

**Testimony for the California Little Hoover Commission
May 27th Hearing in Sacramento, CA on California's System of Long-Term Care**

My name is Pamela Doty. I have a Ph.D. in sociology from Columbia University and have been a policy analyst and policy researcher in the U.S. Department of Health and Human Services for almost 30 years. I have worked in the Office of Legislation and Policy in the Centers for Medicare and Medicaid and, since 1987, in the Office of the Assistant Secretary for Planning and Evaluation.

My written testimony for the Little Hoover Commission is based solely on findings from policy research on state long-term care (LTC) systems, primarily my own research and that conducted by contractors under the auspices of my office or other federal agencies. I do not represent DHHS on matters of policy.

LHC staff asked me to address how California's LTC system compares to other states' systems. Clearly, state LTC systems can be compared on many different measures, so it is important to consider the values and policy goals that the selected measures reflect. Ideally, they should embody a non-partisan national consensus about the goals to strive for and what an excellent long-term care system should look like, even if no state, as yet, has fully realized the ideal.

Fortunately, such a consensus exists. It is that long-term care financing and delivery systems should encourage use of home and community-based services to the extent that people with chronic disabilities who require long-term care prefer to reside in the community and can get their needs met there. There has been widespread agreement on this goal for at least the past thirty years.

Recently, I had occasion to look up the first report on long-term care that I contributed to, shortly after joining the federal government (CMS) in 1980. The report stated:

A consistent theme in policy deliberations on long term care reform is the desirability of expanding in-home and community-based services. Several governmental and independent publications document the lack of funding for non-institutional services and the problems this creates: inappropriate institutionalization, inadequate care for the disabled in the community, heavy burdens on the family, and excessive public expenditures.¹

When this report was published in January 1981, an estimated 90 percent of all Medicaid and other public expenditures for long-term care were for institutional care. As of 1980, only 14 states plus the District of Columbia had elected to include the optional personal care services benefit in their Medicaid state plans. In 1981, Congress amended Medicaid law to permit CMS to approve state requests for 1915 (c) waivers to use Medicaid to finance a wide range of home and community based services (HCBS) in lieu of care in nursing homes, ICFs/MR, or long-term hospitalization.

I. Expansion of Funding for HCBS: California in National Perspective

State Plan Personal Care Services: By 2002, 36 states, including California, had elected to cover state plan personal care services in their Medicaid programs. California's state plan PCS program is called In-Home Supportive Services. This program was launched in 1974 under social services auspices and funded with state general revenues. California was thus far in advance of most other states in promoting access to HCBS. California did not begin to bring IHSS into its Medicaid program until 1993 and, only completed the process of bringing all but 1 percent of IHSS into Medicaid last year.

For California, both of these decisions proved prescient and gave the state historical advantages over other states. By creating a statewide entitlement to HCBS for the low-income elderly and disabled, California appears to have short-circuited the nursing home building boom that Medicaid instigated across most of the country through the 1970s. Other states that established high nursing home bed capacity per 1000 elderly residents during the 1970s later found it difficult to "re-balance" toward greater reliance on HCBS. In contrast, California was less "institutionally biased" to begin with.

In addition, by keeping IHSS outside of Medicaid for almost two decades, California was able to design and operate the program in accordance with a "social" rather than a "medical model" of personal assistance services. During that period of time, federal Medicaid policy put strong pressure on states to impose "provider qualifications" for personal care that favored professionally managed, agency-delivered personal care services rather than consumer-directed individual providers. By 1993 Congress amended Medicaid law to drop "medical model" requirements that personal care be prescribed by a physician and supervised by a nurse. Within the next several years, CMS issued a regulation that explicitly permitted "consumer-directed" services and permitted family members other than spouses and parents of minor children to be paid providers. However, it still took until 2005 for Congress to further amend Medicaid law so that states could claim Medicaid match for program participants having these relatives as paid providers, making it possible for California to bring all of IHSS into Medicaid.

HCBS Waivers: Forty-eight States and the District of Columbia currently offer services through HCBS waivers, and Arizona operates a similar program under section 1115 research and demonstration authority. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time, and currently there are approximately 287 active HCBS waiver programs in operation throughout the country, including 3 HCBS waiver programs in California.

California uses IHSS (Medicaid state plan personal care services) as its primary Medicaid vehicle for financing HCBS for the elderly and younger physically disabled adults. A minority of Medicaid aged/disabled recipients receive HSBS waiver services (MSSP), in some cases as a supplement to state plan personal care services (IHSS). In contrast, most children and adults with developmental disabilities in California receive HCBS through a 1915 (c) HCBS waiver program, although some children and adults with developmental disabilities who need personal care services receive those services via IHSS. California

is somewhat unusual in relying primarily on the state plan benefit (IHSS) to finance HCBS for the elderly and younger persons in need of personal care rather than HCBS waivers. However, California is not unique in this respect; for example, New York also relies more on state plan personal care services than HCBS waivers to finance HCBS for elderly and younger physically disabled adults. States with sizable state plan PCS programs are typically states that began investing in HCBS earlier than others; however, states that started these programs under Medicaid auspices (e.g. New York, Arkansas) rather than under social services auspices typically succumbed to pressures to abandon or de-emphasize use of independent providers in favor of agency-delivered personal care and more intensive and costly models of professional case-management.

II. Finding the Appropriate Balance between HCBS and Institutional LTC: California Compared to Other States and the Nation

For the nation as a whole, progress toward greater reliance on HCBS was gradual from 1981 until the later part of the 1990s.

As late as 1997, the percentage of national Medicaid LTC funding going toward HCBS exceeded 20 percent in only five states.²

Over the first twenty years after the Medicaid HCBS waiver legislation was enacted, social services funding for HCBS (via Title XX, which had been converted to the Social Services Block Grant in 1982) had largely disappeared and many states, including California, decided they could no longer afford sizable HCBS programs funded solely with state revenues. Thus, some – albeit an unknown percentage – of the growth in Medicaid funding for HCBS did not represent real “net” growth in public funding for HCBS. Rather, it involved a “re-financing” of programs previously funded with Title XX or state-revenues. Greater reliance on Medicaid provided a more stable funding base for expansion of HCBS and the federal financial participation rate of 50 percent or greater made investing in HCBS more affordable for states. However, there were also drawbacks to greater reliance on Medicaid. The stringency of the Medicaid means-test has made it difficult for Medicaid-funded HCBS to be used to deter long-stay nursing home admissions among severely disabled individuals (mostly elderly) who qualify for Medicaid only after spending down their savings after paying privately upon nursing home entry and for at least a few months thereafter.

During most of the 1990s, Medicare’s role in financing “long-stay” home health buffered states from pressure to increase Medicaid funding for HCBS more rapidly. From 1989 until 1999, expenditures under Medicare’s home health benefit on long-term aide services exploded. ASPE’s research, based on the National Long-Term Care Survey, a representative survey of chronically disabled elders living in institutions and in the community (begun in 1982 and conducted every five years from 1984-2004) indicated that users of such services were primarily chronically disabled elders living in the community. National Long-Term Care Surveys were linked to Medicare claims, so it was possible to track utilization and cost patterns for home health agency (HHA) services. In 1994, half of all chronically disabled elderly living in the community who required

assistance with three or more personal care tasks (a rough measure of “nursing home” level of care need) received Medicare-funded HHA services at some point during the year and one in four such NLTCS respondents were receiving HHA services when the in-home interview took place.³

Some states (especially in the South and not including California) kept Medicaid spending on HCBS very limited to pursue, whether deliberately or more tacitly, a “Medicare maximization” strategy. Congress decided that the escalating Medicare home health expenditures for “long-term” as distinct from “post-acute” care were a threat to the solvency of the Part A trust fund and contrary to legislative intent. Medicare home health services reimbursement reforms intended to curb such utilization and costs were enacted in the 1997 Balanced Budget Act. The result was a noticeable decline in access to paid HCBS among older Americans (age 65 and older) with chronic disabilities living in the community, especially those not eligible for Medicaid means-tested HCBS. The 1999 National Long-Term Care Survey found that reported use of any paid home care, which had risen from slightly over one quarter of NLTCS respondents in 1984 to over two-thirds of respondents in 1994, declined back to the 1984 use rate and remained at that same level in the 2004 NLTCS.⁴

After the Medicare HHA payment reforms went into effect, Medicaid programs came under pressure to make up for the Medicare home health cutbacks experienced by dually eligible individuals with chronic disabilities. From a national perspective, reported use of Medicaid as a funding source for NLTCS respondents using paid care almost doubled between 1994 and 2004.⁵ Unfortunately, we cannot say what portion of this growth may have been attributable to the Medicare HHA cutbacks in funding for aide services or other factors. Reports by the California Legislative Analysts Office and other within-state policy research organizations have highlighted the high growth rate of IHSS since 1999 and observed that this growth cannot be explained solely by California’s population growth rate.⁶ Few hypotheses have been offered to explain IHSS growth, but one to consider is that factors external to California, including the Medicare home health services cutbacks, may have played a role, perhaps an important role, especially during the five years or so following the Medicare home health payment reforms. Because NLTCS findings are representative nationally, but not state-specific, we cannot estimate increased use of Medicaid to finance HCBS in California compared to the nation or how the Medicare cutbacks affected California’s Medicaid financing of home care, in particular.

Other factors that quickened the pace of “re-balancing” toward greater reliance on HCBS include the Supreme Court’s 1999 *Olmstead* ruling, Congressional appropriation of \$350 million dollars in Real Choice/Systems Change grant funding, of which CMS awarded \$284 million competitively to states 2001-2009 to improve their long-term care systems, and the Bush Administration’s “New Freedom” Initiative to facilitate and encourage federal/state efforts to reform Medicaid-financed long-term care in accordance with *Olmstead* principles.⁷ However, the shift away from reliance on institutional care has occurred much more rapidly for Medicaid beneficiaries with developmental disabilities compared to other populations in need of LTC, especially the elderly.

A. Alternative Measures of HCBS and Institutional Care “Balance:” California’s Comparative Ranking

In measuring and ranking state progress toward shifting the balance in their LTC systems, the primary focus has been on the percentage of Medicaid LTC expenditures on HCBS compared to institutional LTC. Annually, for over two decades, Brian Burwell of Thomson (Medstat) has provided CMS and other federal officials with comparative cost data on Medicaid spending on long-term care services compared to acute care and total Medicaid spending, by type of service and by state, based on analysis of the CMS 64 state cost reports. As of 2008, total national spending on HCBS as a percentage of total Medicaid LTC expenditures had increased to 43 percent. California ranked 9th with 54.4 percent of total Medicaid LTC spending on HCBS. California was one of twelve states where spending on HCBS exceeded fifty percent of total Medicaid LTC spending.⁸

Such a single global measure masks important differences in progress toward greater reliance on HCBS for particular target populations, such as the elderly compared to younger disabled adults, especially those with intellectual developmental disabilities. A majority of Medicaid spending on services for beneficiaries with IDD is now going toward HCBS rather than ICFs/MR. Nationally, LTC spending as a whole appears more balanced than it really is because three quarters of expenditures financed via HCBS waivers are spent on individuals with IDD and because HCBS waiver spending accounts for a greater share of all Medicaid expenditures for HCBS than spending on state plan PCS which goes primarily toward the elderly and younger adults with physical disabilities. However, numerically, there are far more elderly and younger physically disabled Medicaid LTC users than Medicaid LTC users with IDD. It is therefore important to look not only at spending ratios but at the percentages of Medicaid beneficiaries receiving LTC who are being served in the community or in institutions by age group.

California is unusual, however, in that the state ranks far higher on comparative HCBS and institutional LTC expenditure measures of predominant reliance on HCBS for the Aged/Disabled (elderly and younger physically disabled population) than for the developmentally disabled population (children and adults, who have primarily intellectual disabilities). In 2008, Burwell’s rankings show California ranking 4th in percentage of total Medicaid LTC spent on HCBS for the aged/disabled (52 %) and one of only four states where HCBS spending for this population exceeded fifty percent. (The states that outranked California on this measure were New Mexico, Oregon, and Washington).

California did not rank so highly in terms of relative reliance on HCBS compared to institutional LTC for the developmentally disabled. Burwell reported that data problems (under-reporting of expenditures) precluded a calculation of California’s exact ranking compared to other states on LTC spending for the developmentally disabled; however, it appears that California would almost certainly rank somewhere in the middle. Also, California funds a major portion of services for the IDD population with state-only revenues under the Lanterman Act.⁹

ASPE funded Mathematica Policy Research to look at a broader range of LTC balance measures based on the Medicaid Analytic Extract (MAX) files that summarize Medicaid claims data reported to CMS by the states. The study analyzed 2002 MAX data from 37 states, including California (data from 14 states were either unavailable or excluded because it was judged to be incomplete or insufficiently reliable).¹⁰

The study found that overall (for all 37 states), 59 percent of LTC expenditures were for institutional long-term care and 34 percent for HCBS. Community-based service expenditures as a share of total Medicaid LTC expenditures ranged from a high of 65 percent in New Mexico to a low of 8.6 percent in Mississippi. California ranked ninth at 45.7 percent. Among long-term care expenditures on the elderly (age 65 and older), California ranked second (38.1 percent) behind only New Mexico (44.3 percent). However, for younger disabled adults (including both those with physical disabilities and those with intellectual developmental disabilities), California ranked only slightly above the national average (54.1% compared to 50.4%).

With respect to numbers of Medicaid beneficiaries receiving LTC being served in the community, California ranks very high compared to other states. California served 77.2 percent of all Medicaid LTC recipients in the community, taking second place behind Alaska which served 86.5 percent of Medicaid LTC recipients in the community (the national average was 58.8 percent). California served 85.7 percent of non-elderly disabled adults in the community, ranking 11th. Where California excels compared to other states is in serving the chronically disabled elderly in the community. California ranks second, serving 71.6 percent of elderly Medicaid LTC recipients in the community, behind Alaska (80.1 percent). Other states that do comparatively well vis a vis most states in serving elderly Medicaid LTC recipients in the community are still far behind; e.g. Idaho (56.1 percent) and New Mexico (53.4 percent), with the national average only at 44.9 percent. What was particularly striking about California compared to other states in the 2002 MAX analyses of Medicaid elderly LTC recipients was that in every age cohort among the 65 and older, those served in the community greatly outnumbered those served in institutions --- except among the “oldest-old” (age 85 and older) and even for this group two fifths were being served in the community rather than in institutions. No other state demonstrated such a strong pattern of reliance on community care for the Medicaid eligible disabled elderly.

California does not spend more per LTC user than other states; in fact, it spends less, especially for community care. For all 37 states in the national sample expenditures per Medicaid LTC user averaged \$31,630 for institutional care and \$12,971 for community care; the comparable figures for California are \$28,892 per user for institutional services and \$8665 for community care.

We also developed several other comparative state measures drawing on a combination of MAX data and budget related data obtained from the National Association of State Budget Officers (NASBO). These measures examined LTC as a percentage of total Medicaid spending, total Medicaid and, specifically LTC and institutional/community LTC spending, as a percentage of total state expenditures, and spending on Medicaid and,

specifically spending on Medicaid LTC, in relation to NASBO's estimate of each state's total taxable revenues (TTR). TTR is a measure of the state's wealth, although states clearly vary in their political will to tax potential available revenue sources. It is important to recognize when comparing states that some states (those with greater percentages of low income residents) grapple with an inherent imbalance in terms of greater demand for Medicaid services and lower TTR; similarly, states with higher percentages of lower income elderly, especially in the older age cohorts) face inherently greater demand for Medicaid-financed LTC.

Without going into great detail, we found that high spending on Medicaid in relation to the state budget or TTR was not systematically associated with a higher percentage of Medicaid spending for LTC and, for those states where there was such an association, LTC spending was primarily for institutional care. Much greater spending on Medicaid HCBS compared to institutional LTC did not appear to be associated with Medicaid accounting for a much greater than average share of total state expenditures or a higher ratio of state Medicaid spending relative to TTR.

ASPE is in the midst of working with Mathematica Policy Research to redo and expand these comparative MAX analyses using 2007 data. We expect to have fewer states missing from the analyses due to unreliable or incomplete Medicaid claims reporting. In the analyses we are planning to carry out, we will also go beyond what we did previously to compare the numbers of Medicaid LTC recipients in each state with measures of low-income residents of the state in need of help with personal care tasks (as measured by the Census Bureau's American Community Survey). We expect to have these analyses completed in October 2010. Unfortunately, however, these analyses will be based on Medicaid claims patterns prior to the national financial crisis of 2008, so we still will not be in a position for several more years to know how the economic downturn and its impact on state budgets has affected LTC "re-balancing" efforts.

B. Which Features of California's LTC System Explain its High Rank, Compared to Other States, with respect to Greater Reliance on HCBS and Institutional LTC for the Elderly and Younger Physically Disabled Adults?

ASPE's research to date cannot answer this question definitively. We have, however, developed some plausible hypotheses derived from asking what LTC system features California has in common with other states that have ranked highest with respect to "re-balancing" LTC, especially for the elderly, in several different studies. The states most consistently included in the top five, in addition to California, are Oregon, Washington, Alaska, and New Mexico. Other states that often ranked in the top quartile include (in no particular order): Colorado, Idaho, Texas, Maine, Minnesota, and Vermont, and Kansas, based on a combination of percentage of LTC funding spent on HCBS and Medicaid LTC recipients served in the community.

All of the top ranking states with respect to greater reliance on HCBS for aged/disabled Medicaid LTC recipients have both state plan PCS programs and HCBS waiver programs for the aged, disabled, or aged/disabled (as well as for Medicaid eligible individuals with

intellectual developmental disabilities). State plan PCS is required by federal statute to operate as an entitlement but HCBS waiver enrollment may be capped, which often results in waiting lists. Among the top ranking states on “balance” indicators for the elderly and disabled (non-IDD) populations, Oregon, Washington, and Alaska operate their HCBS waiver programs as entitlements (no waiting lists). Most other states that are not in the top rank have waiting lists for their elderly/disabled waiver programs. Nationally, waiting times for these programs are estimated at nine months.¹¹ California has a waiting lists for its two aged/disabled waiver programs; however, California services the aged/disabled primarily through IHSS (state plan PCS). New Mexico is the only top ranking state that relies primarily on HCBS waivers to serve the elderly and maintains a sizable waiting list.

Only 11 states have no waiting lists for any HCBS waiver programs. Most states have lengthy waiting lists for HCBS waiver programs for Medicaid eligible individuals with IDD (an average two year wait). Even though California is not a top ranked state with respect to reliance on HCBS for the IDD population, California has no waiting lists for its HCBS waiver program for Medicaid LTC recipients with IDD. Although HCBS enrollment caps are used to control Medicaid LTC costs, they have drawbacks. In many states, courts have ruled that wait listed applicants cannot be prioritized and must be enrolled into the waiver as slots become available on a first come, first served basis. This makes it impossible to target HCBS to those imminently like to be admitted to nursing homes. If there is any significant waiting time, enrollment caps actually result in HCBS being mainly provided to those whose family supports are sufficient to keep them in the community until a slot comes open; making it highly unlikely that those with high levels of need but weak family supports or highly stressed family caregivers can avoid nursing home placement.

In only five states in the country is “consumer-directed” personal care the predominant mode of service delivery. However, four of the states that rank in the top five have in common is a predominance of “consumer-directed” HCBS. The exception is New Mexico, where consumer-directed services were introduced more recently than in California, Washington, and Oregon; however, the take-up rate has been growing rapidly, primarily in the HCBS waiver context. Vermont is the only other state and the only Eastern state where the majority of personal care services providers are consumer-directed independent providers. Vermont has often ranked very highly on “re-balancing” measures (always in the top ten, often higher, but is unranked in recent reports because all of the state’s LTC services are being provided under an “1115” waiver and, as a result, expenditure data comparable to other states has not been readily available). All of the top ranked states permit family members to be paid caregivers and California, Oregon, and New Mexico permit both spouses and parents of minor children to be paid caregivers. The other states in highest quartile on re-balancing measures all offer consumer-directed aides as an alternative to agency-delivered personal care, but the latter appears to be the predominant mode (except in Kansas, Maine, and Colorado, where consumer-directed aides appear to be the predominant or rapidly increasing preference among younger physically disabled adults but where this option has historically not be as readily available to the elderly). In addition to such consumer-directed “employer authority,”

Washington, Oregon, New Mexico, and Minnesota all have “cash and counseling” or related programs. Although a number of lower-ranking states have introduced consumer-directed services via “cash and counseling” programs over the past decade, the participation rate has not yet exceeded 25 percent in any of these states; thus, agency-delivered care remains the dominant service delivery mode.

ASPE has twice evaluated California’s IHSS programs, the first time in the mid to late 1990s and the second time in 2005. In the first evaluation, the program scored quite well on various quality indicators, particularly so when program participants used consumer-hired independent providers rather than agency providers¹² and, in both evaluations, outcomes on quality indicators were often significantly better (and never worse) when IHSS program participants’ paid caregivers were family members (including spouses and parents of minors) rather than non-relatives.¹³

Another attribute of several of the top ranking states (e.g., California, Oregon, and Washington) is that they have 31 or more “assisted living” beds per 1000 elderly compared to the national average of 22.9. Although Oregon and Washington State pioneered in making high quality assisted living (as distinct from “board and care” facilities) available to Medicaid beneficiaries, in California and most other states assisted living serves predominantly private payers. Nevertheless, availability of high quality assisted living that costs less than nursing home care helps keep private payers from entering nursing homes and spending down to Medicaid.

California has been a pioneer in policies that tend to keep private payers off Medicaid. These policies include promoting private long-term care insurance (LTCI) purchase and licensing more assisted living facility beds per 1000 elderly than the national average. California was one of the original four states that launched Medicaid/private LTCI partnerships to encourage people whose income/assets put them at the lower end of LTCI affordability to buy private LTCI. Such individuals are at greater risk of spending down to Medicaid in a nursing home and giving them enhanced Medicaid protection if they purchase LTCI and exhaust their benefits while still receiving formal long-term care services makes it LTCI more affordable to them. They can buy LTCI without fear that they will exhaust their insurance benefits and end up having to use up all of their savings anyway before becoming Medicaid eligible. LTCI purchase greatly decreases their chances of entering a nursing home at all (because LTCI benefits can be used to cover home care or assisted living) and very few partnership purchasers over the past 15 years have ever spent down to Medicaid eligibility. California has also encouraged private LTCI purchase among state, county, and municipal employees via CalPERS (the public employee pension plan). These factors along with Medicaid policies that promote greater reliance on HCBS may explain why California’s rate of nursing home use among state residents 65 and older is only about 60 percent of that for the U.S. population aged 65 and older.

Finally, California has been a pioneer with respect to other widely praised innovations in LTC services; most notably, On Lok in San Francisco was the prototype that inspired PACE (Program of All-Inclusive Care for the Elderly) sites around the country (a

managed care model integrating Medicare and Medicaid funding for both acute and long-term care).

C. Why Do Some Other States – in particular, Oregon and Washington – Consistently Outrank California on LTC Balancing Measures?

Oregon and Washington State have more generous financial eligibility standards for HCBS coverage. These two states provide HCBS waiver services to individuals who meet the special needs cap financial eligibility standard for nursing home coverage, which is annual income up to 300 percent of SSI (currently just under \$25,000 per year for a single individual). Moreover, Oregon and Washington State allow HCBS users to retain income up to this standard to cover living expenses in the community. In contrast, California's financial eligibility standard for IHSS and for HCBS waiver is limited to the cash assistance (SSI/SSP) level. Individuals with income above this level may become eligible via "medically needy" financial eligibility rules by paying "share of cost." This requires them to apply all of their income above SSI/SSP (currently a little less than \$900 per month) toward the cost of HCBS. These tighter financial eligibility rules may make Medicaid-funded HCBS in California less effective than similar services in Oregon and Washington at preventing or postponing nursing home placements among the elderly who have incomes above the cash assistance need level who are not eligible for Medicaid in the community but who become Medicaid eligible immediately upon or within a few month of nursing home admission.

Oregon and Washington State have also had much more experience over many years with identifying individuals residing in nursing homes who could be successfully transitioned back to the community. This includes residents who had only recently been admitted to nursing homes who could go home and residents who had been there for some time but whose conditions had improved sufficiently to make return to the community possible.

Finally, Oregon and Washington State have established highly centralized state administrative control over all publicly-funded long-term care programs in their states. For example, Medicaid and Older Americans Act funded services are administered through a combined Medicaid agency/state unit on aging structure. In recent years, services for the ID/DD population have also been brought under the same long-term care services administrative umbrella. Both states have also developed comprehensive information/referral systems that conform to single-entry-point or no-wrong-door principles. In contrast, California's long-term care system is more fragmented and appears to have developed in a less organized, more incremental fashion, without the strategic vision that a series of nationally-known, highly-respected leaders brought to the original design and subsequent tradition of continuous quality improvement of the Oregon and Washington state LTC systems.¹⁴

D. Has Investing More in HCBS or Promoting Increased Use of HCBS Reduced California's Nursing Home Use?

There is considerable debate over whether or how much, across the U.S., greater proportionate Medicaid LTC spending on HCBS results in actual reductions in use of nursing homes or other institutions. Study findings are equivocal; that is, some show reductions; others do not. It very much depends on the measures used and also on the time frames studied.

However, in the specific case of California there is very strong evidence that California's long-term investment in HCBS has paid off in lower use of nursing home care especially for the chronically disabled Medicaid-eligible elderly. For example, it is especially interesting to compare the annual rate at which elderly IHSS program participants are admitted to long-stay (Medicaid-financed) nursing home care with the annual rate at which a nationally representative sample of chronically disabled older Americans with at least one ADL limitation (personal care) entered nursing homes for stays of 60 days or longer (regardless of payer source). Our national data are from the 1999 National Long-Term Care Survey linked to nursing home Minimum Data Set (MDS) assessment data. These data enabled us to measure the rate and characteristics of chronically disabled elders residing in the community in 1999 who were admitted to nursing homes for stays of at least 60 days over the next several years.¹⁵ The IHSS annual nursing home admission rate for elderly program participants in 2005 comes from an ASPE-sponsored evaluation of IHSS, with special emphasis on the IHSS Plus "1115" waiver population¹⁶.

The annual incidence of nursing home admission for elderly IHSS recipients was 5.9 percent, compared to 9.5 percent for all similarly disabled NLTCs respondents. However, the more meaningful comparison is between elderly IHSS recipients and NLTCs respondents receiving any paid care (regardless of income, Medicaid eligibility or payer source for paid care). This is because, even though paid HCBS is intended to prevent or postpone nursing home use, it is actually (for the NLTCs nationally representative disabled elderly population) a strong predictor of subsequent long-stay nursing home use. Within the elderly population with ADL needs, use of paid care is associated with higher physical and cognitive disability levels and high caregiver stress. High family caregiver stress (especially high physical strain and financial hardship) is, independent of ADL disability, a strong predictor of long-stay nursing home placement. In the NLTCs, 14.8 percent of respondents with ADL limitations receiving paid care were admitted for long-stay nursing home care within the following year. This indicates that IHSS was more than twice as effective in reducing long-stay nursing home admissions among similarly disabled elderly users of paid care nationally.

Another indicator that strongly suggests California's historical pattern of greater investment in HCBS has paid off in lower Medicaid nursing home use emerged from another one of the MAX Medicaid claims analyses that ASPE contracted with Mathematic Policy Research to carry out. This was an analysis of Medicaid enrollees beginning spells of Medicaid financed nursing facility service use between July 1, 2001 and December 31, 2002 in 46 states.¹⁷ This analysis found that duration of nursing home spells was negatively associated with availability of (relatively higher spending on and use of) Medicaid community care. Moreover, higher percentages of Medicaid enrollees with new nursing home spells who had previously used Medicaid-financed HCBS tended

to be associated with shorter nursing home stays. California and Oregon had the shortest median lengths of stay (4 months), followed by Alaska, Maine, and Washington (5 months) compared to the average for all 46 states in the study of 8 months. In California over a quarter (25.6%) and in Maine over one third (36.8 %) of Medicaid enrollees with new nursing home spells had previously received Medicaid financed community care (use rates of Medicaid community care prior to nursing home use were not available for Oregon or Washington state). In contrast, low percentages of Medicaid enrollees with new nursing home stays who had previously received Medicaid-funded community care was associated with longer than average nursing home stays in Louisiana, North Dakota, and Maryland.

III. Cost Effectiveness of HCBS Compared to Institutional LTC

Advocates often argue that HCBS will pay for itself via nursing home cost savings. Policy researchers have known for a long time that this is highly unlikely in the short term.

It is important to note that when Congress passed the 1915 (c) waiver legislation in 1981, much federal government-sponsored policy research had already been done or was underway on HCBS alternatives to institutionalization. This included numerous controlled experimental design demonstration programs. Many study results were already in and it was clear that expansion of HCBS was unlikely to pay for itself with savings from reduced institutional use. Indeed, subsequent research only confirmed such findings. The January 1981 CMS report stated:

There is little evidence that coverage of community-based and in-home services reduces total public expenditures in an open-ended fee-for-service system. Indeed, most of the evidence is to the contrary. This is because expanded service benefits largely go to a new (additional) service population rather than substituting for nursing home care.¹⁸

Accordingly, the report emphasized reasons other than net LTC cost savings for expanded funding for HCBS, including the preferences of those in need of long-term care and their family caregivers, reducing family caregiver stress and burden, meeting unmet needs for assistance among the persons with disabilities residing in the community (especially those with weak informal supports), and improved quality of care and quality of life (given what was known about the generally low quality of life and poor quality of care in institutional settings). Based on this and other available policy analysis, Congress knew (or should have known) in 1981 that the costs of HCBS provided under 1915 (c) waiver programs would not be fully offset by reductions in nursing home use that could be expected to occur as a result of HCBS waivers.

Nevertheless, the 1915 (c) waiver legislation stated that HCBS waiver coverage should be limited to Medicaid eligible individuals who “but for” these services would “require care in a nursing home.” The federal Office of Management and Budget interpreted this language to mean that HCBS waiver coverage should be restricted to Medicaid

beneficiaries who not only qualified for institutional coverage based on the state's medical and functional need criteria but who were virtually certain to actually enter institutions in the absence of Medicaid-financed HCBS. Moreover, OMB imposed a further condition that states had to have sufficient institutional capacity available to serve all HCBS waiver program participants since, if there were insufficient bed supply, such individuals could not and would not actually be served in institutions in the absence of HCBS coverage. Over time, these requirements proved untenable.

Initially, both policy researchers and state officials invested considerable effort in devising methods to help states target newly available HCBS benefits only to those Medicaid beneficiaries with the greatest likelihood of entering nursing homes. However, subsequent evaluation research found that whereas severity of ADL disability and cognitive impairment were (and remain) powerful and reliable predictors of increased likelihood of nursing home admission, targeting primarily on the basis of these factors and even adding others such as weak family supports, did not yield highly accurate predictions concerning which Medicaid beneficiaries entitled to nursing home coverage would actually be admitted. Decades later, we now know a little more about who uses institutional care and who does not. For example, we know that having family caregivers available, especially spouses or other family caregivers living in the same household decreases likelihood of nursing home admission. On the other hand, high informal caregiver stress (especially physical strain and financial hardship) is the most powerful predictor, once disability severity is controlled, for long-stay nursing home placement. However, it is still not easy to predict which informal caregivers will experience high stress and, if they do, which ones will burn out and which ones will keep going. It is especially difficult to build such measures into bureaucratic assessment instruments. In sum, "precision targeting" of chronically disabled elders certain to require institutional care in the absence of HCBS (or enough HCBS) remains elusive.

In the meantime, the prevalence rate of nursing home use among older Americans regardless of income or Medicaid eligibility has decreased by a full percentage point (from 5 percent to 4 percent) since 1995.¹⁹ This has occurred both because of increased availability of Medicaid-funded HCBS and also because of increased private spending on HCBS, including spending on assisted living. It is impossible to say how much nursing home use has been prevented or postponed as a result of Medicaid's shift toward greater reliance on HCBS and how much is due to the growing private market for alternatives to nursing home care. In any case, nursing home residents are now much more severely disabled than they were three decades ago and more disabled and the average nursing home resident has a level of disability well above the minimum required to qualify for Medicaid coverage. The acuity level of California nursing home residents is the fourth highest in the nation.²⁰ This, however, means that all those easiest to divert have been diverted. At increasingly higher levels of disability and lacking strong family supports there may be increasing certainty about the risk of nursing home, but by the same token there is increasingly less certainty that enough, lower cost, HCBS can be made available to prevent institutionalization.

As an LTC system re-balances toward HCBS, institutional bed capacity ceases to expand. Indeed, once a “tipping point” in favor of HCBS has been reached, bed capacity declines (although in states that “over-bedded” during the 1960s through early 1980s, reduction in bed capacity has often been a very slow process). Situations have arisen in some states where institutional bed capacity (particularly in state owned/operated ICFs/MR) decreased much more rapidly than growth in capacity to serve eligible individuals in the community. This occurred in Florida a little over ten years ago. Advocates for people with developmental disabilities sued. The state argued that HCBS waiver programs were optional and enrollment could legally be capped at any number the state chose, even if this resulted in lengthy waiting lists (waiting times then averaged at least two years). However, the court ruled that the state ICF/MR benefit, although optional, was a state plan benefit and therefore had to be provided as an entitlement to all who qualified for and requested it. Therefore, unless the state chose to eliminate all optional coverage for the developmentally disabled, the state had to decide either to re-build institutional (ICF/MR) capacity or fund a sufficient level of alternative HCBS. The Governor and the legislature elected to increase HCBS waiver funding for the developmental disabled by 400 percent over the next three years.²¹

We have yet to observe, however, the outcome of a scenario involving a state with nursing home bed capacity well below the national average deciding to cut Medicaid spending by significantly reducing access to previously available HCBS among SSI/Medicaid eligible elders and physically disabled younger adults. Nursing home occupancy rates nationally averaged 84 percent in 2008 (85 percent in California). Thus, in most states, including California, a significant increase in demand for long stay nursing home care among Medicaid eligible individuals having a need-based entitlement to this mandatory covered service could not be accommodated by the existing bed supply.

One possibility is that unmet demand for nursing home care would end up being met via the Medicaid home health benefit. Certified HHAs are the only permissible provider of Medicaid home health services and they are paid a considerably higher rate for an hour of personal care services than non-certified home care agencies or independent provider personal care aides. Home health services are a mandatory Medicaid benefit and coverage of HHA services cannot be denied to Medicaid beneficiaries entitled to nursing facility coverage. Specifically, Medicaid law does not permit states to apply the Medicare HHA rules limiting coverage to individuals who are homebound or limiting coverage of home health aide services to individuals who require skilled nursing or therapy services.²²

Given the changes that have occurred in federal and state LTC policy, I am not certain how much current policy relevance can be attributed to the findings of past research on cost-effectiveness of HCBS alternatives to institutionalization that, for the most part, is now over two decades old. Ten years ago, ASPE published a paper I had written summarizing those research results.²³ The studies found that home and community-based services did not generate sufficient savings from reduced nursing home use to pay for themselves. Indeed, total spending on LTC increased because many individuals who would not otherwise have used nursing home care received HCBS.

That said, it is also true that we now have a better sense of the flaws and limitations of the existing body of research on cost-effectiveness of HCBS alternatives to nursing home care, especially the research carried out in the late 1970s through the mid 1980s.

Although most of these studies were scientifically rigorous in relying on controlled experimental design, they were problematic in other ways. For example, the largest research and demonstration program, the ten-site National Channeling Demonstration (1981-1984), recruited volunteer participants who were non-Medicaid eligible. Thus, even had these frail elderly been more likely to be admitted to nursing homes than they actually were found to be, they would not have generated any Medicaid nursing home costs until after staying long enough in a nursing home to spend-down to Medicaid eligibility. Channeling only measured outcomes, including costs, for a maximum of 18 months. This is a very short-time frame. Nearly twenty years later, the same evaluation contractor compared treatment/group costs participants in Arkansas' Medicaid Cash and Counseling demonstration. In this study, costs were tracked for three years. Although nursing home reductions were seen in the first year, it took three years for cost savings from reduced nursing home use to fully offset the increased costs to Medicaid that resulted from treatment group members having improved access to HCBS.²⁴ In retrospect, it is also clear that Channeling and some other earlier demonstration programs incorporated expensive models of professional case-management that did not generate enough nursing home savings to offset case management, let alone direct HCBS, costs. Cash and counseling and other consumer-directed service delivery models (like California's IHSS program) spend far less on administrative overhead.

IV. Concluding Recommendations for LTC System Improvements in California

I was asked to offer some thoughts about how California might improve its LTC system. From my vantage point in the federal government, it is clear that, in response to the national financial crisis of the past two years, many, indeed most states, are struggling simply to protect and sustain the substantial gains they have made in regard to overcoming Medicaid's historically entrenched institutional bias. For most states, these gains have been made primarily over the past decade. In the case of California, the threat posed by the financial crisis is particularly poignant because California has built, over a period of some 35 years, one of the top five LTC systems in the U.S. for the elderly and younger physically disabled. Under the circumstances, it would be presumptuous of me to say to Californians, as the saying goes: I'm from the federal government and I'm here to help you! I think my advice is best confined to suggesting improvements that can be implemented at no or low cost to the state via making use of available federal grant monies. Two such recommendations come to mind. First, California already has a Money-Follows-the-Person grant and can take advantage of the opportunity CMS will soon be offering to MFP grantee states to extend their program for a longer period of time under provisions enacted in the recent health reform legislation. Second, California already has a five year grant (still ongoing) from CMS to improve its infrastructure for long-term care services information/referral. California has an excellent aging/disability resource center in San Diego, established several years ago with grant funding from the Administration on Aging and CMS. I have been reliably informed that the San Diego

ADRC is among the best in the country. California could benefit from propagating the model in other areas across the state.

¹ U.S. Department of Health and Human Services, Office of Legislation and Policy, Health Care Financing Administration (now Centers for Medicare and Medicaid). 1981 (January). Long-Term Care: Background and Future Directions. Washington, D.C.: Health Care Financing Administration, p. 26.

² Smith, Gary, et al. 2000 (October). Understanding Medicaid Home and Community Services: A Primer. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/primer.htm#Chap1> (downloaded May 17, 2010). It should be noted that, during this time period, California routinely under-reported HCBS spending on IHSS and HCBS waivers for the IDD population. Thus, California may have deserved to be ranked among the top-performing states but this was not reflected in statistics that relied on HCFA 64 reporting.

³ Jackson, M.E., Doty, P. 1999 (March 4). Medicare Home Health Services 1989-1994: Patterns of Benefit Use Among Chronically Disabled Elders. Washington, D.C. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at: <http://aspe.hhs.gov/daltcp/reports/medhhs.htm> (downloaded May 17, 2010).

⁴ Spillman B, Doty P. Formal and Informal Eldercare: Key Findings, Trends, and Policy Implications from the 2004 National Long-Term Care Survey and Informal Caregiver Supplement. Presentation at NIA/NACDA Workshop, May 28-29, 2009. Bethesda, MD.: National Institute on Aging, Behavioral and Social Science Division.

⁵ Unpublished tabulations prepared for ASPE by Brenda Spillman, the Urban Institute.

⁶ Legislative Analyst's Office (California). January 21, 2010. Considering the State Costs and Benefits: In-Home Supportive Services Program. downloaded May 14, 2010 from http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.aspx

⁷ For more information on the RealChoice, Systems/Change grant funding see http://www.cms.gov/CommunityServices/30_RCSC.asp#TopOfPage

⁸ These statistics are available at http://hcbs.org/moreInfo.php/nb/doc/2795/HCBS_Waiver_Expenditures_FY03-08 (downloaded May 17, 2010).

⁹ Mollica, R. and Hendrickson, L. 2009 (November). Home and Community-Based Long-Term Care: Recommendations to Improve Access for Californians. Prepared for California Community Choices, California Health and Human Services agency, downloaded May 14, 2010 from http://www.hcbs.org/moreInfo.php/topic/205/doc/2730/Home_and_Community-Based_Long-Term_Care_Recommend

¹⁰ Wenzlow, A, Schmitz, R., Shepperson, K. 2008 (January 18). A Profile of Medicaid Institutional and Community Long-Term Care Services Use and Cost among the Aged and Disabled Using MAX 2002: Final Report. Prepared by Mathematica Policy Research, Inc. Princeton, N.J. for the Office of the Assistant Secretary for Planning and Evaluation. Downloaded May 14, 2010 from <http://aspe.hhs.gov/daltcp/reports/2008/profileMAX.htm>

¹¹ The Personal Assistance Services(PAS) Center at the University of California/San Francisco regularly tracks HCBS waiver waiting lists under a grant from the Department of Education's National Institute for Disability and Rehabilitation Research. Some reports are available at <http://www.kff.org> However, in recent years UC/SFs findings have been most readily available on the Kaiser Family Foundation website. The most recent (2008) wait list statistics are available at <http://www.statehealthfacts.org/comparebar.jsp?ind=246&cat=4> See also, Auerbach, R., Reinhard, S. 2006. Challenges Posed by Waiver Waiting Lists. New Brunswick, N.J.: Rutgers University Center for State Health Policy available at <http://www.hcbs.org/moreInfo.php/nb/doc/1786> (downloaded May 17, 2010).

¹² Doty P, Benjamin AE, Matthias RE, Franke, T. 1999 (April). In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-directed and Professional Management Models of Service Delivery: A Non-Technical Summary. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/ihss.htm> (downloaded May 14, 2010).

¹³ Newcomer, R, Kang, T. 2008 (July). Analysis of the California In-Home Supportive Services (IHSS) Plus Waiver Demonstration Program. Prepared by the University of California/San Francisco and Research Triangle Institute for the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services. Downloaded May 14, 2010 from <http://aspe.hhs.gov/daltcp/reports/2008/IHSSPlus.htm>

¹⁴ These leaders include Dick Ladd, Jim Wilson, Roger Auerbach, and James Toews in Oregon and Charlie Reed and Kathy Leitch in Washington State.

¹⁵ Spillman, BC, Long, SK. 2009 (Summer). Does High Caregiver Stress Predict Nursing Home Entry? Inquiry. 46: 140-161 and additional unpublished tabulations conducted for ASPE by Brenda Spillman of the Urban Institute.

¹⁶ Newcomer, R, Kang, T. 2008 (July). Analysis of the California In-Home Supportive Services (IHSS) Plus Waiver Demonstration Program. Prepared by the University of California/San Francisco and Research Triangle Institute for the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services. Downloaded May 14, 2010 from <http://aspe.hhs.gov/daltcp/reports/2008/IHSSPlus.htm>

¹⁷ Wenzlow, A, Schmitz, R. and Gurvey, J. 2008 (January 30). Medicaid-Financed Nursing Home Services: Characteristics of People Served and their Patterns of Care, 2001-2002. Prepared by Mathematica Policy Research, Inc. Princeton, N.J. for the Office of the Assistant Secretary for Planning and Evaluation. Downloaded May 14, 2010 from <http://aspe.hhs.gov/daltcp/reports/2008/mfNHserv.htm>

¹⁸ U.S. Department of Health and Human Services, Office of Legislation and Policy, Health Care Financing Administration (now Centers for Medicare and Medicaid). 1981 (January). Long-Term Care: Background and Future Directions. Washington, D.C.: Health Care Financing Administration, p.43.

¹⁹ Federal Interagency Forum on Aging Related Statistics.. Older Americans 2008, Key Indicators of Well-Being, p.58 Washington, D.C.: U.S. Government Printing Office. March 2008.

²⁰ Harrington, C., Carillo, H., Blank, BW. 2009 (November). Nursing Facilities, Staffing, Residents, and Facility Deficiencies, 2003 through 2008. San Francisco, CA: Department of Social and Behavioral Sciences, University of California/ San Francisco.

²¹ *Wolf Prado-Steiman v. Bush et al.* cited in Ng, T, Wong, A, Harrington, C. 2009 (August). Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans. San Francisco, CA: PASCenter, University of California/San Francisco. See Table II Olmstead and Related Lawsuits <http://www.pascenter.org/olmstead/olmsteadcases.php>

²² Smith, Gary, et al. 2000 (October). Understanding Medicaid Home and Community Services: A Primer. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/primer.htm#Chap3> (downloaded May 17, 2010).

²³ Doty, P. 2000 (June). Cost-Effectiveness of Home and Community-Based Services. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/costeff.htm> (downloaded May 14, 2010).

²⁴ Dale, S, Brown R. 2006. Reducing nursing home use through consumer-directed personal care service. Medical Care. 44(8)760-7.