuals by their urgency.

The function of waiting lists in Wisconsin is illustrated by a senior state administrator's description of them as a tool for controlling assisted living utilization. The alternative, as she described it, would be to use rate setting, and, ultimately, to lose access to private pay facilities and to have an assisted living market tiered into private and Medicaid sectors. In assisted living, as elsewhere in its HCBS Waiver system, then, Wisconsin has chosen to ration high-cost (and arguably, higher quality) services using waiting lists, rather than to offer lower-cost services as an entitlement. Nursing homes and state plan personal care services in Wisconsin, in contrast, are Medicaid entitlements, with below market rates and lack of access to private pay providers (and, presumably, top quality services).

3. The Issue of Administrative Fragmentation

Departments with programs delivering or coordinating physical assistance services in California are fragmented at the state level more than in most states. This represents a major source of policy inertia both within IHSS and outside of it. The California Department of Health Services is the state agency that administers Medicaid, operates nursing home and home health reimbursement, and operates three tiny HCBS Waivers. The California Department of Social Services operates the largest community long-term care program in California, the In-Home Supportive Services program. The California Department of Aging manages a small parallel program to deliver home-based services to seniors, along with a variety of social service programs for the elderly that provide some long-term care. Most states have not gone as far as the most aggressive integrators (Washington and Colorado), which have placed nursing home and HCBS administration into one department. But California, in allowing its largest HCBS program, IHSS, to remain separate from other long-term care programs in other agencies, has allowed a particularly significant level of administrative balkanization to persist.

Figure 4. Administrative Structure for Long-Term Care for the Elderly and People with Physical Disabilities in California, Colorado, Washington, and Wisconsin



* Wisconsin has implemented managed long-term care in Milwaukee and several other counties, giving counties responsibility for both HCBS and nursing home services.

As multiple observers have noted, the administrative isolation of the IHSS program leads to a lack of responsibility for IHSS within Medi-Cal at the state level. The broader departmental divisions lead to different eligibility levels for various HCBS programs and a lack of information about various programs for beneficiaries, depending on which agency (if any) is their point of contact with the state. Furthermore, almost all HCBS programs are administered separately from the California Department of Health Services, which is the state agency that funds the HCBS programs through Medi-Cal. According to knowledgeable observers both in and out of state government, the separate administration leaves DHS broadly suspicious of nonmedical long-term care services and almost exclusively oriented to cost, rather than to service delivery. Perhaps most importantly, and unlike Washington and Colorado, nursing home budgets are kept separate from HCBS budgets.

At the county level, welfare offices handle IHSS, medical providers are typical entry points to home health and nursing homes, and a variety of local contractors including Area Agencies on Aging (AAA) and county welfare offices run the little-known MSSP program, which is the only formal source of coordination and case management of long-term care program options. Individuals must apply separately at different agency offices to access different programs, rather than accessing them through a central long-term care agency. This limits both the choice among long-term care programs and the opportunity that Medi-Cal applicants have to learn of alternatives to nursing homes.

The most recent of several California initiatives to address administrative fragmentation was the establishment in 2000 of an interagency body called the Long Term Care Council. The council is comprised of the directors of nine departments and agencies with long-term care responsibilities and is intended to increase coordination. No one interviewed for this report in the legislative, advocacy, or research communities—that is, no one outside of the state administration—regards the council as a significant integrative step. While there are some outside observers who see important potential in the formal *Olmstead* planning process the council has undertaken, many feel that the superficial early pronouncements of the council and the lack of detail in the recently released state Olmstead Plan confirm their fears that, as of mid-2003, the *Olmstead* planning process is not intended to be the vehicle for a major administrative reorganization.

4. Recommendations

Recommendation 1: More Intensive Services. California could learn from other states how to use its existing resources to fund a more expansive service package needed to provide real alternatives to nursing home services for those who need more than unskilled, part-time personal assistance. A step toward improved HCBS programs in California is recognizable in the MSSP-enhanced case management waiver described above. Notably, case managers in this waiver have the professional outlook and flexibility that mark HCBS Waivers at their best in Washington, Wisconsin, and Colorado. But MSSP has neither the range of direct service provision nor the scale—its enrollment, as a proportion of the population, is smaller than the enrollment of analogous programs in the three focus states by a factor of five to more than ten.

One option would be to integrate IHSS and other community-based care modalities into an HCBS Waiver, including skilled home care and perhaps homelike residential options such as

adult family homes and assisted living. If administration of such a waiver were placed in the same agency as nursing home screening and reimbursement, California's system would look much more like those in Washington and Colorado, which have shifted resources into home and community-based services more than California has.[27] But such an approach has dangers as well, mainly because of the strengths of IHSS. The IHSS program is very strong politically; it also has the advantage of being a large state plan entitlement with no waiting lists. Many California stakeholders (both in and out of government) prefer to build on IHSS rather than to attempt drastic reconfiguration of California's long-term care provisions with waivers. Still, many of the same stakeholders see an important potential role for expanded waivers as sources of Medicaid funding for case coordination, residential care, and other supplements to the in-home care that will always be the central mission of the IHSS program.

Recommendation 2: Tighter Screening of Nursing Home Admissions. Tighter screening of nursing home admissions should serve as the foundation of a reformed long-term care system in California—particularly given the state's current fiscal circumstances. Freeing up some of the resources currently spent on nursing homes would make a more comprehensive HCBS system possible.

Recommendation 3: Administrative Integration. Long-term care programs in California directed at people who need physical assistance are divided among multiple state departments. California's administrative balkanization keeps the administration of nursing home screening separate from the administration of home care programs and maintains the IHSS program in a separate department from all of the state's health care programs. These administrative barriers contribute directly to California's lack of substantial nursing home screening and to the lack of skilled and medical services available in the IHSS program. California also houses the only program to offer case management and coordination (of the state's various home and community-based services) in different local offices and in a different state department than the programs that it seeks to coordinate. Individuals must apply separately at different agency offices to access different programs, rather than accessing them through a central long-term care agency. This limits both the choice among long-term care programs and the opportunity for Medi-Cal applicants to learn of alternatives to nursing homes.

Recommendation 4: More Flexible Use of State-Only Funds. Wisconsin, like California, has a state-only portion of its largest HCBS program that was "left over" when the program was integrated into Medicaid. But while California has restricted its state-only funds to home care services, Wisconsin, with its case-management-based system, made a portion of such funds available for more flexible gap filling. This includes services that are not Medicaid-reimbursable, including housing and energy costs and personal assistance by spouses or parents, and supplements to state reimbursement rates for waiver services—both of which would be useful additions in California.

B. Services for People with Mental Illnesses

1. Overview

California's county-run mental health system has sharply reduced utilization of state psychiatric hospitals in recent years. A dedicated, off-budget state trust fund for the counties has provided a measure of fiscal stability to county mental health departments that is particularly valuable given the state's current fiscal crisis. But reductions in inpatient usage have been offset substantially by increased utilization of other locked, long-term facilities that share some institutional characteristics.[28] As alternatives to mental hospitals, most areas of California have nursing homes (or nursing home-based facilities)—many of which are outside the county-run behavioral managed care system—or group homes with limited mental illness treatment. Most of the state lacks the short-term crisis treatment and long-term intensive mobile treatment teams ("assertive" or "intensive" community treatment) that have proven effective in other states. Discharges from psychiatric hospitalizations in much of California are likely to lead to spells in homeless shelters, nursing homes, or jails rather than to a set of outpatient services and supports or an affordable housing arrangement. California has started in the direction of a stronger mental health system with the growth of integrated adult and child system of care programs and the pilot of an assertive mental illness treatment program for homeless individuals (AB 2034); but, these still-modest steps are currently at risk as a result of the state's fiscal crisis.

A budgetary reform in California in the early and mid-1990s shifted state dollars and financial responsibility for nonforensic (that is, noncriminal) psychiatric hospitalizations to the counties. Counties now receive a block grant from the state according to a legislated formula, and the counties (county mental health departments, or CMHDs) are now at risk of receiving all outpatient mental health services and inpatient mental health services in psychiatric facilities. But the CMHDs do not pay for care of the mentally ill in nursing homes that keep their mentally ill census under 50 percent to avoid designation as an institution of mental disease (IMD)—in effect, a locked facility that is Medi-Cal eligible and likely to be paid for by the state rather than the counties. In contrast, counties in Wisconsin's county-run system are financially liable not only for admissions to state institutions but also for admissions to nursing homes.

All three focus states have a highly decentralized system for treating mental illness. Wisconsin, like California, relies on counties to operate local systems, while Washington and California capitate regional behavioral managed care entities of varying kinds. Wisconsin has done the best job of combining devolution with effective mandates on local mental health authorities to build intensive outpatient capacity. Colorado, in a system that is similar to California's, with similarly ambiguous outcomes, has differed from California in making substantial (and instructive) use of Section 8 housing vouchers *within* its human services department to build supported housing capacity for the mentally ill.

2. Financing and Administration in California's County-Run Mental Health System

California's counties have historically had a prominent role in community mental health services, with their involvement dating back to the beginnings of large-scale deinstitutionalization in the late 1950s. A budgetary reform in the early 1990s shifted both funding and financial responsibility for psychiatric hospitals more completely to the counties. Counties are now predominantly responsible for administering California's mental health system as a whole.

The key elements of the "realignment" of mental health funding and responsibilities in California passed in the Bronzan-McCorquodale Act of 1991 were to: (1) shift financial responsibility for nonforensic psychiatric hospitalizations to counties from the state; (2) stabilize and even out state mental health grants to counties; and (3) in 1993 and 1995, integrate Medicaid fee-for-service mental health services into county mental health services. As mentioned, counties receive a block grant from the state according to a legislated formula and are at risk receiving all mental health services. California counties manage mental health services under the 1915(b) Medicaid managed care waiver; they also receive state-only funding through a dedicated sales tax and automobile license fee-based account. Nominally, the counties receive a capitated Medicaid payment for Medicaid enrolled clients; effectively, the counties draw down a federal match for whatever portion of the state block grant and/or their own funds they spend on services for Medicaid clients. The state incorporated into its block grants the funding it had previously spent on noncriminal psychiatric hospitalizations.

According to senior state administrators, the state has a limited operational role that includes: advocating for the mental health system in state legislation and with the federal government; providing best practices and technical assistance; providing oversight for Medicaid compliance and quality or licensure regulation; and managing the civil and forensic commitment process in state hospitals. The state mental hospital system continues to be managed by the state, but revenue for nonforensic state mental hospital beds comes from the local mental health programs.

This realignment of revenues succeeded in providing a measure of budgetary stability to the counties. Previously, mental health services represented the largest discretionary item in the state General Fund. As a result, these services have always been vulnerable to budget cutting. Mental health now has a dedicated funding source from sales taxes transferred directly to the counties—off the state budget. Sales taxes were increased to fund the account as part of realignment. But while the sales tax and licensing fee-based mental health trust account has been relatively stable, it has also fallen substantially short of projected revenues.

3. California's Programs and Services

a. Use of Mental Institutions and Locked, Institution-Like Facilities

In terms of its programmatic impact, realignment places clear, intense incentives on counties to reduce the use of state hospitals and institutions of mental disease; however, it frees them from any mandates to have any particular alternative system in place. Consequently, California has shifted people and money out of (non-Medicaid) state psychiatric hospitals. Fewer than 3,600 residents remain in these hospitals (as of 2001)—three-quarters of whom are forensic (criminal). The civilly committed population of state psychiatric hospitals shrank from 1,869 in 1992-93 to 857 in 2000-01.[29] Published research on the systemic impacts of realignment is very broad. For example, a study using administrative data sought to measure the impact of realignment on mental health service access found increased outpatient services; however, inpatient service spending declines strongly exceeded increases in outpatient service spending, indicating some substitution but possibly not enough. The same study showed that counties with particularly high institutional usage before capitation dropped both inpatient and outpatient utilization, clearly indicating absolute service reductions.[30]

A closer look appears to show that reductions in inpatient usage have been offset considerably by increased utilization of other locked, long-term facilities that share some institutional characteristics, including special treatment programs in nursing homes, and, particularly, mental health rehabilitation centers—a new service type legislated in 1995. Special mental illness units in nursing homes had 3,384 beds in 2001, and rehabilitation centers had 1,283 beds, representing a combined increase of almost 1,700 from 1991 to 1992.[31]

Furthermore, the state does not track the numbers of mentally ill individuals in non-IMD-designated nursing homes or in loosely supervised board and care arrangements. As noted earlier in this report, California has weak enforcement of PASSR screening for mental illness in nursing home admissions. Both senior state administrators and knowledgeable nongovernmental observers confirm that a large but unknown number of mentally ill individuals are housed in nursing homes that keep their mentally ill census under 50 percent to avoid IMD designation. In effect, these are locked facilities that are Medi-Cal eligible and may be nonbillable against counties realignment funding. Generic nursing homes lack the state requirements for therapy and other targeted treatments for mental illness that specialized facilities provide. The Laguna Honda nursing home in San Francisco is a particularly large example, with many of its 1,200 residents being housed there primarily because of mental illness.[32]

While state officials acknowledge that some people do languish in nursing homes without rehabilitative services, they maintain that, overall, the county prioritization on shifting beds from state hospitals and traditional IMDs to more specialized nursing home-based facilities for the mentally ill is appropriate, as nursing home-based facilities have a greater focus on community discharge and more case management. State administrators emphasize the Mental Health Rehabilitation Center (MHRC) program (in which most facilities are designated as IMDs), with requirements for intensive support and rehabilitation and with vocational and discharge planning services starting immediately upon admission. This program began in 1995 and had almost 1,300 beds in 2001. Almost all participating beneficiaries are in nursing homes, with the great majority of beds in former nursing home "special treatment units" for the mentally ill that converted to the new designation; therefore, it is unclear how dramatic a departure the MHRC program represents. California also recently initiated an IMD resident transition assessment pilot, but legislative staff described this pilot as both unnecessary and dilatory.

b. Community Services

Observers both in and out of government emphasize that community mental health services, including residential services, are highly variable throughout the state and that it is hard to offer even minimal generalizations about them. One senior state administrator described this as largely a matter of regional and racial disparities: "Place and race matter." The state has documented low utilization rates by Latinos and Asian Americans together with limited services in Spanish, Chinese, and Southeast Asian languages. Problems have also been reported in rural areas because of distance and staffing issues. And service limits have been documented in low-income areas of Los Angeles, San Francisco, Oakland, and San Diego that are driven by the reluctance of many mental health professionals to work in relatively poor, high-crime areas. State requirements for minimum county services are limited, covering inpatient and 24-hour crisis

services, medication, case management, language appropriateness, and "some outpatient capacity"—that is, there are no extensive requirements for outpatient service capacity or mandates for specific programs. More broadly, state monitoring of county mental health capacity is sharply limited in the realigned system.

Still, many nongovernment and legislative observers are harshly critical of the state's community mental health services, noting not only a lack of capacity but also a very high county screen for eligibility for mental health services; both are the result of inadequate funding.[33] The areas of local strength described above are more evident for short-term crisis services in the community, which are strong in some parts of the state but not others. Throughout most of California, however, long-term community services for serious mental illness are weak.

A set of residential alternatives to short- and medium-term psychiatric hospitalizations exists in some counties; these are called either crisis residential facilities (CRFs) or transitional facilities. Unlike the longer term, group home-style facilities, these facilities are Medi-Cal funded and intensively staffed. Many of these facilities are in small, homelike settings dispersed in the community. There are 300 CRF beds and 650 transitional beds in the state, with crisis facilities concentrated in San Diego and the San Francisco Bay Area and transitional facilities found in the Bay Area and, to a lesser extent, Los Angeles. Gaps are apparent in the Los Angeles exurbs and in the Central Valley.[34] Notably, despite complaints about lack of coverage in some areas of the state, Colorado has about six times as many crisis beds and three times as many transitional beds on a per capita basis.[35]

A widespread alternative for long-term care of people with serious mental illness in California are congregate facilities that often have limited services rather than intensive treatment and an orientation toward recovery. California county mental health spending on residential facilities more than doubled from 1991 to 2000.[36] Many counties make heavy use of congregate adult residential facilities or, in small numbers, various other community-based residential facility types, designated as group homes or residential care facilities. These cover a wide variety of facilities ranging from private homes to large, locked facilities that are essentially institutional. According to mental health advocates and researchers, these facilities can play an important role in providing homelike environments for people with mental illnesses who cannot live independently. However, without access to more intensive, recovery-focused therapy, these residential services are sorely inadequate for many people with severe psychiatric needs who could be served better by more recovery-oriented services. Both senior state administrators and knowledgeable nongovernmental observers confirm that a large but unknown number of mentally ill individuals are also housed in generic nursing home beds.

c. AB 2034

California recently expanded an important new initiative to address the problem of urban homelessness and mental illness with the AB 2034 program (named for the assembly bill number), which is a community mental health treatment program. The AB 2034 program is separate not only from Medi-Cal (according to a senior state administrator, it would take four to six months to determine eligibility for homeless individuals for Medicaid), but also from the realignment block grants issued to counties. The state contracts directly with counties for a

specific number of people served, and the contract requires specific outcomes based on pre- and post-measurement. Most notably, the program incentivizes county mental health departments to go out into the streets and enroll homeless people with mental illnesses. The program, which was increased from 3 counties to 32 counties and cities in 2000, served 5,000 people in 2002, and it has achieved and documented dramatic drops in homelessness, hospitalizations, and jail time.[37] State administrators are enthusiastic about the program, noting its single point of accountability, availability of mobile crisis teams, and its involvement of law enforcement and peer counseling. California's pilot Adult System of Care (ASOC) and Child System of Care (CSOC) programs also emphasize coordinated, team-based provision of mental health services in the community.

4. Wisconsin as an Alternative Model

California's pilot programs, which rely heavily on outreach, mobile interdisciplinary teams, and silo-breaking flexibility, bear a strong resemblance to a more extensive mental health system developed in Wisconsin. Wisconsin's system has established intensive community treatment teams in most counties that focus not only on homelessness but also on the much broader seriously mentally ill population. Although Wisconsin is approximately one-fifth California's size, its intensive community treatment program serves the same number of people at about the same cost (total and per person served) as AB 2034 in California. This system has achieved strong results in Wisconsin, although it is now facing fiscal pressure and increasing the use of waiting lists. The strength of the Wisconsin mental health system is strongly endorsed not only by researchers and administrators but also by mental health advocates who might otherwise be expected to be critical of their state's existing services.

The cornerstone of Wisconsin's mental health system is the mandate on counties to establish intensive, team-based community treatment programs. This legislative mandate resulted in Wisconsin's "Community Support Programs" (CSP).[38] To operate a CSP, a team of mental health professionals seeks to treat mental illness by delivering a package of medical and social services, including medications, therapy, substance abuse treatment, employment support, housing, and personal assistance. The critical elements are outreach into the community, flexibility, continuity of caregivers, and the capacity to access and combine medical, therapeutic and social services. For all of these elements, a CSP depends heavily on strong case management and nursing support. A CSP team consists of 10 to 12 members who are on call seven days a week, 24 hours a day, in two shifts. As with Wisconsin's HCBS Waivers for those with personal assistance needs, Community Support Programs establish an ethos of doing "whatever it takes" to keep clients out of institutions or group homes.

Wisconsin mandates CSPs, but counties fund most of the system through Medicaid using state block grants as well as some supplementary state funding. (Most, but not all, Wisconsin counties fulfill this mandate.) Most of these services receive a federal Medicaid match. Of the $49 million in CSP expenditures in 2001, almost $30 million was county and federal Medicaid spending. Of the 88,000 individuals in Wisconsin who were served in the public mental health system in 2000, only 4,900 were using Medicaid-funded CSP services. However, CSP accounts for approximately 30 percent of Wisconsin's Medicaid mental health spending and it is the largest expenditure among the state's mental health granting to counties.

If AB 2034 is converted from a growing pilot program into a mandate on California's counties, the state could take a major step toward achieving a strong and effective mental health system like the one in Wisconsin. California could do this while integrating AB 2034 into Medi-Cal. Currently, California threatens to go in the opposite direction. Wisconsin mandates "assertive community treatment," but counties fund most of the system through Medicaid using state block grants as well as some supplementary state funding. California has initially funded its similar program outside of its regular mental health system; this is a luxury that California may not be able to afford much longer. Governor Gray Davis's 2002-03 budget proposed simply withdrawing the existing funding and leaving counties to fund intensive treatment of the mentally ill homeless through their regular realignment funds, with the opportunity to bill services to Medicaid. The legislature restored funding of $55 million and that funding survived in the 2003 budget. Senior state administrators in California voice concern about "Medicaid addiction," with integration of mental illness services into Medicaid leading to a fee-for-service mentality in which what is reimbursable drives what is offered—excluding extremely cost-effective services like family education and peer support. Furthermore, with many of those receiving services uninsured (50 percent in Los Angeles), channeling services through Medi-Cal could lead to discrimination. Given AB 2034's recent vulnerability, and given California's relatively generous Medicaid eligibility for people with disabilities, a reexamination of the potential for mandating and integrating intensive community treatment into Medicaid seems in order. Wisconsin's experience shows that county administration, Medicaid funding, and state mandates can coexist to build an innovative, recovery-oriented system of community mental illness treatment.

5. Housing and Mental Illness—The Colorado Model

Particularly given high rental and real estate costs in much of California, the nexus of mental illness, poverty, unaffordable urban housing, and homelessness is especially acute. Stakeholders in the state administration, the legislature, and the advocacy community all emphasize the central importance of adding housing to the mix of supports and services offered to individuals with severe mental illnesses. The housing problem is a major driver of California's and other states' reliance on group homes and other congregate facilities as sites of care for the mentally ill. Whether or not they offer strong mental illness services, these facilities provide relatively low cost housing. A small supported housing grant initially administered by the California Department of Mental Health—the Supportive Housing Initiative Act (SHIA)—was widely respected by observers, both in and out of government, as an effort to tie rental assistance in independent housing to mental illness treatment and disabilities services. Yet, this program was first cut back sharply and then eliminated in the 2002 budget negotiations. Senior state administrators were hopeful in the fall of 2002 that the program would be re-funded through the housing bond proposition passed in the 2002 elections, but this did not happen. The housing bond revenues did support significant new grants for development of supportive housing units through the California Department of Housing and Community Development, but these grants are not linked to rental assistance or disabilities services.

Colorado has demonstrated another path toward the goal of integrating housing supports with mental illness services using federal housing vouchers. Colorado's "Supportive Housing and Homeless Programs" (SHHP) section within the Department of Human Services is distinctive in

two ways: (1) it is housed within a disabilities services agency, giving it an exclusive focus on people with disabilities and the capacity for direct collaboration with service provider agencies; and (2) it has used a variety of federal resources to provide Section 8 housing vouchers dedicated to people with disabilities and/or homeless people. In practice, SHHP aggressively pursues federal housing vouchers for the disabled and then uses its contacts with disabilities service providers to serve people with disabilities and link them with supportive services. SHHP does not deliver supportive services itself, and it generally does not operate any buildings or work with specific residential facilities. Rather, it works with disabilities and homelessness service providers to get housing vouchers to their clients. SHHP contracts with independent living centers, regional MR/DD agencies, community mental health centers, and homelessness service providers to refer clients to the housing vouchers and to screen for eligibility. After individuals have moved into the Section 8-funded housing, these agencies maintain and/or develop a service delivery relationship with them. This approach is innovative and appears to be effective. Colorado uses both of the methods available to state or local housing agencies for receiving federal Section 8 housing funds to serve people with disabilities, including: (1) giving the disabled enhanced access in the normal housing voucher process (known as "fair share") by automatically moving them up the waiting list; and (2) using a separate, dedicated voucher program for people with disabilities called "Mainstream." Although senior mental health administrators in California expressed skepticism about the Section 8 program for people with mental illness, noting that landlords do not want tenants who are difficult to deal with, Colorado has been successful in working with landlords to overcome that obstacle. The Colorado program works with a variety of special housing types, including group homes, SRO facilities, live-in aide and rent-from-relative arrangements, and it allows people with mental or cognitive impairments to fail at one or more apartments and remain in the program.

6. Recommendations

Recommendation 1: Build a Statewide Mandate for Intensive Community Treatment Within Medicaid. If AB 2034 is converted from a growing pilot program into a mandate on California's counties, the state could take a major step toward the strong and effective mental health system in place in Wisconsin. California could do this while integrating AB 2034 into Medi-Cal.

Recommendation 2: Make Counties Pay for Mental Illness Services in Generic Nursing Homes. This step, which Wisconsin has taken successfully, could be the next major stride in California's systematic effort to encourage community mental health services by shifting control and financial responsibility for institutional care to the counties.

Recommendation 3: Develop an Organizational Linkage between Section 8 Housing and Disabilities Services. Section 8 options for people with disabilities and people with mental illnesses are underutilized in California and not integrated into long-term care policy. The Colorado model for pursuing vouchers and linking vouchers to service providers has proven effective and would serve California well.

C. Services for People with Mental Retardation or Developmental Disabilities

1. California's Programs and Services

Numerous observers both in and out of government have described MR/DD services as the strongest sector of the long-term care system in California. The heart of California's long-term care system for individuals with mental retardation or developmental disabilities is a broad entitlement to services administered through regional, community-run agencies, called "regional centers" (RCs). Under California's Lanterman Act, this entitlement is universal, without regard to income.

The MR/DD system has grown rapidly and it is expensive. Nevertheless, implicit rationing of services takes place within the system, and, in recent years, there has been a relatively passive attitude toward the use of institutions. Also, California's MR/DD agencies (RCs) have not made as much use of Medicaid funding as they might have if they shared in the benefits of federal funding, as do California's county mental health departments. After a critical federal investigation of quality and safety problems, California's MR/DD Medicaid Waiver program was mandated to freeze enrollment in 1998. The enrollment freeze was progressively lifted in 1999, 2000, and 2001.

There are three levels of MR/DD services in California, including: (1) traditional, large, state institutions called "developmental centers" (DCs) or, in some cases, intermediate care facilities (ICF/DDs); (2) smaller to medium-sized ICF/DDs and community facilities (CFs); and (3) home-based and day services. MR/DD services are an entitlement for all Californians diagnosed with mental retardation, cerebral palsy, epilepsy, autism, or a similar disabling condition that originates before the age of 18. Eligibility is not based on income and there is virtually no cost-sharing requirement. This is not true of other states examined for this report and it is unique nationally. Because RC services are not means-tested, a large number of Californians who do not qualify for Medi-Cal because of their income or assets are able to receive case management or other services through RCs.

Including both the DCs and the larger ICFs and CFs, there were 9,000 residents in MR/DD institutions in 1998; of these fewer than 4,000 were in the five large state DCs.[39] More than 30,000 people are cared for in their families' homes, in independent apartments, or in small family-run residential facilities through the state's MR/DD Medicaid Waiver, and an additional 100,000 individuals receive nonwaiver or non-Medicaid services from the same waiver programs. (Some 50,000 of the latter group receive nothing but case management from the RC system.[40]) The MR/DD Medicaid Waiver is California's only large 1915(c) HCBS Waiver. The developmental centers represented approximately 22 percent of California's MR/DD spending in 2001-02 ($629 million), with most of the remaining Department of Developmental Services (DDS) budget ($2.1 billion) going for community services. Slightly more than 60 percent of the total DDS budget is through Medi-Cal or the HCBS Waiver; slightly more than half of that and 33 percent of the total DDS budget is for the HCBS Waiver.

Community facilities are reimbursed and managed by 21 regional centers that are essentially independent nonprofit agencies. The RCs are supervised by community boards with heavy consumer and family representation. They receive all of their funding from DDS using a formula that uses caseload growth and baseline expenditures from the late 1970s. The waiver is capped at 46,000 slots—well more than current enrollment.

The DDS budget has grown an average of 14 percent a year since 1996, more than doubling in that period.[41] Almost all of the growth has been in community services. Caseload growth has been about 45 percent in that period. Most of the spending growth stems from increased services and higher service costs. Aside from adherence to a state fee schedule and an annual global budget, these services are allocated and budgeted to each client at the discretion of the regional centers. The RC budget has increased dramatically from year to year in response to increasing demand. Residential services represent a third of RC service spending; day programs another third; and all other health and support services account for the remaining third.[42]

Two controversies have dominated California's MR/DD policy in recent years: (1) ongoing utilization of the developmental centers and large ICFs; and (2) the only recently lifted federal freeze on California's MR/DD Medicaid Waiver. Partly as a result of the 1998 enrollment freeze, waiver enrollment has stagnated at 30,000 to 35,000 while broader MR/DD service utilization has climbed dramatically since 1996. This has resulted in a substantial loss of federal Medicaid revenue. Protection and Advocacy Inc., a nonprofit organization established to advocate for the rights of people with disabilities, successfully pursued litigation in the early 1990s with the *Coffelt* lawsuit, complaining of unnecessary admissions into the centers. As a result of a settlement in *Coffelt*, 2,837 individuals with MR/DD were transferred out of developmental centers in the mid-1990s (with a net census decline of approximately 2,000) and two DCs were closed. However, after the settlement terms were fulfilled, transfers stopped. The transfers stopped, in part, because the federal Centers for Medicare and Medicaid Services (CMS)—formerly named the Health Care Financing Administration (HCFA)—froze enrollment in California's waiver program between 1998 and early 2002. Developmental center utilization has continued to be the focus of advocate lawsuits, as advocates raise concerns about both the slow pace of community placement assessments in DCs and the lack of any formal community placement process in the larger non-DC residential facilities.

The controversial issues surrounding DC admissions and the federal freeze may have distracted the California MR/DD policy community from two underlying but related issues: (1) the closeted rationing process for services; and (2) the unaggressive use of available Medicaid funds. Bringing more resources for people with developmental disabilities into California's HCBS system and creating a statewide framework to direct those resources according to need will be critical in allowing the state to resume a more rapid pace of community placements for the relatively high-need individuals currently residing in DCs and other institutional settings.

Although regional centers are specifically forbidden from creating waiting lists, knowledgeable observers state that rationing takes place in implicit ways in RCs. Primarily, it happens through allocation of clients between the MR/DD Medicaid Waiver and the regular Medi-Cal system, and through various unofficial waiting lists for services. According to these observers, a substantial number of individuals who qualify for the MR/DD Medicaid Waiver are steered toward ordinary

Medi-Cal or placed on waiting lists while waiting for access to specialized services. (Regular Medi-Cal long-term care services include IHSS personal assistance, nursing home care, home health, and medical services. The MR/DD system provides a much more intensive array of services, including access to assisted living and supported living residences, extensive skilled nursing services, additional personal assistance hours, and a variety of therapies and skills training.) This rationing is said to take place generally at the case manager level in writing client plans; it is not subject to open policy decision making and receives limited state-level tracking.

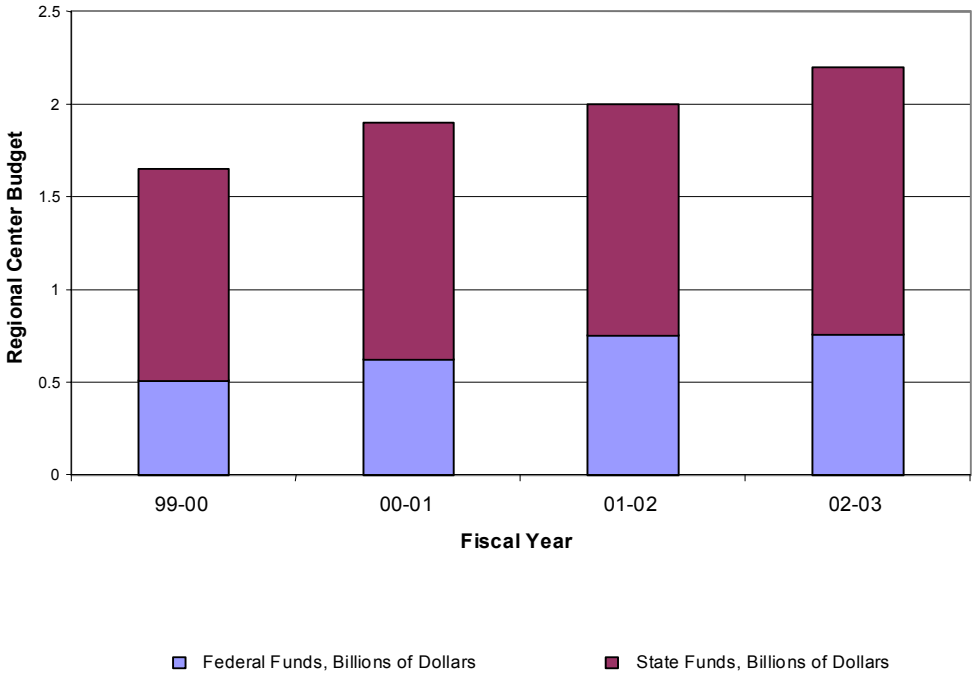
2. Comparisons to Colorado, Washington, and Wisconsin

Unfortunately, the focus states examined for this report do not provide particularly attractive models for a more explicit system of allocating scarce service resources. Washington is, if anything, a cautionary tale for California. As in California, Washington operates one comprehensive Medicaid HCBS MR/DD Waiver for all ages and severity levels, although the state is preparing to change to a different waiver structure. But the allocation of these services was both arbitrary in many cases and, according to federal auditors, in clear violation of Medicaid rules. On the one hand, waiver enrollment growth has been dramatic and fueled by generous eligibility rules. On the other hand, there are waiting lists for many waiver services. These waiting lists were not approved in any waiver application—Washington's waiver was written, like California's, with an entitlement to necessary services—and were arbitrarily managed. Washington's Division of Developmental Disabilities has proposed replacing its comprehensive waiver with several more targeted waivers, primarily as a way of allocating services more selectively. These waivers would be stratified by cost of services into a basic waiver (covering most current waiver enrollees with up to $15,000 a year in services), a core waiver, an intensive waiver, and an exception waiver (for costs of more than $85,000 a year).

Colorado also has multiple MR/DD Medicaid Waivers, with one high-end waiver with a waiting list and one fallback, low-end waiver for children and adults. Yet, this structure has apparently contributed to serious problems in beneficiaries' ability to access needed services. Services for adults with MR/DD are much more extensive and widely available than services for children, and state administrators point to the availability of housing and informal care from parents for children as a reason. As for adults, Colorado keeps supported employment services in a separate waiver from residential services as a way of limiting unnecessary access to residential care. There are significant waiting lists for the adult waivers, which are the subject of a current *Olmstead* lawsuit. Wisconsin's MR/DD system is administered by counties, as are all human services in that state. There are significant waiting lists for waiver services in most counties: some 2,500 to 3,000 individuals with mental retardation are waiting for long-term care services, including residential and home care services. With enrolled MR/DD clients typically using services for decades at a time, waiting lists run from one to five years. In many counties, waiver services are authorized to a significant extent on an emergency basis only.

These three states show—by their negative example—that any effort to make service allocation more explicit risks degrading California's strong service provision for people with developmental disabilities. Yet, decision making about who gets what level of service is entirely appropriate. Indeed, it is basic to all human services policy. Relegating these decisions to the realms of the individual case manager, the fair hearing, and the administrative law courts ultimately inhibits the statewide planning that is necessary to reduce institutionalization. Reducing censuses and eliminating admissions to DCs and other large residential facilities will require a capacity to direct community services to those who need them most. California now has a structure in which community placement planning for residents of institutions is separate from the normal operations of the regional centers and in which decisions about cost and need in the regional centers are made without explicit and open regulatory standards. In order to effectuate more fully the Lanterman Act's goal that people with developmental disabilities receive services in the least restrictive setting possible, California would be well advised to open up decision making about allocation of resources.

Figure 5. Federal and State Funding for Regional Centers in California



Source: California Legislative Analyst's Office. Analysis of the 2002-03 Budget Bill; Department of Developmental Services, Community Operations Division

There is also clear evidence that, as a whole, the California system is not using Medicaid funding as much as it could to fund its own specialized services. Medicaid has been steadily declining as a source of funds, and it has fallen from 39 percent to 33 percent of service spending in the last two years alone, despite the lifting of a federal enrollment freeze.[43] As Figure 5 shows, while Medicaid and other sources of federal funding have been increasing in California's MR/DD system, funds have not been increasing as fast as the broader regional center budgets. Here,

California could look elsewhere in its long-term care system for a solution. As described above, California's county mental health departments are funded by the state, delivering long-term care services out of that budget—much like the MR/DD regional centers. Unlike the counties that administer California's mental health system, the regional centers that run the MR/DD system receive only limited financial incentives from accessing federal waiver resources by enrolling clients. In contrast, the county mental health departments draw down a federal match for whatever portion of their state funding and/or their own funds they spend on Medicaid services. Similarly, Wisconsin allows counties to pass through their costs for the main MR/DD Medicaid Waiver to draw down federal Medicaid matching funds.

3. Recommendations

Recommendation 1: Rationalize Rationing of Services. The focus states examined for this report show mainly how *not* to address the problem of allocating levels of service. Breaking up California's strong MR/DD entitlement into multiple Medicaid waivers, as Washington is preparing to do and as Colorado and Wisconsin have done, is a recipe for extensive waiting lists and ultimately an allocation of resources more punitive than what California has now. California could make service allocation decisions more uniform and more explicit in its current system without jeopardizing its historic commitment to universal services for developmental and cognitive disabilities.

Recommendation 2: Incentivize Regional Centers to Maximize Medicaid. California currently gives regional centers almost no reason to channel their services through Medicaid. If they could draw down Medicaid funds directly through the state, as Wisconsin county MR/DD agencies and California county mental health departments do, California would bring in a great deal more federal resources.

IV. Conclusion

California has some wonderful home and community-based care programs in place. Yet, California has for too long accepted the: administrative fragmentation at the state level; misconceived incentives placed on county and regional agencies; failure to link housing policy to disabilities services; and, most importantly, gaps in intensive services for mental illness and for personal assistance. In most cases, the state could address these problems by redirecting resources currently spent on institutional care or by drawing down federal Medicaid dollars more effectively, rather than by increasing state spending. California's first round of *Olmstead* planning has refrained from recommending fundamental reforms to long-term care policy. Hopefully, this paper and the examples of other states described in it can help spur California policymakers to reexamine the state's fulfillment of the *Olmstead* mandate to understand unnecessary institutionalization as a form of discrimination.

Appendix: List of Interviewees

California

State Senate

Diane Van Maren, Principal Consultant, Senate Committee on Budget and Fiscal Review
Peggy Collins, Consultant, Senate Select Committee on Developmental Disabilities and Mental Health

Health and Human Services Agency

Catherine Campisi, Director, Department of Rehabilitation
Bill Campagna, Deputy Director, Department of Rehabilitation
Joyce Fukui, Deputy Director, Department of Aging
Margaret Griffin, Health Program Specialist, Department of Aging
Stephen Mayberg, Director, Department of Mental Health
Renee Mollow, Chief, Medical Care Coordination and Case Management, Department of Health Services
Robert Schladale, Assistant Secretary of Health and Human Services, Olmstead Coordinator

Department of Housing and Community Development

Gwen Espinosa, Assistant Director, Multifamily Housing Program

World Institute on Disability

Bryon MacDonald, Project and Policy Development Manager

University of California, San Francisco

Charlene Harrington, Professor

Protection and Advocacy Inc.

Deborah Doctor, Attorney
Ellen Goldblatt, Attorney
Michael Stortz, Attorney
Kim Swain, Attorney

Policy Consultants and Lobbyists

Curtis Richards, Independent Public Policy Consultant
F. Burns Vick, Independent Public Policy Consultant

Colorado

Department of Human Services

Marilyn Kirby, Program Manager, Supportive Housing and Homeless Program, Office of Behavioral Health and Housing

Tom Barrett, Director, Mental Health Services
Denise Ellis, Manager, HCBS-Mental Illness Waiver
William West, Administrator, Consumer-Directed Attendant Support, Department of Health Care Policy and Financing
Peggy Spaulding, Administrator, Long-Term Care Benefits, Department of Health Care Policy and Financing
Ann Selling, Administrator, Assisted Living Program, Department of Health Care Policy and Financing
Dann Milne, Manager, Delivery Systems Development, Department of Health Care Policy and Financing
Todd Coffey, Director, Community Based Long-Term Care, Department of Health Care Policy and Financing
Jay Kauffman, Assistant Director, Developmental Disabilities Services
Kerry Stern, Acting Director, Developmental Disabilities Services

Adult Care Management, Inc.

J.C. Lodge, President

Colorado Cross-Disability Coalition

Julie Reiskin, Executive Director

Denver Center for Independent Living

Carol Reynolds, Executive Director
Brandon Williams, Board Member
Brent Belisle, Caseworker

Washington

ADAPT of the Great Northwest

Katrinka Gentile, Chair

Department of Social and Health Services

Kathy Leitch, Assistant Secretary, Aging and Adult Services Administration
Penny Black, Division Director, Home and Community Services, Aging and Adult Services Administration
Bill Moss, Office Chief, Home and Community Services, Aging and Adult Services Administration
Pat Lashway, Division Director, Residential Services, Aging and Adult Services Administration
Tim Brown, Assistant Secretary, Health and Rehabilitative Services Administration
Cathy Cochran, Olmstead Coordinator, Health and Rehabilitative Services Administration

King County Regional Support Network

Amnon Shonfeld, Acting Director

Community Psychiatric Clinic, Seattle
Shirley Havenga, Chief Executive Officer

Long-Term Care Ombudsman
Kary Hyre, State Ombudsman

Developmental Disabilities Council
Ed Holen, Executive Director

Home Care Quality Authority
Charles Reed, Chair

National Alliance for the Mentally Ill—Greater Seattle
Frank Jose, Executive Director

Washington Protection and Advocacy Services
Jillian Maguire, Director of Resource Advocacy

Wisconsin

Department of Health and Family Services, Division of Supportive Living
Donna McDowell, Director, Bureau of Aging and Long-Term Care Resources
Joyce Allen, Interim Director, Bureau of Community and Mental Health
George Hulick, Clinical Consultant, Bureau of Community Mental Health
Ken Golden, Section Chief, Quality Assurance and MA Waiver, Bureau of Developmental Disabilities
Beth Wroblewski, Section Chief, Family Centered Services, Bureau of Developmental Disabilities
Thomas Swant, Section Chief, ICF-MR, Bureau of Developmental Disabilities

Dane County, Department of Human Services
Susan Crowley, Director
Francis Genter, Administrator, Adult Community Services

Board on Aging and Long-Term Care
George Potaracke, Executive Director, Board on Aging and Long-Term Care

Wisconsin Coalition for Advocacy
Lynn Breedlove, Executive Director

National Alliance for the Mentally Ill—Wisconsin
Donna Wrenn, Executive Director

University of Wisconsin
Deborah Allness, Professor, School of Social Work

National

Susan Reinhard, Co-Director, Center for State Health Policy, Rutgers University
Sara Rosenbaum, Director, Center for Health Services Research and Policy, George Washington University School of Law
Alexandra Stewart, Research Scientist, Center for Health Services Research and Policy, George Washington University School of Law
Lee Partridge, Director, Health Policy, American Public Human Services Association
Amy Sander, American Public Human Services Association

Endnotes

[1] Lisa Alecxih, et al. "Estimated Cost Savings from the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States." American Association of Retired Persons. November 1996; "Across the States: Profiles of Long-Term Care Systems." American Association of Retired Persons. 1996, 1998, 2000, and 2002. (2001 figures show Washington and Colorado spending 48 percent and 51 percent of their Medicaid long-term care budgets on HCBS, while California spends about 40 percent. [from "Across the States . . ." 2002 and 2003; see Rankings p. 27)

[2] See California Olmstead Plan, Appendices A and C. California Health and Human Services Agency. Surveys conducted by both the state and an advocacy coalition as part of the formal planning process are also included as appendices to the Olmstead Plan, but these surveys make no claim to accurately reflect the population-level scope of unmet need for long-term care and supportive services in California.

[3] William Weissert and Susan Hedrick. "Lessons Learned from Research on Effects of Community-Based Long-Term Care." *Journal of the American Geriatrics Society, 42, 3*. (March 1994); Janet O'Keeffe. "People with Dementia: Can They Meet Medicaid Level of Care Criteria for Admission to Nursing Homes and HCBS Waiver Programs?" American Association of Retired Persons. August 1999; "Determining the Need for Long-Term Care Services: An Analysis of Health and Functional Eligibility Criteria in Medicaid Home and Community-Based Waiver Programs." American Association of Retired Persons. December 1996; Pamela Doty, "Cost-Effectiveness of Home and Community-Based Long-Term Care Services." U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. June 2000; "Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs." General Accounting Office, GAO/HEHS-94-167. 1994; Lisa Alecxih, et al. "Estimated Cost Savings from the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States." American Association of Retired Persons. November 1996; William Weissert, et al. "Cost Savings from Home and Community-Based Services: Arizona's Capitated Medicaid Long-Term Care Program." *Journal of Health Politics, Policy and Law, Vol. 22, No. 6.* December 1997; Abt Associates. "The Impact of PACE on Participant Outcomes." 1999.

[4] Rosalie Kane. "Long-Term Care and A Good Quality of Life: Bringing Them Closer Together." *The Gerontologist, Vol. 41, No. 3.* 2001; Lori Simon-Rusinowitz and Brian Hofland. "Adopting a Disability Approach to Home Care Services for Older Adults." *The Gerontologist, Vol. 33, No. 2.* 1993.

[5] Pamela Doty. "Cost-Effectiveness of Home and Community-Based Long-Term Care Services." U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. June 2000. (p. 16); Lori Simon-Rusinowitz and Brian Hofland. "Adopting a Disability Approach to Home Care Services for Older Adults." *The Gerontologist, Vol. 33, No. 2.* 1993.

[6] Bruce Vladeck. Testimony before U.S. House of Representatives Committee on Governmental Reform and Oversight. January 18, 1996.

[7] Figures from the National Institute for Mental Health.

[8] David Mechanic. "Emerging Trends in Mental Health Policy and Practice." *Health Affairs, Vol. 17, No. 6.* Nov./Dec. 1998.

[9] David Mechanic. "Emerging Trends in Mental Health Policy and Practice." *Health Affairs, Vol. 17, No. 6.* Nov./Dec. 1998.

[10] See, for example, the series in the *Los Angeles Times*, "Broken Contract: How California Neglects Its Mentally Ill." November and December 1999.

[11] Some California counties do maintain waiting lists of one to two months for IHSS assessments.

[12] Although state IHSS regulations allow up to 283 hours a month in IHSS services, in practice the average is well under 100 hours a month, as determined by the county social service department caseworkers who administer the program on the front end.

[13] California Senate Health and Human Services Committee. 2001-2002 Budget Analysis, C58.

[14] Cowles Research Group. *Nursing Home Statistical Yearbook, 2001.* (Provided by AARP Public Policy Institute; personal communication.)

[15] California Senate Health and Human Services Committee. 2001-2002 Budget Analysis, C58. The committee's total comparison of institutional versus home and community-based services incorporates spending for developmental disabilities services that is heavily oriented toward HCBS and shows a more evenly split spending picture.

[16] Medicaid law and regulations require that states maintain a Preadmission Screening and Resident Review (PASRR) program. PASRR determinations are particularly important, given the *Olmstead* decision mandating that states provide community-based treatment options for people with mental disabilities when treatment professionals deem them appropriate.

[17] "Across the States: Profiles of Long-Term Care Systems." American Association of Retired Persons. 2003.

[18] Major lapses in supervision and failures to detect abuse of COPES clients were described in multi-article investigations in the *Seattle Times* on December 12, 1999, and in the *Olympian* on December 17, 2000.

[19] Joshua Wiener and Steven Lutzky. "Home and Community-Based Services for Older People and Younger Persons with Physical Disabilities in Washington." Center for Medicare and Medicaid Services. June 5, 2001.

[20] "Across the States: Profiles of Long-Term Care Systems." American Association of Retired Persons. Forthcoming 2003.

[21] "Across the States: Profiles of Long-Term Care Systems." American Association of Retired Persons. 2003. (See Rankings, p. 27.)

[22] Lisa Alecxih, et al. "Estimated Cost Savings from the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States." American Association of Retired Persons. November 1996.

[23] Wisconsin Bureau of Aging and Long-Term Care Resources. "Community Options Program." Report to the Legislature, Calendar Year 2000.

[24] Wisconsin Legislative Fiscal Bureau. "Community-Based Long-Term Care Programs." Informational Paper #49. January 2001.

[25] "Across the States: Profiles of Long-Term Care Systems." American Association of Retired Persons. 2002; Wisconsin Legislative Audit Bureau. "Community Options Programs: An Evaluation." May 1999. (p. 7)

[26] Wisconsin Bureau of Aging and Long-Term Care Resources. "Community Options Program." Report to the Legislature, Calendar Year 2000; Wisconsin Legislative Fiscal Bureau. "Community-Based Long-Term Care Programs." Informational Paper #49. January 2001.

[27] As noted earlier in the report, unlike California, Washington and Colorado spend more on home and community-based services than on nursing homes. Washington and Colorado also have made intensive physical assistance services available in the community on a larger scale than has California, as discussed above.

[28] Michael Stortz. "A Tale of Two Settings: Institutional and Community Mental Health Services in California." Protection and Advocacy Inc. 2003.

[29] Charlene Harrington, et al. "The Role of Medi-Cal in California's Long-Term Care System" California HealthCare Foundation. 2001. (Chapter 6); California Senate Health and Human Services Committee. 2001-2002 Budget Analysis.

[30] Richard Scheffler, et al. "The Impact of Risk Shifting and Contracting on Mental Health Service Costs in California." *Inquiry, 37.* Summer 2000.

[31] Michael Stortz. "A Tale of Two Settings: Institutional and Community Mental Health Services in California." Protection and Advocacy Inc. 2003.

[32] The United States Department of Justice has repeatedly cited Laguna Honda for violating the requirements of the Americans with Disabilities Act and the *Olmstead* decision, although it has not pursued litigation as of mid-2003.

(See the DOJ Civil Rights Division's Letter, "Re: Investigation of Laguna Honda Hospital and Rehabilitation Center." April 1,2003. [Available at http://www.usdoj.gov/crt/split/documents/laguna_honda_hosp.pdf]

[33] For rough estimates of unmet need for community mental health services in California, see Charlene Harrington, et al. "The Role of Medi-Cal in California's Long-Term Care System" California HealthCare Foundation. 2001; and California Mental Health Planning Council Report. April 2000.

[34] Michael Stortz. "A Tale of Two Settings: Institutional and Community Mental Health Services in California." Protection and Advocacy Inc. 2003.

[35] "Colorado Assessment of Community Resources." TriWest Group. 2000.

[36] Preliminary Data for Realignment Study. California Department of Mental Health.

[37] "Effectiveness of Integrated Services for Homeless Adults with Serious Mental Illnesses." Report to the Legislature on AB 2034, 2001; "Mentally Ill Find Dramatic Success in State Program." *Los Angeles Times*. May 12, 2001.

[38] These programs are also referred to as "assertive community treatment" in Wisconsin and other states.

[39] Charlene Harrington, et al. "The Role of Medi-Cal in California's Long-Term Care System" California HealthCare Foundation. 2001. (p. 4)

[40] State Council on Developmental Disabilities. "System Review Policy Initiatives." January 2000.

[41] California Legislative Analyst's Office. "Analysis of the 2002-2003 Budget Bill." February 2002.

[42] California Legislative Analyst's Office. "Analysis of the 2002-2003 Budget Bill." February 2002.

[43] California Legislative Analyst's Office. "Analysis of the 2002-2003 Budget Bill." February 2002.