Long-Term Care: Aging and Disabled Adults
Literature Review

Part I

Larry Polivka

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Direct correspondence to:
Larry Polivka, Ph.D.
The Claude Pepper Center at
The Florida State University
636 West Call Street
Tallahassee, FL 32304
lpolivka2@fsu.edu

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Long-term Care (LTC) has slowly emerged as a public policy issue over the last several years, but has yet to achieve the level of visibility of issues such as the growing number of medically uninsured, or the fiscal sustainability of Medicare. The aging of the Baby Boom generation, however, is likely to make LTC an increasingly urgent concern for individuals and policy makers as the age 65 plus population doubles over the next 30 years, and the age 85 plus population triples. These demographic trends will create a growing demand for LTC services which will substantially increase the financial pressure on families and the public sector as they struggle to cover the cost of care. The growth in LTC needs and costs is likely to push LTC to the top of the domestic policy agenda within the next ten years, and increase public awareness of the gap between what we know and what we do in LTC. These populations are increasing at even faster rates in most of the states in the Appalachian Region, which is likely to make LTC an even more urgent public policy issue here than elsewhere.

Approximately ten million Americans require some form of LTC assistance with the activities of daily living (ADLs) which include eating, bathing, dressing, toileting, walking, and transferring. This population is set to increase by eight to ten million with the growth of the age 65 plus population over the next three decades from 36 to 78 million. About 1.4 million people now receive LTC assistance in nursing homes; over a million receive paid assistance from either private or public sources; and the remaining six million plus are cared for by unpaid caregivers in the informal system, mainly wives and daughters (Johnson, Toohey and Wiener, 2007). This informal help, which constitutes 70 to 80 percent of all LTC assistance was worth over $350 billion in 2006, which is about $125 billion more than the dollar value of all paid (public and private) assistance, and four times the amount of privately paid formal care ($77 billion). In November 2006, between 30 and 38 million adult caregivers provided care to adults with LTC needs. Caregivers averaged 21 hours of care per week and much higher for those providing care for someone with Alzheimer’s disease. Caregivers averaged about $200 per month in out-of-pocket spending on LTC-related expenses. LTC is clearly a very big issue from both a public policy and personal experience perspective, and its saliency will increase enormously over the next several decades (Gibson and Houser, 2007).

The health and functional status of the age 65 plus population has improved significantly over the past 30 years and further improvement is expected in the future. Nevertheless, the need for LTC assistance will increase very substantially with the doubling of the older population over the next 30 years unless there is a dramatic breakthrough in the prevention and treatment of Alzheimer’s disease. The capacity of the “unpaid” informal care system to provide the current level of assistance is likely to shrink due to relatively low birth rates since 1960 (smaller families) and an increase in the divorce rate over the last several decades. In 2040, there will be only nine adults ages 25 to 64 to support each disabled older adult, down from 15 younger adults in 2000. The number receiving paid home care is likely to more than double by 2040, growing from 2.2 million to over 5 million, and the number receiving care in nursing homes will double to about 2.7 million. The average number of hours of paid help per disabled older person will grow by about a third, from 163 hours per month to 220 hours. This projected growth in the need for LTC services, and the declining availability of paid and unpaid caregivers is likely to drive future LTC costs well above average annual increases of the past. These trends are likely to increase the cost of paid LTC services to over $1 trillion by 2035. This growth in LTC
spending will make the issue of how these resources are used an increasingly urgent matter (Johnson et al., 2007).

About 75 percent of all public LTC expenditures currently support nursing home care, and the other 25 percent is used to provide LTC services in the community, mainly in-home services like home health care, personal care, homemaker, and respite services (Trizt, 2006). Nursing home care now costs $60,000 to $100,000 annually; assisted living costs $25,000 to $50,000 annually; and in-home care between $10,000 and $20,000 a year for those at risk of needing nursing level care (Genworth Financial, 2008). Total LTC spending exceeded $200 billion in 2006, with Medicaid covering 49 percent; Medicare 19 percent; private insurance 7 percent; and out-of-pocket spending covering 21 percent. Medicaid also paid over $25 billion for home- and community-based services (HCBS), which, unlike nursing home care, are not entitlement services for those who meet stringent financial and level-of-need eligibility criteria (Kaiser Commission, 2007). About 25 percent of this $25 billion was spent on those age 65 plus, and most of the remaining 75 percent on the younger, developmentally disabled population. This level of spending on HCBS programs for the developmentally disabled reflects the success of advocacy efforts on behalf of this population since the early 1970s in most states, as well as at the national level (Kassner, Reinhard, Fox-Grage, Houser & Accius, 2008).

Another recent study found that institutional and community LTC expenditures were much more balanced among young disabled Medicaid enrollees than their aged counterparts in 2002: over half of LTC expenditures were for community-based services among younger disabled enrollees, but less than 20 percent were for community-based care among those over 65; community-based service expenditures as a share of total LTC expenditures ranged from 50 percent for people under age 65, 31 percent for people between ages 65 and 74, 21 percent for people between ages 75 and 84, and 13 percent for those age 85 and older; and rates of community-based service utilization were higher, but followed a similar pattern by age, which reflects the greater priority that most states have historically placed on the development of HCBS programs for younger disabled populations than for the frail elderly (Wenzlow, Schmitz & Shepperson, 2008).

This paper is divided into four sections. The study begins with an assessment of the gap between what we know and do in LTC, and follows with a discussion of barriers that have prevented ending these differences. The second section describes LTC trends in the U.S. A brief description and analysis of factors which been successful in bridging the gap among states are noted in section three. The fourth and final section addresses the labor shortages in LTC services, and discusses strategies for responding to them in the future.

Section I. The knowledge-practice gap: Long-term care in the U.S.

The fact that we spend so much more on nursing home care than community-based care for older individuals with LTC needs is the fiscal manifestation of the still large gap between what we know and what we do in publicly supported LTC in most U.S. states. This gap needlessly damages the lives of people who require LTC assistance whose preference is to receive this care in their own homes, or in a community-residential setting rather than in the institutional constraints that still characterize the vast majority of nursing homes. The relatively limited level
of public funding for HCBS alternatives to nursing home care in most states, however, severely restricts their availability for those without the means to pay for them privately.

Disabled persons of all ages vastly prefer HCBS to nursing home care or any other form of institutional care. This preference is likely to be even stronger among members of the baby boom generation from whose ranks those needing LTC assistance will emerge over the next 30 years (Matthew Greenwald & Associates, 2003). The choice for in-home- and community-based LTC services is matched by a growing body of research which demonstrates the relative cost-effectiveness of these services, if properly administered, and the success of a few states in developing an expansive array of community-based services over the last 20 years.

Only nine states, however, now spend 40 percent or more of their public LTC dollars on HCBS programs. Oregon, Washington, New Mexico, and Alaska now spend 50 percent or more on HCBS programs, which is a threshold most states passed years ago in their programs for the developmentally disabled (CMS 64 Data, 2007). Every state spending 40 percent or more on HCBS programs for the elderly is close to, or below the national per capita age 65 plus LTC spending average. This level of efficiency permits these states to meet a greater share of the need for LTC services than other states with less balanced LTC systems, while containing total LTC spending.

Another recent analysis found that duration of nursing home spells was negatively associated with availability of community-based services in a state. States with significant community-based programs tended to have a higher percentage of people using community-based services before entering nursing homes. Oregon, the state with the most extensive community-based LTC system, had the smallest percentage of enrollees with spells lasting longer than a year (Wenzlow, Schmitz & Gurvey, 2008).

One of the reasons for the relatively slow growth of home- and community-based long-term care for the frail elderly is the perception that community-based care is not cost-effective because it lacks the capacity to substitute for institutional care by diverting seriously impaired elderly from nursing home placement. Findings reported, however, in articles by Greene et al. (1995); Harrow et al. (1995); Jette et al. (1995); Miller et al. (1998); Rhoades (1998); Weissert et al. (1997); Hollander and Chappel (2002); APS Healthcare (2005); and Mitchell et al. (2006) indicate that there is substantial potential for cost-effective and improved LTC in the expansion of well-designed and administered home- and community-based programs. These studies have found that by targeting certain services to high risk recipients in increased quantities (number of nurse visits, hours of homemaker services, etc.), community programs tend to reduce nursing home use. These findings have been used to help identify combinations of client and service characteristics that produce the most cost-effective results in terms of avoiding unnecessary institutionalization of impaired older people.

Recent studies of Medicaid-funded HCBS programs in Florida covering a five-year period from 2000 to 2005 found that all of them were cost-effective alternatives to nursing home care (Mitchell, Salmon & Polivka, 2006; Mitchell, Polivka & Wang, 2007). These programs ranged from one-quarter to one-half as expensive as the Medicaid nursing home program after matching the impairment and caregiver resource profiles of entrants to the HCBS programs with the
profiles of the nursing home new entrant population over the three-year study period. One-quarter to one-half of the HCBS entrants had profiles similar to those of the nursing home entrants. Nursing home admission rates from the HCBS programs ranged from 9 to 27 percent over a 36-month follow-up period. Many more participants died while in the HCBS programs (40 percent plus) than exited for a nursing home (20 percent or less).

The difference between Nursing Home Diversion only and the least expensive HCBS waiver experience (Aged and Disabled Adult Waiver only) was $954 PMPM (per member, per month costs). This was after controlling for frailty, chronic health conditions, demographics, living in the community, and change in living situation and functional status. Nursing Home Diversion beneficiaries enter long-term nursing home care approximately two months later than the HCBS waiver program with the lowest months until long-term nursing home entry (again Aged and Disabled Adult Waiver only). The average Medicaid nursing home per diem was $120. The $7,740 in savings from delayed long-term nursing home entry come at a cost of $36,372 over the 36-month follow-up period in total Medicaid claims for the Nursing Home Diversion only HCBS entrants compared with the least expensive HCBS alternative, Aged & Disabled Adult Waiver only entrants.

Given the increasing trajectory in Nursing Home Diversion enrollments (between SFY 2002-03 and SFY 2005-06: an annual increase of 261 percent), a different apportionment of available slots across HCBS programs or a reduction in the capitation rate for NHD could increase the number of Medicaid beneficiaries receiving needed HCBS services and potentially divert more of them from nursing home placement. The Nursing Home Diversion statewide average capitation rate was reduced in 2005, and is now set at the provider level clearly increasing efficiency within the program. Nursing Home Diversion, however, is still substantially more expensive than the other waiver programs and additional efficiency initiatives may be in order. Cost data from the 2006 utilization study, conducted for DOE by the Data Center, would seem to indicate that an efficiency reduction in the NHD capitation rate might be appropriate. The study reported on data regarding service utilization by 9,100 consumers enrolled in the Long Term Care Nursing Home Diversion Program from nine plans in SFY 2004/2005. The study (Mitchell et al., 2007) found that:

PMPM utilization averaged $1483, of which $363 was for acute care services and $991 for long-term care services. There was considerable variation among the plans. Prescriptions cost is the largest acute care service category, exceeding every other acute care service category for each plan. On average, across the plans, PMPM prescriptions cost averaged $278, 76.6 percent of the acute care service utilization experience. Most of the plans make wide use of assisted living facilities as a locus for personal care. The estimate for average PMPM cost for ALF care was $460 among the plans. The use of long-term skilled nursing facility care is mixed among the plans. For the Long Term Care Nursing Home Diversion Program, reported PMPM long-term nursing home costs were $128, which is 11.95 percent of long-term care services.

The issues raised in the State Data Center on Aging evaluations should be considered in the context of the state’s largely successful effort over the last 25 years to construct a better balanced, consumer-oriented LTC system based on the expansion of HCBS programs and improved quality of nursing home care (staffing increases). All of Florida’s HCBS waiver
programs are relatively cost-effective alternatives to nursing home care for several thousand poor, frail elderly persons, especially those without caregivers. Even the most expensive program Nursing Home Diversion is about $2,500 less expensive per month than Medicaid-funded nursing home care.

The mere availability, however, of HCBS programs is not sufficient to maximize opportunities to create a more efficient and cost-effective LTC system. Methods of organizing, administering, and financing LTC are critical to achieving these goals and will be discussed at length later in the article. The availability of HCBS programs, however, is a necessary, if not sufficient, condition for the development of more efficient and consumer-oriented LTC systems and for closing the gap between what we know and what we do in providing LTC services in most states.

Many states are focusing less on closing the knowledge and practice gap in LTC and more on limiting the growth of their Medicaid-funded HCBS programs (Kaiser Commission, 2007). The survey found that the number of persons on waiting lists for waiver services was increasing. In 2006, 280,176 individuals were on waiting lists for 93 waivers in 31 states, up from 260,916 individuals in 2005 and 206,427 individuals in 2004. The average length of time an individual spent on a waiting list ranged from 13 months for aged/disabled and children’s waivers to 42 months for aged waivers. As noted earlier, even with the declining impairment rates among the elderly and an overall improvement in health care status, the need for LTC is projected to increase by 50 to 100 percent over the next 25 years, which will put a great deal of pressure on Medicaid budgets in many states (Johnson et al., 2007). Creating more balanced LTC systems by expanding HCBS programs and containing the use of nursing home care is critical to meeting the large projected growth in the need for LTC services over the next two decades in a cost-effective manner.

**Barriers to closing the gap**

Creating more balanced LTC systems by expanding HCBS programs and containing the use of nursing home care will require that policy makers, advocates, and the media confront the several factors that have made change slow and limited the influence of the 20-year old Oregon and Washington model despite the growing evidence of public support for community-based care. These factors include the following:

- Although public surveys show support for community-based alternatives to nursing home care, the issue has not achieved much political salience. This reflects the fact that advocacy efforts for LTC reform for elders have been weak to non-existent in most states and at the national level in comparison to the advocacy activities of the DD community over the last 30 years. Oregon is a major exception to this central tendency. Several voluntary organizations, especially the Oregon Retired Teachers Association, played major roles in achieving passage of the landmark 1981 LTC legislation mandating the development of a home- and community-based LTC system.¹ Increased advocacy efforts

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¹ Private communication with Richard Ladd, Director of the Division of Senior and Disabled Adult Services, in Oct. 1989.
will be essential in offsetting the still powerful influence of the nursing home lobby in most states in resisting a qualitative shift in the allocation of LTC resources.

- Policy makers’ fear of the “woodwork” effect continues to slow the expansion of HCBS programs in many states. This fear is based on the perception that the HCBS programs are so much more appealing than nursing home care that their expansion will attract many new consumers and eventually make the LTC budget unsustainable. The experience, however, in Oregon, Washington, and the few other states with relatively balanced LTC systems should assure policy makers that the costs of HCBS-oriented LTC systems can be effectively contained through uniform and rigorous needs assessment, service planning, care management, and the expansion of community-based services that cost less than nursing home care. Oregon, after 25 years of HCBS growth, spends $225 annually per resident on LTC services, which is $75 less than the national average and the 11th lowest among the states (CMS 64 Data, 2007). A recent report by Kassner et al. (2008) on state LTC systems noted that:

States like Oregon and Washington have demonstrated that they can serve more people at a lower cost per case by using noninstitutional settings whenever preferable and feasible. These states do serve more people with “unmet needs,” absorbing them in the savings achieved through lower nursing home utilization and overcoming the fear of uncontrollable spending demands. Other states are just learning these lessons, which may become more evident through the Money Follows the Person demonstration.

- The aging services agency in most states is relatively weak in comparison to the power exercised by the state Medicaid office and tends to have relatively limited influence on Medicaid policy, either administratively or legislatively. In Oregon and Washington, control over the Medicaid LTC budget has been lodged in the state aging services agencies, which gives them consolidated authority to make policy and budget decisions regarding the allocation of LTC resources. This kind of organizational arrangement gives control of all public LTC to the aging network and is one of the major reasons Oregon and Washington have been able to make such dramatic changes in their LTC systems.

State Medicaid offices and the Center for Medicare and Medicaid Services (CMS) have become more supportive of increased HCBS funding over the last 20 years, but they have not tended to strongly support the kind of qualitative shift in funding priorities carried out by Oregon and Washington. In the absence of administrative consolidation and aging network control of all LTC resources, a few states have adopted managed LTC systems that fold all Medicaid LTC funds under a single capitated rate and empower the LTC agency and the consumer to make decisions about how these resources will be used.

- The earlier mentioned influence of the nursing home industry has also been a factor in slowing the growth of HCBS programs. Nursing homes receive about $48 billion in Medicaid funding annually, which gives them considerable leverage with many governors, state legislatures and Congress (Kaiser Commission, 2006). Their influence has declined over the last several years and some nursing home state associations have adopted more sophisticated lobbying and public relations’ strategies that include support
for increased HCBS funding, but only after the annual budget needs of the nursing home industry have been met. One indication of the continuing strength of the industry is that nursing home budgets continue to increase even as nursing home populations level off or decline. Some of this increase reflects efforts to meet the greater health and nursing needs of an increasingly greater percentage of patients with high acuity (more impaired and sicker) levels.

- A fifth factor that has the potential to hinder the growth of publicly funded HCBS programs in the future is the view in some quarters that private LTC insurance should be an alternative to expansion of public coverage for LTC services. The effort to expand the use of private insurance is associated with the initiatives designed to restrict eligibility and funding for Medicaid supported LTC programs. These initiatives include the recently successful Deficit Reduction Act of 2005 effort to extend the “look back” period for asset transfers from three to five years (Kaiser Commission, 2008). The rationale for this initiative was the claim that many Medicaid LTC consumers are relatively affluent and deliberately impoverish themselves to become eligible for Medicaid by transferring large amounts of assets to relatives and friends. This claim was believed by some policy makers, even in the absence of any empirical support for its validity. In fact, the most recent study indicates that the percentage of Medicaid LTC consumers who have transferred significant assets in the last five years is well under five percent. This reflects the reality that most older people do not have many assets other than their own home.

Our findings indicate that relatively few people who become Medicaid nursing home residents have transferred a substantial number of dollars. Asset transfer patterns were most common among nursing home residents who were “always private pay” meaning they did not receive Medicaid assistance to cover the cost of their nursing home care. Our analysis also estimated the maximum number of dollars that could possibly be recovered by Medicaid if all cases of transferred assets were deemed inappropriate and were collected as program savings and found that even the most aggressive pursuit of transferred assets would recover only about 1 percent of total Medicaid spending for long-term care. (Waidman and Liu, 2006, p. 1)

A major reason for this limited take-up rate is that purchasing private LTC insurance is simply not a prudent strategy for most people under age 60 and is largely unaffordable for those over age 65. According to an extensive analysis by Merlis (2003):

... three out of four married couples could theoretically afford LTCI, using the affordability criteria adopted in a recent study by the American Council of Life Insurers. Yet, only one in five is adequately protected in all the other areas, including retirement savings, life insurance, health insurance, and disability insurance. The data suggest that a great many families who could afford LTCI are not preparing for retirement, or are not protected against life contingencies that could arise before expected retirement age. Most couples, if they have discretionary funds available, would probably be better advised to put them into savings or other forms of insurance before buying LTCI. (p. iv)

Private sources now cover about 28 percent of the costs of formal LTC services which totaled over $200 billion in 2006. About 7 percent of these costs were covered by private
insurance payments and over 9 percent of those ages 60 plus now have a private insurance policy. This percentage has grown rather slowly over the past several years and most LTC policy analysts do not anticipate that more than 20 to 25 percent of the 65 plus population will purchase LTC insurance by 2020. This percentage could probably be increased through innovative savings initiatives, including a variety of state and federal tax incentives, especially sizable tax credits. Several states are now participating in the Medicaid LTC insurance partnership program. Individuals in this program are able to purchase LTC insurance with subsidized provisions that will cover the first two years of LTC services with Medicaid picking up coverage after that. The individual’s assets up to a designated amount are protected in the Partnership Program.

Private insurance may become an increasingly important source of LTC funding over the next 20 years for the more affluent elderly in need of LTC, covering possibly as much as 25 to 30 percent of all LTC costs by 2025. This trend, however, is not likely to reduce the need very much for publicly supported LTC services, including HCBS programs, under the Medicaid program. The vast majority of Medicaid LTC beneficiaries do not have the income needed to purchase LTC insurance nor many assets to protect with insurance. This reality is not likely to change much over the next 30 years. In fact many future retirees will be at substantially greater risk than current retirees of failing to maintain retirement income levels at 80 percent or more of their last wage earned while working (Munnell, 2007). The percentage of retirees failing to achieve this level of retirement income will increase from about 40 percent for the oldest baby boomers to over 60 percent for the youngest boomers by 2030. This means that future retirees are likely to have less income to purchase LTC insurance than current retirees and are likely to be even more dependent on publicly provided LTC services.

Some policy analysts have proposed using reverse mortgages to extract home equity wealth for the purpose of purchasing LTC insurance. Older persons certainly have a lot of asset wealth tied up in their homes, some of which could be used to purchase insurance through reverse mortgages. The potential of this source, however, is limited by the fact that older persons with disabilities have only $57,000 in median home equity. Those with severe disabilities have only $36,000 in home equity. Furthermore, given high loan-related costs (closing costs, insurance), which reduces home equity value by one-third on average, and the high overhead (marketing, commissions, etc.) associated with individually sold LTC insurance, which results in only 60 percent of premiums going to benefits, only about one in three home equity dollars are used to provide LTC services. As noted by Joshua Wiener (2006), this is not an efficient method of funding LTC. Finally, there is a question of why people would want to use home equity to purchase a product designed to protect their major asset.

Section II. Long-term care program trends in the U.S.

Although the gap between what we know and what we do continues to characterize LTC services for the frail elderly, some states have made considerable progress over the last several years. Long-term care services for the DD population are now provided mostly in community settings and almost 70 percent of all public LTC dollars are spent on community-based programs, compared to about 25 percent in the LTC system for older people. Nine states, however, were spending 40 percent or more on home- and community-based services for older persons by 2006, four were spending 50 percent or more, and four were spending 5 percent or
less. Oregon spent 55 percent of their public LTC dollars on HCBS programs, Washington and New Mexico spent 54 percent and Alaska spent 51 percent.

These nine states serve more persons in HCBS programs than in nursing homes. These states achieved these increases by spending $250 to $340 million more on Medicaid-funded HCBS programs between 2001 and 2006, which placed each of them in the top seven states for increased HCBS spending during this period (Kassner et al., 2008).

Progress toward the development of more balanced LTC systems for older persons and disabled younger persons is occurring, albeit at a much slower rate than for the DD population. Between 1999 and 2004, the number of older persons and younger disabled individuals receiving HCBS increased far more than the number served in nursing homes—401,850 vs. 91,877, or 43 percent vs. 6 percent. The HCBS number includes those receiving Medicaid waiver supported services and state plan personal care services. In terms of spending increases, HCBS programs received almost as much ($6.1 billion) as nursing homes ($6.6 billion) between 2001 and 2006, which represented a 65 percent increase for HCBS and 16 percent for nursing homes. In 22 states the total dollar increase was greater for HCBS than for nursing homes and in 27 states the increase was greater for nursing homes. These numbers represent substantial progress toward a more balanced LTC system for the elderly and younger disabled populations, but unless the pace of progress is accelerated, the nation will not reach a 50/50 balance between HCBS and nursing home care until 2020, or over 25 years after this objective was achieved for the DD population.

As noted earlier, a few states have made very substantial progress over the last 20 years and are approaching levels of LTC system balance achieved in most states for the DD population. Oregon and Washington have been the trend setters in developing balanced LTC systems through the use of Medicaid waiver funds since the early 1990s. They have been joined since the late 1990s by New Mexico and Alaska, which now also spend over 50 percent of their public LTC dollars on HCBS programs. Three other states (California, 47 percent; Texas, 42 percent; and Minnesota, 40 percent) were spending over 40 percent on HCBS programs in 2006 and Idaho (39 percent), North Carolina (38 percent) were very close to 40 percent. Minnesota and New Mexico’s progress was especially impressive between 2001 and 2006 when both states increase their percentages spent on HCBS programs by 21 percent and 20 percent, respectively. Seven other states increased their percentage by 10 percent or more between 2001 and 2006. According to the AARP report by Kassner et al. (2008), “A Balancing Act,” from which these data are drawn, Florida is listed as the 41st state in the level of HCBS spending at only 9 percent. This estimate, however, is probably several percentage points too low because the AARP HCBS spending and numbers served estimates do not include managed LTC programs like the Nursing Home Diversion Program, which was funded at about $200 million in 2005/06 and served over 8,000 persons. If these numbers were included in the 2006 estimates, Florida would probably rank somewhere between number 30 and 35 among the states, which would still be considerably below the DD program, which was ranked 27th in 2006, with over 60 percent of their LTC dollars in HCBS programs.

Nine states increased their HCBS Medicaid spending by more than $200 million from 2001 to 2006. California ($1.4 billion), New York ($599 million), Texas $473 million), Minnesota
($368 million) and Pennsylvania ($340 million) increased their HCBS Medicaid spending by over $300 million. On the other hand, 12 states, including Florida ($693 million) increased Medicaid spending on their nursing home programs by $200 million or more. The increase in Florida was mostly a function of appropriations designed to elevate staffing levels among caregivers in nursing homes in an effort to improve the quality of care provided to residents. Nationally, Medicaid HCBS expenditures for disabled populations increased by $6.1 billion to $15.4 billion or 65 percent between 2001 and 2006 and Medicaid nursing home expenditures increased by $6.6 billion to $47.5 billion, or by 17 percent between 2001 and 2006. Florida increased its Medicaid HCBS expenditures by 86 percent and nursing expenditures by 41 percent between 2001 and 2006. The HCBS expenditure percentage would be substantially higher if the Medicaid managed LTC funds were included in the total HCBS amounts for 2006. Fifteen states increased their Medicaid HCBS expenditures by at least 100 percent between 2001 and 2006. In 2004 the average annual spending per HCBS beneficiary was $8,440 and $24,500 per Medicaid nursing home beneficiary. Expenditures per personal care program beneficiary were $9,200 in 2004.

The number of participants in Medicaid HCBS programs grew by 43 percent from 935,160 to 1,34 million between 2001 and 2006 and by a much smaller 6 percent in the Medicaid nursing home program, from 1,615,695 to 1,707,572. In 23 states, the number of nursing home admissions actually declined between 2001 and 2006. This is a clear indication that many states have reached a point in the development of their HCBS programs that allows them to divert enough people from nursing home placement to begin reducing their total nursing home populations. This trend is reflected in the fact that while nursing home admissions increased by 6 percent at the national level, the number of Medicaid nursing home residents on a given day actually declined by 4 percent, from 999,414 to 955,861, between 1999 and 2004, with 12 states experiencing a decline of 10 percent or more, including a 22 percent decline in Oregon, which already had the lowest per capita nursing home population in the nation in 1999.

One major reason for the relatively slow progress in most states in recent years may be the fiscal shortages that many states have had to struggle with since the 2001-02 recession. Many of these “slow progress” states are characterized by a high and growing levels of need for LTC services and below the national average fiscal prospects. That is, these states, many of which are in the Appalachian and Southern Regions, confront a higher than average need for LTC services with fewer fiscal resources than most other states have. On the other hand, however, other states, including Appalachian states like Ohio, have also experienced intermittent fiscal shortages over the last 20 years while continuing to build their home-and community-based LTC systems and enhancing their capacity to offer an expanding array of cost-effective alternatives to nursing home care. Oregon, for example, experienced a very serious fiscal crisis between 2002 and 2004 without losing its hold on first place among the states in offering a balanced system of LTC services. Oregon has continued to reduce its Medicaid-funded nursing home population and now serves over three times as many people in Medicaid-funded HCBS programs as in nursing homes (Kassner et al., 2008).

In short, fiscal shortfalls do not fully account for the fact that LTC system transformation stagnated in many states between 2001 and 2006. Effective sustained advocacy and political leadership are also important factors in LTC reform as they are on every other public policy
issue. It may well be that qualitative change in the balance of LTC services cannot be achieved until reaching a level of HCBS program capacity that is sufficient to break a state’s dependence on nursing home care as the principal site for publicly provided LTC services, as seems to have occurred in nine to ten states at this point. Reaching this tipping point in LTC system transformation is probably at least as dependent on sustained advocacy and political leadership as state fiscal capacities and, in their absence, adequate fiscal resources will not be sufficient to sustain LTC reform initiatives, which will always require enduring champions.

The continuing effectiveness of advocacy efforts and political leadership in support of LTC transformation in Ohio and Pennsylvania is evident in the fact that both recently received almost $100 million in five-year Money Follows the Patient (MFP) grants from CMS, which were the fourth and fifth largest grants awarded the state. Oregon’s interest in maintaining its LTC primacy among the states is clearly demonstrated by their $114 million MFP grant, third highest after Texas and California, which are also among the leading states in HCBS program expansion.

A greater federal role in financing the development of balanced, cost-effective consumer LTC systems may be particularly important for states facing the largest projected increases in the need for publicly supported LTC services due to the fact that many have disproportionately large populations of low-income and functionally impaired elderly persons. These states, which include most of those in the Appalachian Region are also at greater risk of encountering fiscal shortfalls generated by lower average incomes and asset wealth and greater dependence on publicly supported services like LTC. This gap between the growing need for LTC services and the fiscal capacity of states to cover the cost of an adequate response may make a substantially expanded federal role in funding LTC increasingly likely within the next decade.

In the interim, poorer states with rapidly growing populations of low-income disabled populations will need to maximize all available resources in their efforts to expand or initiate efforts to build their HCBS programs and improve their capacities to provide those who need LTC the kinds of individualized community-based services they greatly prefer and in as cost-effective a manner as possible. The best available resource for serving the low-income disabled elderly with few assets in HCBS programs is Medicaid HCBS-waiver funding. Most states, however, 27 years after the inception of this funding source, are still using this funding source to a far more limited extent than they could, as demonstrated by the nine to ten states, led by Oregon, Washington, and California, that are now using Medicaid funds to serve more people in HCBS programs than in nursing homes, including one state, North Carolina, in the Appalachian Region.

North Carolina managed to increase the number of participants in its Medicaid HCBS program from 20,000 in 1999 to over 53,000 in 2004, compared to 43,000 Medicaid-supported nursing home residents (Houser, Fox-Grage and Gibson, 2006). Only California increased the number of HCBS participants more than North Carolina during this period. The state achieved this by increasing HCBS spending from $423 to $717 million, which was $63 million more than the state increased Medicaid spending for nursing homes. Many of these HCBS participants are residents in community-based residential programs, mostly assisted living residences, which North Carolina, along with Virginia and Washington, has pioneered the development of over the last two decades for both the younger disabled and frail elderly populations. In 2004, North
Carolina was serving 34,000 in publicly supported community-residential programs, which was the highest number in the U.S. North Carolina is now spending over 40 percent of its LTC funds on HCBS programs and is the only state in the Appalachian and Southern Regions to achieve this level of balance in its LTC system (Houser et al., 2006).

Twelve states have received $50 million to $130 million over a five-year period through the Money Follows the Person (MFP) grant program to reduce their nursing home populations by moving residents into community-based programs. This is a major Medicaid-funded nursing home transition initiative, which has provided the states with almost $1.5 billion since 2003. Several of the states receiving $50 million or more in MFP funding were already among the leading states in the development of more balanced HCBS-oriented LTC systems, including Oregon ($114 million), California ($130 million), Texas $142 million), and Wisconsin ($56 million). Florida has not received any MFP funds at this point. Florida has, however, received $3.8 million in CMS system change grant funding, which totals $242 million nationally since 2002.

According to a recent analysis by Alexxih (2008) at The Lewin Group, the drop in the nursing home daily census is partially a result of the substantial decline in the percentage of persons age 85 plus residing in nursing homes since 1974 (from 21 percent to 13.9 percent) and the equally substantial increase in the number residing in assisted living facilities (ALFs) since the early 1990s. Between 1985 and 2004, the number living in ALFs increased from 1.4 percent to 9 percent.

The Alexxih (2008) analysis identifies three measures of effectiveness in the development of more balanced LTC systems featuring the expansion of HCBS program:

**How Do We Know What Works? Three Measure of Progress**

- Proportion of Medicaid HCBS spending of the total Medicaid long-term care spending.
  - Subset of states with 30%/+ in 2005 (11 states)
  - National average 23.6%
- Change in institutional placements
  - Decline in per 65+ Medicaid NF use of 25%/+ from 1995-2005
  - National average – 15.2%
- Change in per capita rate of Medicaid long-term care spending
  - Less than or equal to 5.2% annual increase from 1995-2005
  - National average 5.2% annually (Alexxih, The Lewin Group, p. 15)
In 2005, three states met all three of the Lewin measures of success in creating balanced LTC systems.

<table>
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<tr>
<th>States Meeting All 3 Medicaid LTC Measures</th>
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<tbody>
<tr>
<td>1995 % HCBS</td>
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<tr>
<td>18.1%</td>
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<tr>
<td>2005 % HCBS</td>
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<td>% pt difference</td>
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<tr>
<td>1995 NF/1,000 65+</td>
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<td>2005 NF/1,000 65+</td>
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<td>% difference</td>
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<td>Annual change $/65+</td>
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Six other states were spending over 30 percent of their public LTC dollars on HCBS programs in 2005 and had managed to reduce the percentage of their age 65 plus population residing in nursing homes by 13 percent to 23 percent between 1995 and 2005. Oregon and Washington decreased their nursing home populations by 34.6 percent and 37 percent, respectively, between 1994 and 2005, compared to the national average decrease of 15 percent. Oregon and Washington were already among the states with the lowest nursing home utilization rates in 1995, which raises the possibility that the presumed national plan for nursing home utilization may be substantially lower than many have assumed in the past. This does not mean that institutional care for the aged and disabled populations can be reduced to levels achieved for the DD population since the 1970s in most states. It may well mean, however, that with sustained and well managed efforts to expand HCBS programs, the current levels of nursing home use in most states can be reduced very substantially over the next several years. It also means that the projected tripling of the nursing home population by 2050, if the 2004 nursing home utilization rate is sustained over the next 40 years, can be avoided if proven policies are broadly implemented as demonstrated by the decline in the nursing home census, even as the age 65 plus population grew since 1995.

In the Lewin Group report, Alexis (2008) identifies several strategies associated with successful efforts to create balanced LTC systems. Many of these strategies have also been identified by other LTC experts. All of the system balancing strategies discussed in these studies are covered under the eight program components that CMS requires the states to address in the development of their State Profile Tool (SPT), which the states must use as part of the planning framework for their Real System Change grants.
Section III. Factors associated with closing the gap between knowledge and practice in long-term care

The most immediate task confronting states committed to creating a more balanced LTC system is to maximize current funding opportunities to expand HCBS programs in the same manner that Oregon and Washington have done for over 20 years, and a few other states more recently. These states have used provisions within the Medicaid program (HCBS waivers) to build a growing array of HCBS programs and limit nursing home use. Oregon and Washington have also created integrated organizational structures at the state and service delivery levels to administer all public LTC resources—nursing home and HCBS funds. This gives them the capacity to use savings generated from reduced nursing home use to expand HCBS programs.

In addition to consolidated administrative and fiscal authority for LTC services, several other factors associated with more balanced LTC systems have emerged in the research and policy analysis literature over the last decade including: Kassner, Reinhard, Fox-Grage, Houser and Accius (2008); Kane, Kane, Priester and Homayak (2008); Alecxih (2008); Gage, Brown, Katutsky, Moore and Auerbach (2002); and Eiken, Nadash and Burwell (2006). The major factors identified in the available literature include the following:

- Clearly articulated vision for creating a balanced LTC system based on an expansive array of HCBS programs that maximize consumer choice. According to Kane et al. (2008), this vision should be incorporated into legislation.

  . . . develop a vision statement for LTSS [long-term services and supports] emphasizing choice and independence; work to enunciate the vision in one or more State statutes; incorporate it into the vision of relevant State agencies; make the vision prominent in related print and electronic materials; and train State employees on the vision and how to make it operational. (p. 57)

- Consolidate administrative and fiscal authority for all LTC services by assigning responsibility and accountability for all state LTC services to a single administrator responsible for managing a “global budget” which includes all LTC-related resources and allows states to transfer funds among programs and enhance the state’s capacity to serve people in the setting they prefer. In the absence of a consolidated administrative structure, states may choose to implement a managed LTC system based on a capitated funding arrangement. Because many LTC policy experts consider this the most important single factor in the creation of more balanced LTC systems, the issue is addressed at greater length later in this section.

- Develop a single-entry point for individuals and families seeking LTC-related information. The single-entry system should include timely eligibility determination processes for both level of care and financial eligibility and be operational for almost half of all nursing home admissions and where the potential for diversion to an HCBS program may be greater than any other site. The single-entry process should also include a standardized assessment tool. According to Kassner et al. (2008):
Some states use a single tool to assess functional eligibility and service needs, and then develop a person-centered plan of services and supports. This standardized tool helps to minimize differences among care managers and prevent unnecessary institutionalization. (p. x)

- Develop an extensive array of HCBS programs funded through both Medicaid waiver and state general revenue (GR) resources. The more recent LTC literature has begun to stress the potential efficiency and consumer satisfaction associated with consumer-directed care strategies like the Cash and Counseling Program, which is now being implemented at an accelerating rate in many states. The recent literature also emphasizes the need for more extensive community-residential programs, including publicly supported assisted living and smaller adult care homes. Kane et al. (2008) summarizes the need for a more extensive system of publicly funded HCBS programs in the following fashion:

  . . . develop a varied array of services, beginning with a capacity for personal care and/or attendant services; build flexibility into the services themselves rather than require multiple services to fulfill particular tasks; redefine case management services to meet current system needs; include a wide variety of residentially-based services in the array; examine nurse practice acts to assure that nurses can perform teaching roles and delegate nursing tasks to unlicensed assistive personnel. (p. 61)

This factor (extensive HCBS) is considered by most LTC experts to be as important as consolidated administrative and fiscal authority in the development of balanced LTC systems and treated at greater length later in this section of the paper.

- Develop a nursing home relocation or transition program designed to identify nursing home residents who want to move to a community-based program and whose medical and LTC needs can be met in the community if appropriate housing and support services are available. The federal Money Follows the Person (MFP) program has spent $1.4 billion to provide just these kinds of services for nursing home residents, almost a quarter of whom, according to MDS data, have indicated a desire to return to the community. The value of this strategy is demonstrated by the fact that Oregon has both the smallest percentage of its age 65 plus population in nursing homes and, counter-intuitively, the shortest average length of stay in nursing homes (Wenzlow et al., 2008), which they have achieved by placing case managers in nursing homes for the purpose of actively helping residents who want to return to the community find the resources they need to make the move. According to Kane et al. (2008), states should:

  . . . develop specific programs to assist those who wish to make transitions from institutions; fund and train a group of relocation specialists to work with transitioning individuals; build transition expenses, including relocation specialist services and expenses for deposits and furnishings into waivers or State-funded programs; ensure an unbiased outside source of information about community alternatives for persons living in institutions. (p. 73)

- Develop an effective quality management/assurance system that:
  "a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement (Eiken, Nadash, & Burwell,
and incorporates participant-defined measures of success in their quality improvement plans.

Kane et al. (2008) recommends that states improve their quality monitoring capacity by developing:

- information infrastructure to support HCBS services with an ability to track experiences of groups of participants with various needs and an ability to track the performance of services providers; develop reporting hotlines and incident reporting systems; make information on quality readily available to consumers; develop feedback on quality directly from consumer surveys or interviews with consumers.

(p. 64)

- Develop an extensive HCBS infrastructure development capacity to recruit and train providers with the skills and knowledge to help consumers achieve the quality of life they desire. This factor also entails helping providers address the growing shortage of frontline LTC workers. This challenge is addressed at greater length in a following section.

1) Consolidated/integrated administration and funding of long-term care services

A consolidated state LTC agency appears to be the most important single factor in facilitating the development of balanced LTC systems, in part by making the other factors associated with rebalancing more achievable. Only two states (Oregon and Washington), however, have fully integrated control over all LTC programs and funds, including the Medicaid Nursing Home Program in their state aging and adult services agencies. In other states, the management of LTC programs is split between departments of aging/senior services (home- and community-based programs) and the departments housing the Medicaid program (nursing homes and some home care). The department that houses Medicaid, in effect, controls on average 70 to 80 percent or more of all LTC resources. The efficacy of a fully consolidated administrative and financing structure for LTC services is demonstrated by the extraordinary success of Oregon and Washington in developing balanced LTC systems by vastly expanding their HCBS programs.

An alternative method of integrating LTC authority that does not require a single state agency, with complete control over policy and all LTC funds, is to develop a managed LTC program at the local or regional level and operate it under a capitated rate based on all major LTC funding sources, including Medicaid nursing home funds. The capitation rate could be constructed through negotiation between representatives of the aging network, under the leadership of the state aging unit, and the state’s Medicaid office, and incorporated into a contract. Wisconsin has taken this approach with the Wisconsin Family Care (WFC) Program and Arizona has operated a Medicaid managed LTC system statewide for several years (Weissert et al., 1997). Texas, Minnesota, and Florida also have substantial managed LTC initiatives underway on a county or regional basis.

The Wisconsin Family Care Program has two components—aging and disability resource centers and care management organizations (Wiener, Tilly, Alexxih et al., 2002). The resource centers serve as single points of entry into the LTC system, providing information and
counseling and access to all LTC services and providers and on preventive health care and early intervention services. An important feature of the resource centers is their capacity to serve not only Medicaid-eligible consumers, but also private-pay consumers and their families. Providing information and assistance to the non-Medicaid population is an important element of any strategy to change LTC systems. A program that assists private-pay consumers holds great potential for empowering all older people to make informed decisions about their care choices, as well as to contain public and private costs.

Not many states have a fully developed, comprehensive integrated single-entry point system for LTC services for the elderly comparable to the Wisconsin Family Care Resource Centers. In order to increase the number of states with integrated single entry point systems, the Administration on Aging and the Centers for Medicare & Medicaid Services (CMS) has funded over 45 states since 2003 to develop Aging and Disability Resource Centers which are based on the Wisconsin Family Care Resource Center model (APS Healthcare, 2005). These centers are designed to provide integrated access to a comprehensive array of information and services, thereby increasing consumer awareness of all LTC options and increased consumer control over the LTC decision-making process.

The second major component of the Wisconsin Family Care Program is the care management organizations (CMOs) (APS Healthcare, 2005). The CMOs are capitated, managed care organizations for all LTC services, including nursing home care. The capitation rate includes Medicaid (nursing home and home- and community-based services), state and county funds consolidated into single monthly payments that average about $2,000 a month. The capitation rate constitutes a strong incentive to keep consumers in the community (nursing home care costs much more) and to create a seamless system in which individuals’ needs dictate the services provided, rather than program eligibility criteria.

A comprehensive evaluation of Family Care found that the program has generated significant savings, high consumer satisfaction, and changed the kinds of services provided (APS Healthcare, 2005). The CMOs purchased (or prompted their members to purchase, in the case of primary and acute care) more of some lower-cost services and less of other higher-cost services, with the result that the cost of the total package was lower for the Family Care members than for a matched comparison sample of individuals receiving Medicaid-funded services who were not in the Family Care Program. For example, average individual monthly costs at the end of the study period for a Milwaukee County frail elder’s care in a WFC community-based residential facility (CBRF) was $462 more than that spent for CBRF care for the comparison group. On the other hand, average individual monthly costs for nursing facility care of frail elders served by the Milwaukee CMO were $1,363 less than those for frail elders in the matched comparison group at the end of the study period. These shifts in services are a direct result of the flexibility in managing resources through the Family Care benefit package. As a result of these findings, the Legislature decided in 2006 to extend the program statewide.

Proprietary HMO-based managed LTC programs are now operational in Texas (STAR Plus program), Florida (Nursing Home Diversion), and the Arizona Long-Term Care System (ALTCS) on an extensive scale and to a more limited extent in a few other states. As described earlier, an evaluation of HCBS waiver programs in Florida found that the HMO-administered
managed LTC program (Diversion) is a relatively cost-effective alternative to nursing homes but less cost-effective than the other aging network-based HCBS waiver-funded programs (Mitchell et al., 2006, 2007). The cost-effectiveness of the Diversion Program has been enhanced over the last two years through modest reductions in capitation rates.

A 1997 evaluation of the Arizona managed LTC System (ALTCS) found that the program had created a far more balanced LTC system (50 percent HCBS) and had effectively contained public LTC costs (Weissert et al., 1997). Before 1997, most of the participating HMOs were non-profit, public agencies, including public health agencies in Phoenix and Tuscan. Since then, proprietary HMOs have become dominant in the ALTCS program.

Managed LTC strategies clearly have the potential, if properly administered, to reduce fragmentation in LTC services, enhance access to consumer preferred services, and improve overall efficiency, Kane et al. (2008) describe some of the steps we should take to insure that managed LTC programs are effectively administered:

Managed LTSS, often introduced as part of overall managed Medicaid services can be used to encourage community care and rebalancing if: the State is clear on incentives for community care; a mechanism is available to ensure that consumer choice of living situation is respected, and consumers are offered consumer-directed models; and assisted living settings are not over-utilized. Managed LTSS is more likely to carry incentives for HCBS if the providers are at financial risk for nursing-home care and/or incur penalties when nursing home residents disenroll. (p. 70)

One of the best ways for the aging network to play this role is to create a managed LTC system which integrates LTC funds (state and federal) and services (community-based and nursing home care) in advance of any effort to integrate long-term care and acute care. This approach would strengthen the aging network’s ability to use managed care to expand community-based services (shifting resources from institutional to community-based programs) and to prepare mechanisms for “downward substitutions” when more fully integrated systems A few states (Minnesota, Massachusetts, and Wisconsin) have developed Medicare and Medicaid managed care programs designed to integrate acute, chronic, and LTC services. These initiatives are based on lessons learned from the PACE Medicare/Medicaid program which was created over 20 years ago and now operates in over 20 states. The relative cost-effectiveness of these relatively early-stage programs has not yet been clearly established but their potential is very promising. Most states, however, may be better served by integrating their LTC systems before implementing Medicare and Medicaid managed care programs (Polivka, 2005).

2) Expanding community-based programs

Organizational innovations and financing strategies based on the more expansive use of Medicaid-waiver options and new administrative structures should be designed to create a wider range of HCBS programs, including consumer-direction programs like the Cash and Counseling program and community-residential programs like assisted living, especially smaller facilities (16 or fewer beds) and adult care homes (Family Care Homes).
a) Consumer-directed care

As Crisp (2008) notes, self-direction goes by many names. While this report uses the term self direction, it is also commonly referred to as consumer direction or participant direction and is an essential component of the independent living movement and the broader-based life philosophy of self-determination. The consumer-directed care service model gives individuals control over the resources that are used to manage their long-term daily care. In general terms, daily care is defined as bathing, dressing, grooming, transferring, housekeeping, and shopping. Almost 2 million Americans receive publicly funded personal care services each year. Within the traditional system, a provider agency (typically a Home Health or Personal Care Agency) hires, trains, and manages employees to provide these home services. The agency performs state, local and Federal employment and payroll tasks such as payment and reporting of state and federal taxes, unemployment insurance, and workers compensation. With consumer-direction, independent workers are hired from a broad-based labor pool including family, friends or those recruited by the individual. Employment and payroll tasks are completed by a support entity referred to as a Financial Management Service provider and serves as the “agent” for employment taxes. Counseling is provided to assist individuals to understand their risks and responsibilities and provides guidance and advice with the self-directed experience. More expanded versions of the model allow participants to use a flexible individual budget to purchase items or goods that promote their personal care and might include home modifications, assistive devices, transportation, and personal care supplies. For example, if a washer, dryer or microwave might reduce the need for human assistance, these items could be purchased so long as the costs do not exceed the individual's budgeted amount.

The Cash and Counseling program gives the consumer control of funds which she can use to organize the kind of LTC assistance she needs in the way she chooses, usually by paying her caregiver who is most often a relative or friend. An extensive evaluation of the RWJ Foundation-supported cash and counseling demonstration projects in Arkansas, New Jersey, and Florida found that the projects were generally cost-effective in comparison to agency-directed in-home programs, especially in terms of caregiver and consumer satisfaction levels and reduced nursing home use (Dale and Brown, 2007). Their study also found that when compared with traditional agency users, those self-directing:

- scored higher on measures of control and empowerment; reported fewer unmet needs;
- scored the same or better on measures of health status; scored the same or better on measures of participant safety; reported a better quality of life; experienced no adverse effects on health; revealed no increased level of risk.

Interviews with those hired reported:

- more emotional involvement; greater satisfaction with their working conditions; well-informed about the participant's condition; level of training was sufficient and felt fully prepared for their responsible tasks; satisfaction with wages and benefits.

The California In-Home Supportive Services (IHSS) Program is the largest and oldest CDC program in the U.S. The program, which is over 30 years old, receives over $500 million dollars annually and serves over 200,000 consumers, of whom about half are age 65 and older. The
program is designed to allow payments to a wide range of caregivers, including family and agency-managed caregivers. These facts make IHSS the most important initiative in CDC in the U.S. and the program from which we may have the most to learn about the feasibility and desirability of this approach to LTC for the frail elderly.

The IHSS program provides two models of care. A consumer-directed model (CDM) permits clients to hire and fire, schedule, train, and supervise their own personal assistance services providers. A full-fledged CDM imposes little or no restrictions on whom a client may hire. In particular, clients in a full-fledged CDM are permitted to choose to employ persons already known to them: friends, neighbors, or family members. A CDM typically puts all of the responsibility for recruiting and selecting an aide on the individual client and any family or friends willing to assist.

In contrast, a provider managed model (PMM) program design requires that aides be employees of authorized home health or home care agencies. In this model, the agency hires workers according to criteria the agency establishes and the agency also determines which of its employees will be assigned to particular clients. Within an agency, client choice of aides is generally restricted to “veto” power; clients who are dissatisfied with a particular worker the agency sends may ask to have that worker replaced and the agency will generally honor such a request if it has a replacement worker available (although, strictly speaking, the agency is not required to do so).

A maximum of 283 hours a month is allowed in the IHSS program for the most seriously impaired clients, and reassessments are done annually. Funding per client is capped at a maximum monthly dollar amount—computed as the maximum hours figure of 283 multiplied by the state minimum wage (which was recently increased to $5.75 an hour) for a monthly dollar cap of $1,627.25 per client.

A comprehensive evaluation of the IHSS program was conducted in 1998. The study (Benjamin, Mathias & Franke, 1998) was based on a telephone survey of over 700 randomly selected consumers and over 500 workers. The criteria for selection were as follows: being at least 18 years old; not having a “severely impaired” rating on memory, judgment, or orientation; and having been in the program for at least six months prior to September 1996. Of all sample members successfully contacted, completion rates were high—77.8 percent for clients, 86.9 percent for workers. The major findings are summarizing below:

1) On several key client outcome measures, the consumer-directed model clearly outperforms the professional management model. Under the most rigorous characteristics, such as severity of disability and differential availability of informal supports, the consumer-directed model of service provision consistently yielded superior results on several measurement dimensions with respect to client satisfaction with services, empowerment, and quality of life.

The IHSS program benefits are, however, by the standards of most other comparable state programs, relatively generous. In another state, with less generous monthly benefit limits, the percentage of clients with significant unmet service needs might well be much
greater. This would likely result in less positive client outcomes for the program as a whole, irrespective of the mode of service provision. It should be noted, however, even relatively generous payments for seriously impaired persons would be less than nursing home costs.

These findings suggest that, on balance, the advantages of permitting clients to hire family providers, in terms of ensuring access to combinations of both paid and unpaid assistance sufficient to meet assistance needs, probably outweigh the disadvantages associated with any marginal substitution of public funding for informal support which may also be taking place. It is also important to note that family providers have a distinct advantage over nonfamily providers in that they are legally permitted to perform such paramedical or medically related tasks as bowel and bladder care and administration of medications.

2) The professional management model was not found to have better outcomes with respect to client safety. Although instances of abuse, neglect, and mistreatment were occasionally reported, consumers in the consumer-directed model reported such occurrences either less frequently or no more frequently than consumers in the professional management model.

3) On subjective measures of job satisfaction, there were no statistically significant differences between workers in the consumer-directed and professional management models. Here again, the findings confounded the conventional wisdom in that worker satisfaction under both models was quite high across a range of measures. Although the average IHSS worker employed by an agency earns about 30 percent more per hour than a client-directed workers. The worker survey data offers little indication, however, that client-directed IHSS workers are generally aware of or resent that they are paid less and However, approximately one-quarter of CDM clients had experienced difficulties recruiting a provider. The professional agency model may be the better choice for severely disabled clients who cannot rely on informal helpers and who lack confidence in their own abilities to make alternative arrangements for backup help.

In assessing the results of the IHSS evaluation, Doty, Benjamin, Matthias and Franke (1999) noted that:

Critics of consumer-directed models of service delivery have expressed concerns about client safety under this model and have generally taken the view that consumer direction should be restricted to a minority of clients (primarily younger adults) who social workers judge to be capable of hiring, firing and giving direction to their workers. This study provides no evidence in support of restricting availability of the consumer-directed model. Critics have also questioned the appropriateness of allowing public program clients to hire family members as providers. This study's findings support the option of hiring family members as providers because the data indicate that, on average, family providers
are more likely to provide a higher quality of service than unrelated workers (p. 4).

Several European countries have implemented CDC programs over the last 15 years. The majority of LTC recipients in Germany and Austria are now in CDC programs. Currently available evaluation findings indicate that these programs are exceptionally popular with recipients and caregivers and are a cost-effective alternative to institutional care and agency-directed home and community-based care for many seriously impaired elderly persons.

Austria implemented the Federal Long-Term Care Allowance Act in 1994. The program is designed to: 1) provide a uniform payment to help compensate for care-related expenses, 2) promote a “self-determination” lifestyle, 3) enable people with disabilities to remain in their own homes, 4) encourage families to provide care, and (5) link previously existing provincial allowances. General tax revenues and payments from employers and employees fund this program.

...to be eligible for the Austrian program, Rubisch et al. (1995) report that applicants must be at least three years old, have a permanent need for personal assistance, and require 50 or more hours of care per month. No means test is imposed on applicants. There are seven benefit levels, which in 1994 ranged from $250 to $2,000 per month. The amount of the benefit increases as dependency rises. Reports on how money is used must be filed, and local authorities can terminate the allowance if it is “flagrantly misused” (Keigher 1997). Beneficiaries with cognitive impairment may have someone appointed to manage their allowance. In 1995, beneficiaries who lived in the community were surveyed about their experience with the new allowance.” (Tilly, 1999, p. 14)

The study, which is based on 3,120 respondents, 75 percent of whom were over age 65 and many were severely impaired, found that 81 percent used their allowance to compensate family caregivers, 29 percent for home modifications, and 71 percent reported greater control over their caregiver arrangements and ability to handle daily pressure.

Germany's program recognizes three levels of dependency. The lowest level applies to individuals who have limitations in two or more activities of daily living (ADLs) and need help at least once a day; the highest level is reserved for those who need assistance “day and night” (Schneider, 1997). Service benefits are available for those in nursing homes if home care or day care is not possible. Beneficiaries in the home and community can select one of three options available to them: a cash benefit; agency services which have twice the monetary value of the cash; or a combination of the two (referred to hereafter as a combination benefit). In 1996, persons with the lowest level of dependency received 400 DM ($250 in U.S. currency) a month, whereas the service benefit was 750 DM ($468) a month.

Germany's Social Dependency Insurance program is similar to Austria's allowance program. In 1995, insurance benefits were made available to persons with disabilities, regardless of age. The program's purposes include the following: 1) compensation of beneficiaries for the cost of care; 2) promotion of home care; and 3) improvement in the lives of beneficiaries and their caregivers.
In the program's first year of operation, 84 percent of beneficiaries with the lowest level of
dependency chose the cash benefit, as did 67 percent of those with the highest level. The cash
must be used to help meet the beneficiary's LTC needs. Beneficiaries who choose cash must
receive periodic counseling, as well as visits from professionals who help assure quality and
proper expenditure of the cash (Schneider, 1997).

German beneficiaries were surveyed about the new program in 1996. The study was based
on 10,400 respondents and over 75 percent were age 65 and older. The study found that
72 percent felt that the program was necessary to maintain their independence. An
overwhelming majority of respondents reported high levels of satisfaction with being able to
decide for themselves how to use their benefits. Forty-three percent of all respondents reported
that their quality of care had improved under the program and only 2 percent reported that
quality had declined (Runde, Goese, Kerschke-Risch, Schjolz & Wiegel, 1996).

According to Cuellar & Wiener (2000), the authors report that virtually everyone in their
country they interviewed for this study considered the cash and counseling, consumer-directed
care system an immense public policy success. The program had:

...achieved or made substantial progress toward several important goals, including
giving security and support to informal caregivers, shifting the balance of long-term
care from institutional to home-care services, increasing attention to quality of care,
providing Länder with fiscal relief, reducing dependence of social assistance;
increasing the supply of providers, and increasing consumer choice. The program
was implemented quickly and remarkably smoothly, although there were enormous
challenges in establishing a large program quickly. Importantly, despite the
possibility of an explosion in the number of beneficiaries, expenditures began well
below projections and now, although rising, are well within a politically acceptable
range. (p. 22)

Among the lessons the authors think we can draw from the German experience with
customer-directed care are the following:

... it is not a law of nature that new social programs, especially non-means-tested ones for
long-term care, must cost far more than originally estimated. The German long-term care
insurance program has an enrollment fairly close to what was originally projected, and
spending has been lower than anticipated.

... the political success of the program can be tied to some of its design characteristics.
Most importantly, the German reform plan provided substantial fiscal relief to the regional
and municipal governmental units that funded long-term care.

... the population was able to see, in a very concrete way, what benefits they would
receive for their new contributions. The program offset the limited range of services that
could be covered as an entitlement by providing a cash alternative, which can be used for any
purpose and thus has maximum flexibility. (p. 22)

The dominant long-term care policy issue in developed countries is the balance between
institutional and non-institutional services. Most countries believe that they are not providing
enough home and community-based services. Germany may be the only country where both a majority of the beneficiaries and a majority of the expenditures are in community-based rather than institutional benefits. (p. 23)

Much smaller CDC demonstration projects were implemented in the Netherlands and France during the early 1990s. The Netherlands project had an experimental design which allowed random assignment to a CDC program and a regular agency-directed program. The evaluation of the project found that:

Participants receiving cash assistance reported greater satisfaction with quality of care, measured in terms of both worker efficiency and continuity of care, than did those in the control group. Based on the demonstration project’s findings regarding quality of life and care, the Netherlands implemented a permanent cash assistance program for people with disabilities. (p.18)

Although the results of the demonstration project in France were more mixed (Tilly, 1999). Findings from all of the studies:

...support the premise that a consumer-directed option can provide beneficiaries with independence, choice, and control. The results of these studies are also consistent with the German study's finding that 43 percent of German respondents perceived that the quality of their care had improved as a result of the new benefit. Study results in the Netherlands are particularly strong, given the randomized assignment of participants to treatment and control groups. The likelihood of choosing cash assistance decreased with age in the Netherlands. Finally, the French study indicates that administrative tasks associated with the employment of workers may present barriers to those who want to manage their own services. (Tilly, p. 19)

Consumer-directed care is not for every frail elderly person in need of LTC services but it could be for far more consumers than are currently provided this option. The available empirical findings suggest that CDC is the most flexible form of LTC in that it can be designed to permit not only the paying of individual caregivers, but also allow consumers to pay for community-residential care and, if necessary, nursing home care. In short, CDC could be designed to empower the consumer across the spectrum of LTC services and have dollars follow consumers rather than going directly to providers.

In a survey of 20 long-term care policy experts in the aging and disability communities, Simon-Rusinowitz, Bochniak, Mahoney, Marks and Hecht (2000) found that while they were generally supportive of consumer-directed care. They also expressed some reservations. Their main concerns were the potential for fraud and abuse, worker conditions, potential incompatibility with managed care and traditional provider resistance.

Although efforts must be made to prevent fraud and abuse in any program, the use of fiscal intermediaries, surrogate decision makers and care advocates responsible for quality assurance monitoring should help states keep fraud, abuse and neglect to a minimum. The results of the IHSS evaluation are reassuring in this respect. Most consumers, "...are likely to elect to have the payrolling and tax withholding for their workers done for them by accounting professionals. This would greatly reduce the amount of cash that consumers receive and manage (Doty et al.,
Those consumers electing not to use accounting professionals would need to participate in a training program and demonstrate competency in payrolling tasks.

The vast majority of workers in all LTC programs are paid low wages. Many do not have benefits. CDC, however, is not likely to make these conditions any worse. In fact, it is specifically designed to improve the lot of the many caregivers who are now working without any remuneration, especially family caregivers.

Managed care is evolving and changing so rapidly it is difficult to assess its current and future capacity to accommodate a CDC approach to long-term care. There does not, however, appear to be any fundamental conflict between CDC and a financing system based on capitation. Whether or not managed care would in any way enhance, or add value to, CDC is an open questions that should be addressed empirically.

As for providers' resistance, Simon-Rusinowitz et al. (2000) point out that:

... many [consumers] would prefer to have an agency be responsible for the administrative aspects of personal assistance services. Thus, there will always be a need to agency-based services...agencies may be less threatened if they understand that consumer-direction principles are not specific to an independent provider model, and they can be incorporated into an agency setting should providers want to do so. Thus, if agencies view consumer-directed services as a means to maintain or increase their business, they can modify existing programs with these principles. As CDC evolves, we are likely to better understand how traditional agency providers and consumer-directed programs can support one another.

Aging network providers should not be alarmed by the prospect of CDC programs. As the frail elderly population grows over the next several decades, they will be pressed to meet the needs of those who cannot benefit from a CDC approach to community-based long-term care. Furthermore, providers themselves may benefit from the development of CDC programs whose popularity with the general public could create a more favorable atmosphere for increased funding of home and community care, including agency-directed programs. Growth in funding for these programs has been slow or non-existent in many states for several years and CDC initiatives could help move home- and community-based care to the top of the policy agenda over the next decade.

Some aging policy experts and advocates have taken the position that CDC may be appropriate for cognitively intact frail elderly persons, but not for the cognitively impaired. There is clearly a difference between these groups in terms of their capacity to benefit from CDC, but the difference should not be made absolute by drawing a bright line between them and blocking access to consumer direction for the cognitively impaired. As long as the cognitively impaired have the capacity to form and express values and have competent caregivers, they should be considered legitimate candidates for CDC. From this perspective, CDC is not just a means of empowering the consumer, it is also a program to empower the caregiver-consumer unit and enhance the capacity of the informal system to provide high quality care for much longer periods of time than many unsupported caregivers can sustain. A CDC design that incorporates family caregivers is likely to be not only more effective than a design that excludes