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Who will care for the women?

Candace Howes
Connecticut College, chow@conncoll.edu

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Candace Howes
Connecticut College
chow@conncoll.edu

Abstract

This paper describes the long-term care system in the United States – what long-term care is, who needs it, in what settings it is provided, and who pays for it. It shows that a substantial portion of the people who need long-term care rely on unpaid care from family and friends, mainly women. It shows that almost half of people who receive paid care, receive it in institutional settings, despite a preference of home- and community-based care. It then argues that, for a number of reasons, states and the federal government will have to respond to the preferences of consumers for home- and community-based care.

The problems of ensuring an adequate supply of caregivers, focusing particularly on home- and community-based settings are discussed and the paper argues that problems of recruitment and retention will be satisfied only when wages and benefits for homecare workers meet their minimal needs for income and health insurance security. The paper concludes by suggesting a set of policies that could be implemented at the federal and state levels to improve recruitment and retention of both paid and unpaid long-term care workers.

Introduction

Long-term care is the assistance provided to frail elderly and disabled individuals so that they can live safely in their own homes, other community settings, or institutions. Over 20 million people today, including children, working-age disabled, and elderly persons, require some sort of assistance to live safely. Almost 15 million care recipients are over the age of 65. Largely because women live longer than men, well into the ages

when the probability of needing care increases, 70 percent of elderly people who need long-term care are women. Furthermore, most long-term care is provided by women, mainly as unpaid care in the home, or as low-paid care in institutions and community settings (Stone & Weiner 2001). Despite the fact that most people would prefer to remain in their homes, half of paid care takes place in institutional settings and most of the residents are women.[2]

The United States faces a severe long-term care crisis because of the nation's inability to plan for the changing demographic balance. In the next 40 years, as the baby boomers age, the ratio of the population in the average caregiving range (aged 50 to 64) to the population aged 85 and older is expected to decrease from 11 to 1 to 4 to 1, leaving a huge potential gap between the need for care and the supply of care givers (Stone & Weiner 2001).[3] Who will take care of these aging boomer women and what kind of care will they receive?

Unlike other advanced industrial countries, such as Japan which recently passed legislation entitling all persons over age 65 to long-term care if they need it (Campbell and Ikegami 2000), the United States is trying to slow the growth of public spending on long-term care, especially for home- and community-based services. Given peoples' preferences for non-institutional long-term care, the limit on public financing means that the United States will have to rely more heavily on unpaid family care. Will families be able to fill the swelling care gap left by inadequate public policies, as the ratio of middle-aged women relative to people over 85 falls from 7.5 in 2004 to 2.2 by 2050 and as working age women continue to increase their time spent on paid employment?

The crisis in long term care has two problems. The first problem is that we are putting too many resources into institutional care relative to home- and community-based care and relying too heavily on unpaid care in the home to meet the real needs of the aging population. The second problem is that we do not, and increasingly will not, have enough people to provide for the volume of care that will be needed in the coming decades. This shortage is exacerbated by the present mix of modes of providing care, as well as by a long-standing tendency to undervalue and underpay long-term care work.

This chapter begins with a description of the long-term care system in the United States – what long-term care is, who needs it, in what settings it is provided, and who pays for it. Using the author's analysis of a national survey of caregivers conducted by the National Alliance for Caregiving and the AARP in 2003 along with other sources, this section shows that a substantial portion of the people who need long-term care rely on unpaid care from family and friends, mainly women. When people do receive paid care, almost half – mostly women -- receive it in institutional settings. The discussion demonstrates that women are far more likely to end up in institutions than men, even controlling for age and level of impairment. It then argues that, for a number of reasons, states and the federal government will have to respond to the preferences of consumers for home- and community-based care.

The following section discusses the problems of ensuring an adequate supply of caregivers, focusing particularly on home- and community-based settings. Using the results of a two surveys of consumer-directed long-term care workers conducted by Howes (2002, 2004, 2005a, 2006) in California, combined with an analysis of California state payroll data, it argues that problems of recruitment and retention will be satisfied

only when wages and benefits for homecare workers meet their minimal needs for income and health insurance security. Comparing results from the national and California surveys, this section also shows that unpaid family caregivers share a similar demographic profile with paid caregivers, which suggests that the same policies that affect retention of current paid care givers - living wages and health insurance for part time work – might draw more family caregivers into the paid care giving workforce. The chapter concludes by suggesting a set of policies that could be implemented at the federal and state levels to improve recruitment and retention of both paid and unpaid long-term care workers.

Long-term Care in the United States

Long-term care is the care that is required, over a long duration or until end of life, by people who suffer from a range of impairments that make it difficult or impossible for them to live independently. Long-term care is often defined by what it is not – acute medical care provided in an institutional setting for a short duration. The need for long-term care among those over 65 increases with age as individuals become progressively frail or the principal chronic illnesses, such as arthritis, diabetes and pulmonary disease, progress.[4] As Table 7.1 indicates, the proportion of people who receive paid long-term care increases with age, from 5.7 percent of those aged 65 – 69 to 40 percent of those aged 85-89 in 1999.[5]

The extent to which an individual needs assistance with activities of daily living (ADLs) is the primary measure of whether she or he needs long-term care. Most individuals who need assistance with two or more ADLs, which include bathing, dressing, eating, toileting, and transferring, would require long-term care. ADLs capture

only physical limitations, however. An additional measure of a person's capacity to perform the instrumental activities of daily living (IADLs), such as handling money, shopping, doing housekeeping, preparing meals, using transportation, managing medication, and talking on the phone, provide a measure of impairment due to Alzheimer's, dementia, and other cognitive problems that would make it unsafe for them to live without assistance.

By these measures, a substantial number of older people are in need of some degree of long-term care. According to author's reestimates of 2003 survey data from a study by the National Alliance for Caregiving (NAC) and AARP (2004), approximately 14.2 million households were providing care, either in a private home, in a community-based facility, or in a skilled nursing facility, to an average of 1.4 people over the age of 65 who needed assistance with one or more IADLs or ADLs. Based on the survey data, the number of people over the age of 65 receiving long term care would be 19.1 million[6] Sometimes the need for long-term care is measured solely in terms of ADLs, ignoring the care requirements of the cognitively impaired, especially the large number of people suffering from Alzheimer's and other forms of dementia.[7] NAC/AARP (2004) calculated, in the report *Caregiving in the U.S.,* a Burden of Care index, which combines ADLs, IADLs, and the time required for care, to construct a 5-point measure of the level of burden for each caregiving household based on the care requirements of the care recipient.[8] For example, a person who required assistance with one ADL but required 9 to 20 hours of care per week would represent a Level-3 Burden of Care, as would a person with 2 ADLs who required less than 8 hours of care. Persons requiring care at a Level-3 burden or higher would generally qualify for long-term care benefits under Medicaid if

they also met the income and asset criteria. The NAC/AARP data analyzed by this author show that 7.6 million households are providing a Level-3 Burden of care to 10.1 million persons living primarily in private residences.[9] Since the advent of Medicaid funding in 1965, nursing homes have been the most common institutional setting for persons with disabilities. However, alternative settings have been growing rapidly, in response to the preferences of long-term care recipients as well as states' efforts to deinstitutionalize people (Spillman and Black 2005). Community-based services can include both skilled nursing and unskilled services such as adult day care, congregate meals, or assistance with shopping and transportation. For those who can afford it and for whom the choices are thus less stark, assisted living facilities and continuing care retirement communities (CCRCs) provide meal service, assistance with housekeeping, and some personal care in environments that often include an array of living arrangements from fully independent apartments to on-site acute care facilities.

Of the 19.4 million over age 65 who are receiving assistance with one or more ADLs or IADLs, approximately 1.4 million were living in nursing homes and another 1.6 in alternative residential care facilities (see figure 7.1a). The remaining 16.3 million people – 85 percent - were being cared for in private home.[10] Sixty percent of all people receiving long term care – 11.5 million people - are being cared for exclusively by unpaid caregivers. Another 25 percent – 4.8 million – receive a combination of unpaid care and .paid care from agency-based nurses and aides or from independently hired aides.[11]

Compared with those living in traditional private homes, elderly people living in residential care facilities are far more likely to suffer from Alzheimer's disease or other forms of dementia and need round-the-clock care or require help with multiple ADLs.

However, there are still many households which are providing home-based care to recipients with very high levels of need.

Using the Level-3 burden of care as the threshold, the author found that 10.1 million people over age 65, were receiving long-term care. Forty-five percent, or 4.6 million people were receiving no paid care whatsoever. This places a very high burden on families to care for extremely disabled people. Thirty-seven percent – 3.7 million people were receiving a combination of paid and unpaid care in the home and the remainder were in institutions. (Figure 1b).

Long-term care is disproportionately a women's issue. Largely because women live longer than men and well into the ages where the need for care increases, women make up nearly 70 percent of the people aged 65 and older who receive long-term care. The percentage of women among long-term care recipients increases with age, since the ratio of women to men rises steeply with age from 1.3 for those aged 65-85 to 2.4 for those aged 85 and older (US Census Bureau 2004). Table 7.2 shows that while 60 percent of long-term care recipients aged 65-74 are women, the percentage who are women increases to 78 percent for those aged 85-89.

Despite consumers' preference for in-home care, women are twice as likely as men to spend the end of their lives in residential facilities, even controlling for age (see Table 7.3). Overall only 9 percent of men receiving long-term care are in residential care facilities, compared with 18 percent of women. The greater likelihood of women to be institutionalized cannot be explained solely by the fact that they are likely to live longer and therefore more likely to reach high levels of need. The percentage of men who are in residential care facilities rather than private homes actually declines after age 84 so that

only 5 percent of men in their 90s are living in residential facilities. For women, the experience is exactly the opposite: Of women who reached their 90s, 33 percent are in residential care facilities. Even when we distinguish men and women by level of impairment, as measured by burden of care, it is striking that for those aged 85 and older women at levels below 3 are more likely to be in institutional care than men and even than men with higher levels of impairment. For example, in the 85-89 range, 30 percent of women who receive less than Burden 3 level care live in residential facilities compared with 22 percent of men who receive higher intensity of care (level 3 and above).

Importantly, it is only the experiences of white and black women that drive the greater propensity for women to be institutionalized. Among Hispanics, women are actually half as likely to be institutionalized as men; among Asians, women are only slightly more likely to be institutionalized than men. The high propensity of white and black women to be in institutional care, for most age ranges and levels of impairment noted in Table 7.3, suggest that there are additional explanatory factors, in particular, women's higher probabilities of being widowed and poor compared with men's. Women are more likely to be without a spouse who can care for them or provide income, and they are poor enough to qualify for Medicaid-supported long-term care which will more likely than not be available only in a residential facility.

Who Pays for the Care

Why is it that 8.5 million people who receive care, including 3.5 million people receiving very high levels of care, are relying exclusively on unpaid care from their family members? Since few people can afford to pay for long-term care on their own or

have long-term care insurance, most long-term care is either provided by family members or paid for through public programs. Despite the high need for long-term care especially among elderly women, Medicare has yet to provide long-term care insurance similar to the social insurance program in Japan.

Most publicly supported long-term care is paid for through Medicaid. Medicaid is a means-tested welfare program. Elderly people who are poor enough to be eligible for Supplemental Security Income (SSI) – their earned individual income is less than about $1,100 per month (or unearned income less than $623 per month) and assets (exclusive of house and car) do not exceed $2,000 for a single person (SSA 2006) - are eligible for Medicaid-financed long-term care, either in a nursing home, or, if the state provides such programs, through a home- or community-based program. Most states have a "medically needy" income eligibility system in which an applicant's medical expenses, including the cost of a nursing home, are deducted from their income when determining eligibility. Since long-term care is expensive, many of the elderly who need long-term care eventually do become eligible for Medicaid. As a consequence of differences in the way the program is administered and in eligibility requirements at the state level, there are substantive differences across communities in the rate at which individuals apply for Medicaid (Moses 2005). Many people are never eligible for publicly funded long-term care and many who are eligible do not know it is available.[12]

Figure 7.2 shows the proportion of long-term care paid for by Medicare, Medicaid, private insurance and out-of-pocket expenditures in 2001. Medicaid accounted for 48 percent of total spending, or $76 billion of the $151.2 billion spent on long-term care in 2001 (House Committee on Ways and Means 2004). By 2004, Medicaid

expenditures on long-term care had increased to $89 billion. Long-term care is also financed privately through health insurance policies (10 percent of total spending), other sources (6 percent), and out-of-pocket expenditures (22 percent of total spending). Even out-of-pocket expenditures are substantially funded by the public since Social Security benefits received by Medicaid-eligible residents must be contributed to help pay for nursing home care (Moses 2005).

Unlike Social Security and Medicare, which are largely funded by payroll taxes, Medicaid is funded directly from general tax revenues. The cost of the program is shared by the states and the federal government. Medicaid expenditures are the fastest growing part of all state budgets, and long-term care is not the fastest growing, it is a very large part of Medicaid budgets, accounting for 37 percent of total Medicaid expenditures in 2005 (Boyd 2003; Burwell, Sredl, and Eiken 2006). Of long-term care expenditures, home- and community-based programs are the fastest growing components. In 1992, 85 percent of Medicaid long-term care spending was on residential long-term care including nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICF/MR), while the remaining 15 percent was spent on home- and community-based long-term care programs (see Figure 7.3) By 2005, the Medicaid long-term care budget had more than doubled (from $42 billion to $94 billion) and, while nursing facility expenditures have been flat since 2002, home- and community-based expenditures have continued to capture a larger and larger share of the long term care budget (Burwell, Sredl, and Eiken 2006). Not surprisingly, there is tremendous pressure at the state and national level to slow the growth of Medicaid long-term care spending and specifically the growth of home- and community-based services (Moses 2005).[13]

Demographic trends portend a huge increase in the demand for long-term care in all settings. The demand for long-term care services grows with the growth of the number of people over age 65 and especially those over age 85—which we have seen will be dramatic, and with trends in disability rates--which are modestly declining (Manton & Gu 2001). However, the quantity of *paid* long-term care demanded varies according to Medicaid eligibility requirements, as people with incomes above the poverty level either deplete their assets paying for LTC or become better informed about how to disperse their assets legally in order to qualify. Most importantly, from a policy perspective, the quantity of paid long-term care demanded depends on the mix of long-term care options that the state offers under its Medicaid long- term care program.

States and the federal government, probably correctly, fear that increasing access to home- and community-based services will increase the overall cost of long-term care to the Medicaid program. Although, on a per capita basis, home- and community-based care is considerably less expensive than institution-based care, especially for people with lower Levels of Care Burden, many people who are currently receiving unpaid care from family members or with extensive unmet needs because they are unwilling to enter institutions, will apply for Medicaid-funded home- and community-based services.[14] Currently, overall growth in the demand for Medicaid-financed long-term care is limited by the fact that many states constrain the growth of home- and community-based care options. This exacts a huge toll, both financially and in terms of physical well-being, on care consumers' families, especially older women who are shouldering most of the burden.[15] Further, as women continue to increase their time in the labor market, it will be unrealistic to assume that families will be able to keep up with the increase in demand.

Therefore, the federal government and the states will need to share more responsibility for caring for the frail elderly population.

Other forces may be pushing the states in that direction anyway. The Supreme Court's Olmstead decision in 1999 ruled that it was illegal under the integration mandate of the Americans with Disabilities Act for a state not to provide adequate services in the most integrated setting, such as home- and community-based settings (Holahan et al. 2003; Holahan & Ghosh 2005; Seavey & Salter 2006). Thus, if legal considerations and popular opinion overwhelm the states' resistance to home- and community-based care, it is possible that the balance between institutional and home- and community-based services will improve and that the effective demand for long-term care will trend up in the next few decades. As a society, we need to plan for a transition to a greater reliance on home- and community-based care that depends not on unpaid family labor but on paid labor. To do so, these jobs must be made into good enough jobs that women and men working in other jobs would be willing to do homecare instead.

Ensuring a Future Supply of Caregivers

Even as the need for a long-term care workforce is rising, it is increasingly difficult to find people who are willing and able to provide unpaid or even paid care for the elderly and disabled. While in 1973 only 42 percent of women were employed, by 2003, 58 percent were in the workforce (Mishel, Bernstein, and Allegreto 2005: Table 3.9). With so many women working, fewer people are available to provide unpaid care for a family member.

Long-term care jobs are stressful low-wage jobs that rarely provide health insurance benefits; those working in facilities are usually working in environments with insufficient staffing levels and outdated management practices (Kaye, et al. 2006; Yamada 2002). Among long-term care jobs, consumer-directed homecare has generally ranked at the bottom of the wage distribution. The median hourly wage for homecare workers (personal care or homecare aides) in 2005 was $8.34, compared with $9.04 for home health aides,[16] and $10.31 for nursing home aides. Despite the low pay and lack of benefits, many homecare workers do choose this kind of work over occupations such as factory worker, cashier, hairdresser, childcare worker, or food service worker, none of which pay well. (see figure 7.4). As discussed below, while some home care workers "chose" the occupation for lack of alternatives, others prefer it for its autonomy and flexibility and out of a sense of commitment to their clients. Like many other low wages jobs, turnover is high and recruitment is often difficult, yet turnover is generally lower and job satisfaction higher in home care than in institutionalized settings.

The problems of recruitment and retention of long-term care workers to nursing facilities, community-based facilities, agency-based homecare, and even independent care jobs are well documented. The annual turnover rate in nursing facilities nationwide is 100 percent. Turnover rates of this magnitude not only make it difficult for elderly people to find care givers but high turnover has a devastating impact on the quality of the care they receive. Turnover in homecare, while much lower than in nursing homes, is still 44 percent (PHI and Medstat 2003; Stone 2000; Stone 2001; Stone &Wiener 2001). Most likely, turnover is lower among homecare workers because the workers have autonomy and flexibility. There is a considerable literature that explores the problems of

organizational culture in nursing facilities, including lack of worker empowerment, some of which has contrasted worker satisfaction in nursing homes to agency-based homecare workers (Bishop et al. 2006; Eaton 2000, 2002; Ejaz et al. 2006; Parker et al. 2006).[17] Studies that contrasted nursing homes and homecare agencies found that there was greater job satisfaction and fewer problems with turnover among homecare workers. Most of this research concludes that to reduce turnover it is important to bundle empowerment with decent jobs, that is, paying adequate wages and benefits.

Given the preference of consumers for home- and community-based care, and given that many workers prefer the autonomy of the homecare setting, the best bet for securing an adequate workforce to meet current and future needs is to allow as much long-term care to be home- and community-based as possible, to make it consumer-directed, to allow consumers to hire friends and family, and to pay providers a decent wage and health insurance benefits.[18] Paying family caregivers--a practice which has been resisted by Medicaid because it would increase the quantity of paid homecare services demanded --makes it possible for many caregivers to care for their family member without having to jeopardize their own household standard of living. Evidence from the author's research on the California In-Home Supportive Services (IHSS) workforce suggests that if homecare workers are paid a living wage and provided with health insurance even for part-time work, that job becomes the foundation of their household income strategy and attachment to the job increases dramatically, likely improving the quality of care of the recipient.

Wages, Benefits, and Labor Supply

In-Home Supportive Services (IHSS) in California is the largest consumer-directed Medicaid-financed homecare program in the country.[19] There are currently about 360,000 consumers in the program and slightly fewer than 300,000 care providers work for IHSS. Until 1996, homecare workers in California were paid the state minimum wage and no benefits. After a long legislative and organizing campaign that began in the early 1980s, however, unions began to win elections and negotiate contracts for IHSS workers at the county level.[20] The first contract for San Francisco IHSS workers was signed with Service Employees International Union (SEIU) in 1996, and wages in San Francisco rose from $5 per hour to $10 per hour between 1996 and 2002. In 2000, San Francisco County gave their IHSS workers a health insurance benefit, for which any worker who had worked 35 hours per month for 2 consecutive months was eligible. As of the summer of 2005, 94 percent of workers in California were paid more than $6.75 an hour and almost half were eligible for employer-sponsored health insurance as IHSS workers (California Association of Public Authorities for In-Home Supportive Services 2005; Howes 2005b). In several northern California counties wages have increased to more than $10 per hour and the work hour requirements for eligibility for health insurance have fallen to quite low levels. While most IHSS workers in California are still not paid a living wage or provided with adequate benefits, the improvements for the workforce in some of the Northern California counties, not limited to San Francisco, have been substantial enough to make homecare one of the best jobs that people with less than college education can obtain.

Howes (2005a) measured the impact of the wage increase in San Francisco on the retention rate of new care providers – those just entering the IHSS workforce each month.[21] Prior to the wage increase, only 39 percent of new providers lasted more than one year in the IHSS workforce (Howes 2002, 2005a).[22] As the wage rose over the next few years, the retention rate of new providers increased to a remarkable 74 percent. A logit analysis that associated changes in wages and benefits with the probability of a new provider staying in the workforce for at least a year after entry showed that at the mean value for all variables, a one dollar increase in the wage rate from the mean wage of $8.85 increased the probability of a new worker remaining in the workforce for a year by 12 percentage points (see Table 7.4). Adding health insurance and dental insurance each increased the probability of a new worker remaining in the IHSS workforce by more than17 percentage points. In fact, going from no health insurance to health insurance for all increased the probability of staying for a year by 20 percentage points. A simulation predicted that if the wage dropped to $6.75 in 2002 (Governor Schwarzenegger had proposed to drop state support for wages in excess of $6.75 in two consecutive budget battles) but workers continued to receive health insurance, the retention rate of new providers would have fallen to 50 percent. If the health insurance was eliminated as well, retention of new providers would have fallen to close to 0.

In a cross-sectional analysis of the effect of wage and benefit differentials by county in California, Howes (2004) also found that wages had a statistically significant impact on the probability of turnover. More significantly, having a good health insurance policy, meaning that providers were eligible even if they worked as little as 35 hours per month, decreased turnover by 15 percent.[23] Both studies (Howes 2005a, 2004) suggest

that wages and benefits have a significant impact on the retention of IHSS workers and that the availability of health insurance, especially for caregivers working part time, is absolutely central.

One of the other consequences of raising wages in San Francisco was precisely the outcome that state budget managers fear most, that is, the quantity of the service demanded increased significantly as it became easier for the consumer to find a good paid caregiver. In San Francisco, the rate of growth of the consumer population, after the wages increased and benefits were added, doubled and was twice the rate of growth for the state as a whole (Howes 2002)

After completing the earlier study that measured the correlation between wage increases and turnover in San Francisco, Howes undertook a survey of California IHSS workers to corroborate that workers were actually staying in the job because of better wages and benefits rather than some other unmeasured factor.[24] In San Francisco, which paid the highest wages of those counties surveyed and where turnover was the lowest, 83 percent of care providers said wages and benefits were the most important reason why they took and remained in the job. In other counties, where wages were lower or where most providers were not eligible for health insurance, on average, only 34 percent cited wages and benefits as the most important reason why they stayed in the job. In the lower wage counties most reported that they took the job because of their commitment to their consumer.

When asked how likely they felt it was that they would be able to find a job with comparable wages and benefits, half the care workers said it was likely or highly likely in the other counties, but only 25 percent in San Francisco felt they could find as good a job.

When asked how high a wage they needed to stay in their current job, 90 percent said they needed at least their current wage in the other counties, whereas only 61 percent in San Francisco needed at least their current wage.

The results of the studies of turnover and the survey of providers described above tell us that workers are caring for the consumers in part because they are paid to do so, and that if they are not paid adequately and if they cannot get health insurance through the job, they will look elsewhere for work.

Implications for Paid and Unpaid Caregivers

The lines between unpaid family caregiver, paid family caregiver, and paid non-family caregiver are highly porous. This reality suggests that paying family members to provide consumer-directed homecare for their elderly and disabled parents or siblings (and children) is one of the best strategies for developing an adequate long-term care workforce over the next several decades. The balance between paid and unpaid care must surely shift in favor of paid care if we are to provide sufficient care for those who need it. Nonetheless, the people who are providing that paid care will most certainly be many of the people who previously provided unpaid care, or who continue to provide both paid and unpaid care. Seventy percent of IHSS workers began working as a paid IHSS worker for a family member or friend. Most of those who are currently working for a non-family member or even someone they did not know entered the workforce as a family provider.[25]

Table 7.5 shows the caregiver demographics of unpaid workers by Level of Burden of Care index for Levels 3 through 5 separately. Unpaid caregivers of care recipients with higher burdens of care tend to be older, are more likely to be black or Hispanic, have lower levels of educational attainment, and have lower household income, compared with all caregivers. Caregivers with higher burdens of care are also more likely to be living in households with the consumer, suggesting that the household cannot afford to pay for long-term care. As a consequence, one or more members of the household may need to withdraw either wholly or partially from the workforce to provide that care. In fact, 15 percent of Level 4 and 37 percent of Level 5 burden caregivers went from full to part-time work in order to care for their recipient, compared to 10 percent of all unpaid caregivers (data not shown). Forty-one percent of Level 5 Burden caregivers took a leave of absence and 37 percent gave up work altogether, compared to 17 and 6 percent of all caregivers, respectively (data not shown)

The last column in Table 7.5 shows that unpaid caregivers providing Level 3 Burden and above care have a very similar demographic profile to the paid caregivers in California's paid IHSS workforce. (Except that there is a much higher proportion of white caregivers in the national sample of unpaid caregivers, just as there is a higher proportion of whites in the national population than in California). Unpaid caregivers have higher incomes and educational attainments, but they are just as likely to be women (especially at lower levels of burden of care), to be working full-time, and, at higher levels of burden of care, to be living with their care recipient. Similarities between these two groups suggest that those things that are important to paid homecare providers – flexible work schedules, a livable wage, and health insurance – if offered to unpaid

caregivers would enable the unpaid caregivers to provide their current or higher level of care with less stress and financial hardship than they now experience. Just as importantly, from the perspective of ensuring an adequate workforce to provide the volume of care that will be needed in the next few decades, paying family members to provide care for their loved ones makes it possible for more middle- and low-income families to provide the care their family members need in home- and community-based settings.

Conclusion

This chapter has argued that there is an imbalance in our long-term care system which favors nursing home over the home- and community-based care that most of those who need long-term care would prefer. The imbalance is apparently in part driven by a misguided goal of restricting the growth of the Medicaid program and the assumption that families will provide on their own for the care needs that are not met by state and federal programs. However, it will only be possible to provide care for the growing population of elderly infirm and disabled persons if we can attract new care providers. Home- and community-based care, and specifically consumer-directed care, provide the best prospects, but only if we as a nation can step up to the need to pay caregivers for the work that they do. An adequate supply of long-term care workers depends crucially on paying family and friend caregivers for some of the unpaid labor that they are already contributing so that they do not have to make the difficult choice between impoverishing themselves and caring for the people they love.

What this means specifically for current public policy is that the federal government must restructure the Medicaid long-term care program to eliminate the institutional bias so that there is a proper balance between facility-based long term care

and home- and community-based long term care. To expand coverage beyond very low-income people so that people do not have to spend down or disperse their assets to become Medicaid eligible, Medicare could create a benefit, analogous to that in the Japanese system, which would provide homecare for everyone at some basic level, to be supplemented by a private insurance wrap around. State Medicaid budgets should be enhanced to provide for higher wage and health benefits for long-term care workers, especially homecare workers in consumer-directed jobs. Other types of changes would make it easier for some to provide unpaid care. Stipends and support systems, including training and respite care, should be provided for family and other caregivers who withdraw from the workforce to provide unpaid care. Early Medicare opt-in should be made available to people who leave the workforce for caregiving before the age of 65. (WHCoA 2005; Seavey and Salter 2006). Changes such as these can ensure that the United States will have a sufficient supply of caregivers for the growing number of elderly women and men who will need care.

Table 7.1. Persons Aged 65 and Older Receiving Paid Long-Term Care Services, 1999
[Population in Thousands]

Characteristics of persons aged 65 and older	Persons aged 65 and older (in 1,000s)	Percent receiving long-term	Percent receiving long-term	Percent receiving long-term care
Number	34,460	5,479	3,824	1,654
Percent	100.000	15.9	11.1	4.8
Age				
65-69	9,443	5.7	5	0.7
70-74	8,785	8.8	7.2	1.7
75-79	7,305	13.6	10.1	3.5
80-84	4,797	24.8	17.3	7.4
85-89	2,601	39.8	24.8	15.0
90-94	1,133	59.8	33.7	26.1
95 years and older	396	72.1	35.7	36.4
Gender				
Women	20,200	18.8	12.8	6.0
Men	14,260	11.9	8.8	3.1
Race		Race		
White	30,367	15.6	10.6	5.0
Black	2,869	20.8	16.6	4.2
Other	1,223	12.5	10.7	1.8
Marital Status				
Married	17,990	9.7	8.3	1.4
Widowed	12,020	24.8	15.7	9.1
Never Married	1,293	23.5	12.1	11.5
Other	3,257	14.9	9.4	5.5

Notes:

[1] Receipt of long-term care is defined as receiving human assistance or standby help with at least one of six ADLs or being unable to perform at least one of eight IADL's without help. The ADL's included are eating, transferring, toileting, getting around inside, dressing, and bathing. The IADL's are meal preparation, grocery shopping, light housework, laundry, financial management, taking medication, telephoning, and getting around outside.

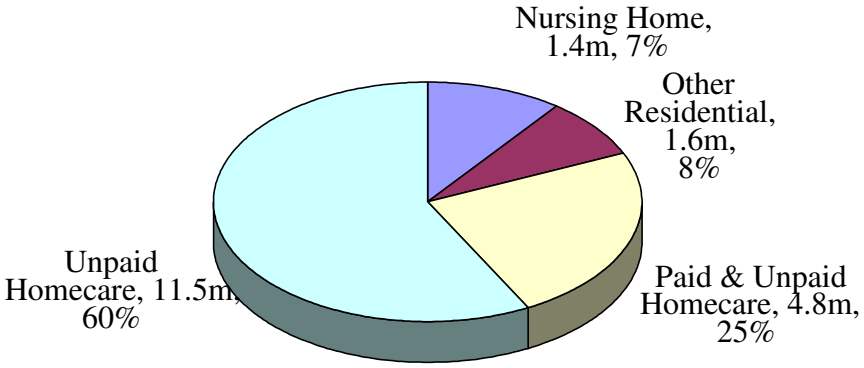
[2] This does not include about 1.3 million persons with disabilities who do not receive chronic help, but use special equipment to manage their disabilities.

[3] This includes about 1.5 million persons in nursing homes and slightly more than 150,000 persons in other care facilities.

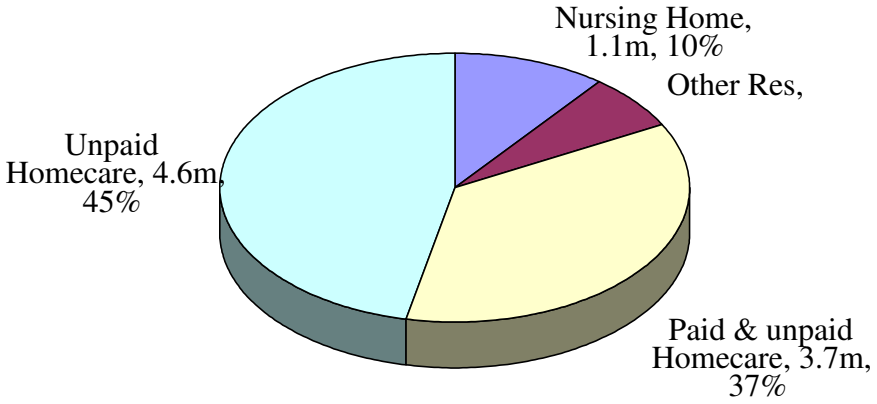
Source: House Committee on Ways and Means (2004): based on unpublished tabulations of the 1999 National Long-Term Care Survey by Brenda C. Spillman, The Urban Institute 2003.

Figure 7.1. LTC Sites in 2003 for persons aged 65 years and older

a. Persons Receiving All Levels of Burden of Care = 19.4 Million



b. Persons Receiving Levels 3+ Burden of Care = 10.1 Million



Note: Burden of care is an index of the intensivity of care needs developed by the NAC/AARP (2004). A higher number indicates a more intense level of care.
Source: Author's analysis of NAC/AARP (2003)

Table 7.2. Percent of those receiving paid and unpaid LTC that are female, by age

	By Burden Level	
Age	All Levels	Level 3+
65-74	60	62
75-84	71	68
85-89	78	78
90+	77	81
Total	70	70

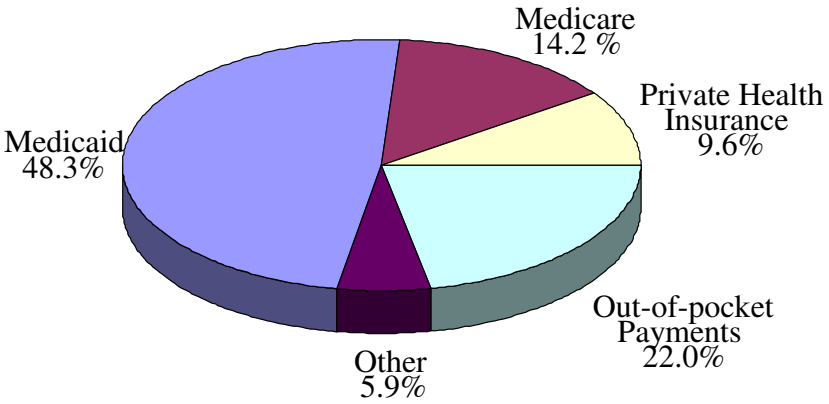
Source: Author's analysis of NAC/AARP (2003)

Table 7.3. Percent of those receiving paid and unpaid LTC that are in residential facilities, by age, gender

	By Burden Level					
Age/Ethnicity	All Levels		Level <3		Level 3+	
	Male	Female	Male	Female	Male	Female
65-74	5	10	8	5	1	15
75-84	14	16	7	12	19	20
85-89	12	20	0	30	22	10
90+	5	33	2	24	6	38
White	9	19	12	22	6	17
Black	4	20	6	22	0	18
Hispanic	14	7	14	5	14	10
Asian	9	11	8	9	9	13
Total 65+	9	18	6	16	11	20

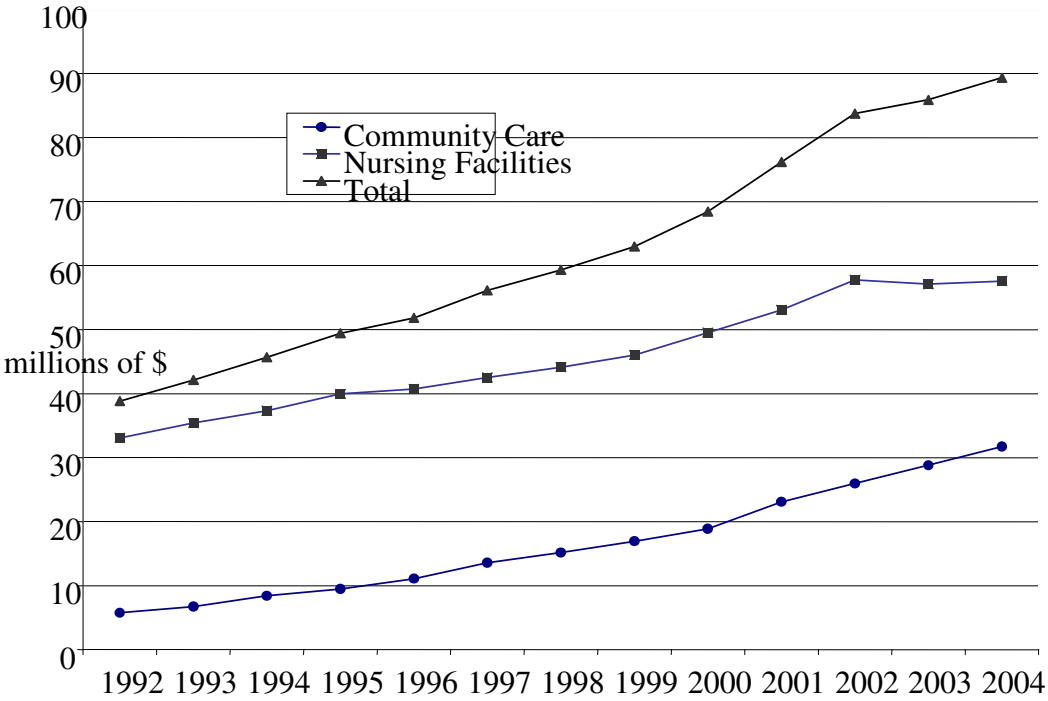
Source: Author's analysis of NAC/AARP (2003)

Figure 7.2. Sources of Long-Term Care Spending, 2001
Total Long-Term Care Spending = $151.2 Billion



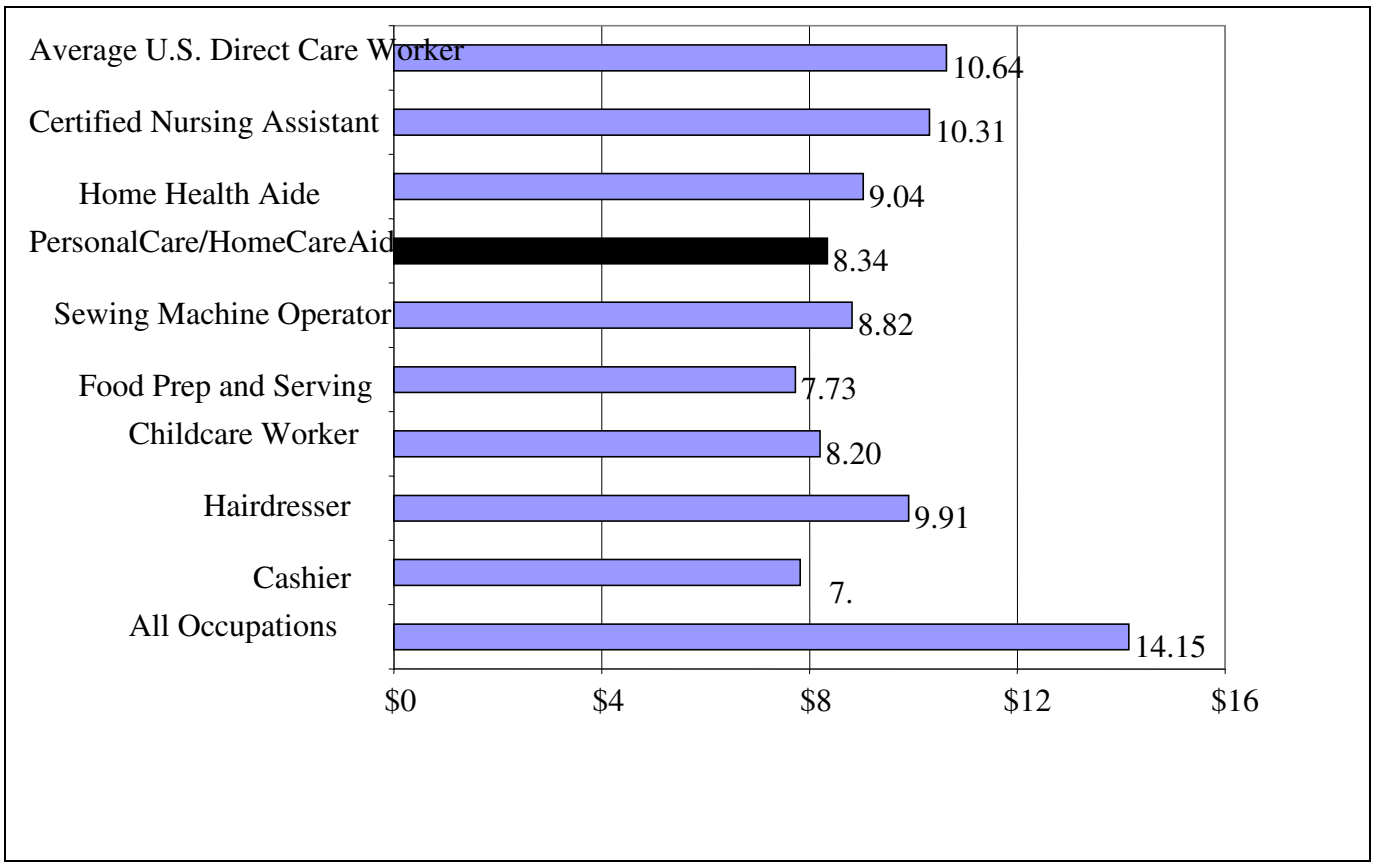
Note: Includes recipient's Social Security benefits which are required to be spent on long-term care for those receiving Medicaid.
Source: House Committee on Ways and Means (2004)

Figure 7.3. Medicaid Expenditures for Long-Term Care Services: 1992-2004



Source: Burwell, et al. (2004)

Figure 7.4. Median Hourly Wages, 2005



Source: U.S Bureau of Labor Statistics, May 2005

www.bls.gov/oes/current/oes_nat.htm#631-0000

Table 7.4. Marginal Probability of a New IHSS Provider Remaining in the Workforce for a Year or More, San Francisco County, November 1997–February 2002

	mean	marginal probability[a]
Wage rate	$8.850	0.123
Family provider	0.495	-0.235
Wage*family	4.487	0.034
Health insurance	0.818	0.173
Dental insurance	0.713	0.193
San Francisco employment	406.900	-0.016

Note: [a]Measures the marginal probability of a worker remaining a year or more associated with an additional unit of the independent variable, measured at the mean of the independent variables

Source: Author's analysis of CDSS CMIPS data, n.d.

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Table 7.5. Demographic Profile of Unpaid Caregivers for Persons Aged 65 and Older for the US by Level of Burden of Care, Compared with California IHSS Paid Workers

	Levels Of Burden of Care				
	ALL	Level 3	Level 4	Level 5	CA IHSS
Gender					
Female	64%	63%	67%	75%	79%
Age of Caregiver					
18-34	16%	22%	11%	5%	
35-54	47	53	53	41	
55-64	22	12	19	26	
65 or older	15	13	16	28	
Ethnicity					
White	100%	18%	19%	12%	--
Black	100%	18	40	5	--
Hispanic	100%	17	28	17	--
Asian	100%	17	20	13	--
Live in household	20%	8%	33%	63%	43%
Primary Caregiver	53%	39%	62%	77%	--
Educational attainment					
Less than high school	5%	5%	6%	11%	25%
High school grad	26	23	25	32	29
Some college	25	23	32	25	30
Technical school	3	2	5	2	
College grad	25	33	20	22	10
Grad school +	15	14	12	8	5
Current employment					
Employed full-time	47%	50%	45%	33%	46%
Employed part-time	10	8	14	9	54%
Retired	19	13	18	31	--
Homemaker	10	11	11	14	--
Household income*					
<$15K	6%	7%	7%	8%	19%
$15K-30K	13	12	10	21	33
$30K-49K	25	15	27	27	23
$50K-99K	27	22	23	24	14
$100K+	18	27	23	9	11

Source: Author's analysis of NAC/AARP (2003) and of California IHSS survey data

* Income categories for California IHSS workers:

<$12 K
12-24 K
24-36 K
36-48 K
48+ K

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[1] This chapter draws on research findings from the Better Jobs Better Care project carried out by the author from 2004 to 2007. I wish to thank Ummuhan Senay Tarhan for her research assistance on this paper and Cristina Nardone for project management and research assistance throughout most of the entire Better Jobs Better Care project. In addition, the following people contributed substantially to the project: Linda Delp, Lea Grundy, Laura Reif, Jeff Wang and Carol Zabin. The project benefited from a partnership with the UC Berkeley Center for Labor Education and Research and California SEIU Locals 434B and 250 (now SEIU – ULTCW and SEIU – UHCW West).

[2] The Center for Medicare and Medicaid Services (CMS) has been conducting a series of surveys by state on the preferences of the elderly for long term care settings. In Alabama 89 percent of persons age 35+ said that they considered having services that would allow them to stay in their own home very important; over 9 out of 10 people age 55+ in Kentucky say it is important for them to stay in their home as long as possible (http://www.aarp.org/research/longtermcare/trends/ky_ltc_07.html; http://www.aarp.org/research/longtermcare/trends/al_ltc_2007.html).

[3] The US Census Bureau (2004) projects that there will be 86 million people over age 65 in 2050, compared to 35 million in 2000. The number of people over age 85 is projected to increase almost five-fold from 4.3 to 20.7 million.

[4] Approximately 37% of the population that needs long-term care in this country is under age 65 (Georgetown University Long Term Care Financing Project 2003). These people require care because of blindness, disability, or chronic illness with which they were born or which they developed later in life, including cerebral palsy, Down Syndrome, mental retardation, multiple sclerosis, brain and spinal cord injuries.

[5] Note that Table 7.1 includes only those people receiving paid long-term care. As will be shown later, many more receive unpaid care.

[6] *Caregiving in the U.S.* by the National Alliance for Caregiving (NAC) and AARP (2004) reports the results of a national telephone survey of 6,139 adults, from which 1,247 caregivers were identified. To estimate the number of caregivers and caregiver households in the United States, demographic and household data were obtained from a randomly selected respondent in each household contacted. Survey results were weighted by household, based on demographic data reported by respondent. A population weight created from the demographic characteristics of the respondent was used to estimate the proportion of caregivers in the population. Statistics on long-term care for persons over 65 that are presented in this chapter are the author's own analyses of the same survey data. The NAC/AARP (2003) survey reported that an estimated 44.4 million Americans or 21% of the adult population, living in an estimated 22.9 million households provide unpaid care to an adult age 18 or older. Using the same data, this author estimated that there were 14.2 million households providing care to an adult over the age of 65. Analysis of the data indicated that each household provided care to an average of 1.37 recipients, so the number of people over the age of 65 receiving long term care at the time is estimated to be 19.4 million, and the number of recipients with Burden levels in excess of level 2 is estimated to be 10.1 million. Although the NAC/AARP survey (2003) focused on unpaid caregivers, it also provides a starting place to estimate the total number of people who receive both paid and unpaid care. Because respondents were asked if the recipient was also receiving paid care and what type of paid care, it is possible to get a household-based estimate of the extent and site of paid care given nation-wide. The survey asked whether the care recipient resided at home or in a nursing home, an independent living or retirement community, an assisted living facility where some care may be provided, or other residential facility. 2.2 million households were providing some assistance to an average 1.37 people in residential care facilities, or about 3 million recipients, of which 1.4 million were in skilled nursing facilities and 1.6 in alternative care facilities. These estimates are consistent with Spillman & Black's (2006) analysis of the 1999 National Long Term Care Survey which found that there were 2.2 million residing in residential care facilities, including 1.45 million in nursing homes and another 750,000 living in alternative residential care settings in the community. Since they argued at the time that alternative care facilities were the fastest growing sites for LTC, it is quite

possible that the number of beds in alternative care facilities has doubled in 4 years while the number of beds in nursing homes has remained the same.

[7] Liu and Sharma (2002) set 3 or more ADLs as a cut-off to measure the need for a long-term care benefit with this measure, they report 2.2 million Medicare beneficiaries who were over the age of 65 and still living in the community would have been categorized as in need of long-term care in 1998. Desai, Leutzer, and Weeks (2001) looked at unmet need among people aged 70 and over who had at least one ADL limitation and found that half of this population reported needing assistance. That suggests that an accurate measure of need for long-term care by the elderly could be based on counting those needing assistance with between 1 ADL and 3 with allowance for IADLs.

[8] The following table (constructed by author from raw NAC/ AARP data) illustrates how people were categorized into the 5 burden levels based on the range of ADLs and IADLs with which they need assistance and the number of hours required:

	Hours of service needed			
# ADL, IADL	0 - 8	9-20	21 - 40	41+
1 IADL	1	1	2	3
2+ IADL	1	2	3	4
1ADL (w, w/o IADL)	2	3	4	4
2+ADL (w, w/o IADL)	3	4	4	5

[9] Author's calculations from NAC/AARP data.

[10] Author's calculations from NAC/AARP data. Other studies show similarly high proportions of care recipients receiving at-home care. Kaye, et al. (2006) state that in 2000, 13 million people required "personal assistance services" in the home. Only 16 percent of the total hours were provided by paid helpers, known as homecare workers, personal assistants or attendants. They also note that of the 13.2 million people needing personal assistance in the mid-1990s, only 3.2 million, or 24.2 percent, got help from one of more paid assistants. Their analysis includes both elderly and non-elderly persons requiring personal care services.

[11] The NAC/AARP survey asked if the care recipient received paid assistance from "an aide or nurse hired through an agency or service," "an aide or nurse hired independently, that is not through an agency or service," "a housekeeper hired to clean or cook," or "any other people who are paid to help him/her" In my reanalysis of the raw data I have measured only the incidence of use of paid aides or nurses hired through an agency or independently (the first two responses listed above). In addition, 30 percent of households used other paid assistance including housekeeping

[12] According to Moses (2005), with careful planning, asset caps are not an impediment to eligibility for Medicaid. He argues that the Medicaid spend down studies of the late 1980s and early 1990s dispelled the view held by "most academics" that half to three quarters of people in nursing homes had been admitted first as private-pay clients and spent down their assets into poverty to qualify for Medicaid. Whether this is true or not, it suggests that people should not have to impoverish themselves or spend their children's inheritance in old age to be cared for in their final years. Moses also suggests that there is tremendous inequity in the rate at which individuals from different communities are able to figure out how to qualify for Medicaid long-term care services.

[13] State budgets pay mainly for services, including education and healthcare, and about 54 percent of expenditures from State General funds go to support two types of services – education and health (Boyd 2003). Health spending, which is largely supported by Medicaid, consists of spending on insurance for low-income children and their families and on long-term care for low-income elderly and disabled persons. In 2002, states spent 12 percent of their general funds on Medicaid. Including federal-financing for state programs, states spent 21 percent of their total budgets on Medicaid (Boyd 2003). While Medicaid currently represents less than one-third of State General fund expenditures and long-term care is less than one-third of that, expenditures on long-term care, most notably homecare, are the fastest growing component of the State Medicaid expenditures which are in turn the fastest growing component of state budgets, the growth of which is hard to control (Lee, Miller, and Edwards 2003; Boyd 2003). Because of this growth, Medicaid and especially Medicaid-financed homecare are being targeted as states try to rebalance their budgets.

[14] The Channelling demonstration of the 1980s showed that costs actually increased when home- and community-based services were made available (Thornton and Dunstan, 1986). More recently, the Cash and Counseling demonstrations showed that consumer-directed home care did not reduce the cost of providing services (Dale and Brown. 2005). In both cases, costs went up as previously unmet needs were satisfied. Consumers and caregivers all reported greater satisfaction.

[15] Delp (2006) shows that home care workers working in the consumer-directed In Home Ssupportive Services program in California, in which consumers have the option to hire family members and friends, derive satisfaction from their work but also experience emotional, physical, schedule-related, and financial stressors from the demands of home care and that these stressors affect their health, level of fatigue, and job satisfaction. NAC/AARP (2004) reported that caregivers who provide high Level of Burden Care reported significant physical strain, emotional stress, and financial hardship. The two greatest predictors of emotional stress and financial hardship were the Level of Burden and whether or not the caregiver felt they had a choice in taking on the care giving responsibilities.

[16] While home health aides do similar work to homecare aides and personal care assistants, including bathing and toileting people who are home bound and unable to care for themselves; home health aides are generally employed through home-health agencies to provide care for people who need convalescent care; they are prescribed by a doctor, must be licensed, have more formal training, and are permitted to perform a wider scope of medically-oriented tasks.

[17] Susan Eaton's work (2000, 2002) explores the problems of the workforce in nursing homes, all of which call for changes in the organizational culture of nursing facilities. Other work done under the auspices of the Paraprofessional Healthcare Institute (PHI) has focused on the workforce issues for direct care workers, not only those in nursing homes, but also those in home- and community-based settings. Several recent projects conducted under the auspices of the Better Care Better Jobs program have investigated the effect of changes in organizational culture on recruitment and retention in nursing home settings and among homecare agencies. For example, Parker, et al. 2006) explored the effect of improving cultural competence such as teaching people how to deal with ethnic- and race-based differences Bishop, et al. (2006), and Ejaz (2006) considered the affect of adopting management practices that empower workers, combined with frequent high quality communication and high quality relationships, ongoing education and training and the expectation of career advancement.

[18] For example, Stone and Wiener (2001) suggest that women transitioning from welfare to work may help ease the labor crunch, or that new immigrants will fill the demand. More recently, there has been a focus on the potential of older workers, including retirees, to do the work. However, few women are now transitioning from welfare to work, and many immigrants are already doing direct care either in nursing homes or in their own communities. While older workers seem eager to join the long-term care workforce, they are not interested in doing the hands on tasks, such as assisting with activities of daily living, which are the core of the work (Hwalek, et al. 2006).

[19] Though IHSS began as an exclusively state-financed program in the 1970s, most people now receive care under the Medicaid program (Howes 2005). The federal government pays for half of the program, and roughly speaking, the state and counties share the remaining costs with the state paying two-thirds.

[20] Beginning in the 1980s, two unions, the Service Employees International Union (SEIU) and the United Domestic Workers (which later became an American Federation of State, County, and Municipal Employees (AFSCME) affiliate, more recently broke from AFSCME and affiliated with SEIU) began to try to organize the IHSS workers in California (Boris and Klein 2006; Delp and Quan 2000; Howes 2005; Walsh 2001). Because these workers were classified as independent providers, they could not legally form a bargaining unit. While they worked directly for the consumer, the state paid their wages, so they had no clear employer-of-record. After a long campaign conducted by a coalition of union and consumer advocacy groups who were concerned with the conditions of the workers and the low quality of the care being provided, a bill was passed by the California Legislature in 1992 which enabled counties to establish Public Authorities (Heinritz-Canterbury 1999). The principal charge of the Public Authorities, which were set up as boards with majority consumer representation, was to improve the quality of the program by maintaining a registry of available providers and providing training to workers, and to serve as a clearing house for consumers' concerns. However, the Public Authorities were also to serve as the employer-of-record for homecare workers, which meant that workers could now be organized into bargaining units.

[21] This study was done using the California Management Information and Payroll Systems (CMIPS) database which maintains records for every consumer enrolled in the program and for every provider working in IHSS. The database, which is owned and managed by the California Department of Social Services, can be used to measure workforce turnover (the database was made available to the author under contract with the CDSS). The author used CMIPS to examine turnover in San Francisco county and its relationship to wage and benefit trends (Howes 2002, 2004, 2005).

[22] Retention is measured as the percent of the workforce, or of new providers, entering each month, who are still there one year later.

[23] Note that the San Francisco study is looking at the retention rate of new providers only, who have much higher turnover than all providers; the cross-sectional California study, on the other hand, examined turnover of all providers. It is not surprising that in the cross-sectional California study the impact of a $1 wage increase on turnover at the low mean of $7.76 is not as great as the impact reported in the San Francisco study, because the San Francisco study showed that wages had an increasing effect on retention at higher wage levels, becoming more important than health insurance only as the wage approached $9 an hour.

[24] The survey was conducted as part of the "Making Homecare a Better Job" project which was part of the Better Jobs, Better Care program funded by the Robert Wood Johnson Foundation and Atlantic Philanthropies. The survey was administered to 2,200 homecare workers in California in 2004 and 2005. Respondents were randomly selected in 8 counties in which wages ranged from a low of $6.75 with no benefits to a high of $10.28 with benefits. Providers were asked a range of questions designed to determine what drew them to the job and what kept them in the job. See www.bjbc.com for a description of the project.

[25] Benjamin (2006) found that many related caregivers, who had initially become IHSS workers in order to care for a family member, would be willing to provide care for an unrelated client in the future.