LONG TERM CARE IN THE UNITED STATES

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INTRODUCTION

Long term care has long been a backburner issue in the United States. Attention has normally focused first on acute care issues and only secondarily on the needs of chronically ill and disabled people. And, unfortunately, prospects for improvement are not good even though the inadequacy of our current long term care system is taken almost as a given by those who study this area. Government support for long term care is mainly limited to the Medicaid program, which is available only to persons with low incomes and other resources. This program is likely to be reduced rather than expanded in the near future. Private insurance protection is also rare.

Even in the 1992-1994 debate over expanding health insurance coverage, long term care issues were treated as nearly an afterthought. The major Democratic proposals offered were limited, although all contained at least a minor expansion of public support for long term care services. Such support recognized the need for further help for the elderly and disabled in this area. However, only one of the major proposals—the so-called single payer plan—offered a comprehensive long term care benefit. The problem was essentially one of cost. Reluctance to raise new taxes or take on major new burdens through the public sector meant that few policy makers were willing to propose the more than $80 billion per year in new public spending that would be required to fully cover long term care services. Instead, the tactic was to offer expansion, but limited in scope and phased in very slowly over time.

After the Congressional elections in 1994, the political landscape dramatically changed. Plans for health reform were dropped and a new focus on reducing government programs took over the political agenda. Republican proposals have generally ignored long term care issues altogether—often neglecting to consider the importance of long term care in the Medicaid program, for example. And since the Congressional proposals on Medicaid would result in dramatic reductions in federal contributions for care under this program, public long term care benefits will likely contract rather than expand if these proposals are ultimately adopted. The only expansion proposed would offer tax benefits for the purchase of private insurance.

THE CURRENT LONG TERM CARE SYSTEM

While options for disabled persons are beginning to change in the United States, care for those with the greatest disabilities continues to occur in traditional institutional settings. The 1990 Census found that 1.77 million persons were in nursing homes in 1989, with most of them over the age of 65 (U.S. Bureau of the Census 1993). The share of the population in nursing homes has been declining slowly, however, while use of formal home and community-based services has grown. These expanding areas of service use may be home-delivered services or adult day care and other activities in community-based settings. Data from 1984 indicated that just 30 percent of all persons with at least one limitation in activities of daily living (ADLs)—the most commonly used measure of disability— used home and community based services (Keenan 1988). In just

three years, that figure rose to 41 percent (AHCPR 1992). Projections of service use in the early 1990s indicate further dramatic expansions.

For those who must turn to formal care, either at home or in an institutional setting, the question quickly arises as to whether there will be sufficient resources to meet the costs of such care. Even those with moderate levels of income may not be able to afford long term care services, especially care in a nursing home. The costs of long term care can quickly consume retirement incomes and then eliminate a lifetime of savings for most Americans. For example, a nursing home stay costs at least $35,000 per year and sometimes much more. In high cost areas, the charge for a nursing home stay can easily reach $60,000. Home care, if not round the clock or very intensive, is less costly. A visit can frange from about $20 to $80 depending upon services received. Data from 1987 found that the average cost of a visit was $49 and that a person with substantial disability (3 or more ADLs) had, on average, charges over $4000 (Altman and Walden 1993). Today these costs are likely to be three times as high.

Promising areas for long term care, such as home modifications and new living environments that are less institutional than nursing homes, still are liminted in availability. Often, they are affordable only to those with substantial incomes. As a result, there is not a good continuum of care in the United States. Spotty availability of home and community-based care and an over-emphasis on formal institutional services characterized the market in all but a few areas such as the state of Oregon where innovation has taken hold.

FINANCING LONG TERM CARE

At present, long term care is funded mainly by the federal/state Medicaid program and by individuals and their families. Other public programs, such as Medicare, play only a limited role. The first area to which we need to look for financing care is thus family resources.

Family Resources

In general, people with disabilities do not have substantial amounts of financial resources. Older women, particularly those living alone, are both more likely to need long term care services and to have substantially lower resources than do the elderly as a whole. For example, a typical woman living alone and over the age of 75 had an income of only $8,365 in 1993 (Bureau of the Census 1994a). This median income amount is about one fourth of the cost of an average annual nursing home stay.

Another element of economic well-being, wealth, needs to be included as well. The image of elderly people as "income poor but asset rich" is considerably exaggerated, however. Generally, those with the highest incomes also control the largest amounts of wealth. And, older persons with modest means are likely to hold much of their wealth in housing—an asset that is difficult to liquidate to meet short term needs and that may carry substantial burdens in the form of high taxes or maintenance costs as well. Financial assets, which can be readily used to meet short term needs, are very unequally distributed across the elderly population. In 1993, for

example, the value of financial assets for elderly families in the top fifth of the nation's households as ranked by income was about $215,000, but only about $3,000 for elderly families in the bottom fifth of the population (Eller and Fraser 1995).

One detraction from the well-being of older Americans is the burden of primary and acute health care spending by individuals. Despite the presence of Medicare and Medicaid, the percent of income spent by individuals over age 65 on unreimbursed health care costs (out-of-pocket spending) and on premiums for Medicare or private insurance is at an all-time high and is projected to increase further (Moon and Mulvey 1995). Incomes have risen for this age group, but out-of-pocket health costs have simply risen faster.

Analyses of the acute care portion of these expenses reveal considerable burdens on those with low or moderate incomes. Feder, Moon and Scanlon (1987) estimated that in 1986, elderly persons with a hospital stay and incomes of less than $10,000 spent 18.3 percent of income, on average, out of their own pockets for acute health care services (both for unreimbursed services and insurance premiums). And the burdens of these acute care expenses rise with age, so that the oldest old would spend even more on acute health care services. By 1994, that figure is projected to have become 29 percent for those over the age of 85, for example (Moon and Mulvey 1995).

Over the last decade, private insurance has emerged as another means for spreading the risk of long term care. Today, about 3.4 million Americans have purchased private insurance policies (Coronel and Fulton 1995).[1] However, policies that promise adequate protection against likely costs (a standard many do not meet) are not affordable by those senior citizens most in need of protection. The Health Insurance Association of America estimated the cost of such a policy at $2525 for a sixty-five year old in 1990; $7713 for a seventy-nine year old (Coronel and Fulton 1995).[2] And part of the "cost" of making such insurance affordable is precluding anyone with a long list of health problems from purchasing policies. Further, acceptance of the purchase of this new type of private insurance is bound to be slow. It will be many years before companies can point to a successful track record in this area since there is likely to be a long lag between purchase of insurance and payment of benefits. Indeed, a number of analysts have argued that the public is responding rationally by not purchasing private long term care insurance (Pauly 1993).

Since costs often exceed $35,000 per year for nursing home services and can be well over $15,000 per year for extensive home care services, these expenses can be devastating to families who lack private insurance. For that reason many Americans ultimately turn for help to the Medicaid program as the other major source of support for long term care.

Medicaid

The Medicaid program, which was originally established to help low income families meet acute care needs, has become the most important public program providing long term care.[3] And since it was not designed to play such a role, it is not surprising that almost no one expresses satisfaction with the long term care benefits provided by Medicaid. Despite current public expenditures of over $44 billion on that part of Medicaid—$25.5 billion of which goes to elderly persons (Liska and Obermaier 1995)—many gaps and inequities remain. Medicaid is a joint federal/state

program, with about 55 percent of its funds coming from the federal government. The amount each state receives depends upon a state's own contribution which is then matched by a formula that varies by each state's ability to pay. As a consequence, there is considerable variation among states reflecting their attitudes towards services for elderly and disabled people, and to some extent capacity to provide care since the federal matching formula is widely viewed to be a flawed measure.

Medicaid provides mostly nursing home coverage and eligibility is limited to individuals who have exhausted their assets or at least "spent down" these resources to a very low level. The term "spend down" refers not only to expending assets but also most of a family's income each year. The value of the home is exempt from this spend down requirement, although states are allowed to seek liens on homes to pay for care of a nursing home resident.[4] As a consequence, Medicaid essentially offers protection after catastrophe has already occurred. Middle income people benefit from the program but only once they have devoted most of their resources to paying for care. Medicaid has been characterized as insurance where the amount that you must pay before becoming eligible (the "deductible") is your lifetime savings and even then you must devote your annual income as your share of the cost (in insurance terms, the "copayment"). Nonetheless, since it is the only public program to offer substantial coverage to the disabled population, Medicaid has been used more and more by middle-class families who find the costs of long term care prohibitively expensive. It is no longer confined to a minority of persons with low incomes.

For many American families, the spend-down requirements represent a very unpalatable option, and have led to systematic efforts to subvert these requirements. Policy makers have become alarmed at the resulting growth and perceived manipulation of the system—for example by those who have substantial resources but choose to dispose of them—often by transferring them to children—in order to qualify for eligibility. While this abuse may not be widespread, it is substantial enough to create considerable concern about fairness. And, in some areas of the country, such as New York, the feeling is that the abuses are large and come from those with very high incomes. Evidence on asset transfers, not surprisingly, is difficult to obtain. But a 1993 Government Accounting Office study found that while one out of every eight applicants for Medicaid had transferred assets within 30 months of the application, one-third of these transfers totaled less than $10,000.

Recent changes in the law to limit transfers of assets reflected a direct response to these perceived abuses. But these new state activities in areas such as estate recovery programs may penalize most those who are least sophisticated while failing to curb abuses by those with the most advanced legal advice. Moreover, states are often reluctant to press for estate recovery activities, for example, because of the often negative response of the public. Making everyone use their own assets before becoming eligible for benefits sounds better in theory; in practice enforcing such behavior has proven to be problematic. Thus, the welfare nature of the program creates problems for both government and the public. The bottom line issue is whether enough is saved through

these stringent spend down requirements to justify the dissatisfaction and abuse that have developed around Medicaid.

The rapid growth in the costs of long term care have also led states to focus on holding down the number of nursing home beds, to limit reimbursement for nursing homes, and to restrict their programs to institutional settings as additional ways to limit spending. For example, limits on home care programs reflect the fact that placing bounds on services is more difficult in a setting where individuals remain comfortably at home. Policy makers fear that such individuals would see government-provided services as a benefit with few costs and hence seek more services whenever possible. This is often termed a "woodwork" effect—that is, the fear that an unexpected number of people would appear (or come out of the woodwork) to demand services. Since many families now provide care for their relatives at home, the chief source of this growth in participation would presumably come from families seeking to have the government pay for services they are now providing for their relatives. In contrast, having to make a major decision to move to an institutional environment is believed to be an impediment to demanding such care and thus acts as a natural limiting mechanism on its use. This, perhaps more than any other reason, is why Medicaid policy continues to be dominated by nursing home care. For example, in 1992, almost 90 percent of all Medicaid long term care dollars for the elderly were for nursing home services (Coughlin, Holahan and Ku 1994). But it also means that we rely on the most institutional and restrictive form of long term care services, limiting flexibility to try other approaches such as residential facilities, adult day care and other similar care.

As of January 1996, the future of the Medicaid program is extremely uncertain. The President and the Congress remain at an impasse over the federal budget and treatment of the Medicaid program is a major area of disagreement. At a minimum, there will likely be substantial reductions in federal contributions to the program. At a maximum, a new program (Medigrant) will be created in which states receive relatively unrestricted (block) grants that over time will result in a substantially lower federal contribution. The goal of this proposal by the Congressional Republicans is to eliminate the federal guarantee of certain benefits to individuals (including long term care for elderly and disabled persons). The pressures on Medicaid (or if passed, the successor Medigrant program) in the near term will thus be to find ways to cut back even further on spending. The legislation passed by the U.S. Congress and vetoed by the President would have resulted in approximately 25 percent lower contributions than would be expected if the program remained unchanged over the next seven years. And for some states, the impact would be even greater. It is expected that states would respond by seeking lower levels of care, reducing payments to providers (which are already quited limited) and in some cases reducing eligibility for benefits.

Prospects for the Future

If the current picture of long term care financing looks bleak, the future looks even worse. Projections are that the elderly population will grow by 73 percent in the next thirty years (Taueber 1992). The population over age 85 and most likely to need long term care is expected

to more than double in that period, growing by 115 percent. The hope is that at the same time that we live longer, we will make important advances against diseases of old age such as Alzheimers and be able to reduce disability at a particular age. Until recently, research seemed to indicate that longer lives have not translated into healthier lives, indicating a substantial increase in the need for long term care (Guralnick 1991). But a more recent study by Manton et al. (1993) indicates that some age-adjusted declines in disability may now be occurring. This is an area where considerable further attention is needed since it will affect the affordability of various long term care strategies. Nonetheless, the incidence of disability would rise as the population ages with the demographic changes ahead, but not by as much as the simple aging of the population would indicate.

In considering prospects for the future, we should not assume that incomes of the most vulnerable will necessarily improve. Incomes of older Americans have grown in recent years, but this growth does not stem from just one component; rather, most sources of income for the elderly have grown substantially. For example, over the last twenty-seven years, Social Security benefit increases have played an important role in income growth, although since 1975, Social Security benefits have remained a relatively constant share of total income (Yeas and Grad 1987; Grad 1990). But this was due to a number of ad hoc policy expansions and Social Security is not likely to be as strong a source of growth in the future. In fact, cutbacks in the program now seem more likely than expansions. Further, the most dramatic growth for the last quarter century has occurred in pensions and asset incomes. But again there is reason to expect a slowing over time. Coverage from private pensions, for example, has stopped expanding (Zedlewski et al. 1990). Consequently, average income growth will also likely slow in the future from this source of income as well.

Private insurance coverage may continue to grow, as future older Americans with higher incomes are better able to afford its costs or to purchase it at younger ages. However, even optimistic projections of private insurance growth suggest that 25 years from now, private insurance will still be confined to higher income elderly persons and will do little to mitigate the potential catastrophic costs of long term care for most senior citizens (Wiener, Illston and Hanley 1994). As a result, Wiener et al. estimate that with no change in policy, the demands on the welfare-based Medicaid program will rise with the growth in the elderly population.

And efforts to encourage expanded purchase of private insurance through public/private partnerships have at least so far not proved to be very popular or successful. That is, several states have experimented with offering expedited eligibility to Medicaid for persons who purchase private policies, allowing them to forego some or all asset spend down if they buy private coverage for several years worth of care. Why have these plans been slow to be adopted by older Americans? Several possible answers have been offered. First, these schemes may protect against spending down one's assets, but to be eligible for Medicaid, a large share of income must be contributed. Consequently, for those with substantial annual incomes, the Medicaid protection may not be very appealing. Moreover, one of the reasons for buying private insurance is the promise that you will not have to go onto a welfare program, and it may not be attractive

therefore to buy less insurance on the promise that you can eventually gain easier access to Medicaid eligibility. Finally, many persons do not seem anxious to think about their long term care needs far enough in advance to lead them to purchase insurance at all. Thus, at least for now, there is little optimism that private long term care insurance can fill in the gaps in protection for persons with long term care needs.

The clouded outlook for public support for long term care early in 1996 also makes the picture for the future a bleaker one. It is likely that there will be at least some return of control over Medicaid to the states combined with less federal support. This will likely increase state-by-state variations. Richer states with a greater commitment to providing such care will likely maintain their efforts to protect those in need of long term care, but elsewhere the situation may deteriorate. In addition, the Medicare program, which mainly serves the acute care needs of the elderly and disabled populations, has gradually expanded to cover some long term care services (although these are supposed to be limited to post-acute or skilled needs). That additional source of help will also likely be reduced substantially as the Medicare program faces future reductions in spending growth as well.

WHY IS THERE A NEED FOR A PUBLIC SECTOR SOLUTION?

It makes little sense for individuals to rely only on their savings to meet long term care needs. Not everyone will require such care, but when they do it can be very expensive. In a sense, this is the perfect "insurable" event, in which the risks ought to be shared across a large group. But the private sector has been slow to develop such insurance despite a well demonstrated need.

Why can't individuals simply seek long term care insurance products through the private market? Insurers are understandably cautious about marketing products where the liabilities will not be known for many years. Indeed, it is prudent for insurers to operate conservatively so they are certain to have the resources to pay benefits in the future. This conservativeness combined with the costs of marketing and selling to a largely to individuals—with the resultant marketing and advertising costs—may make the price too high for many persons 65 and over. Further, private insurers often offer coverage only to individuals in good health at the time of enrollment (Rice et al. 1990). In addition to current disability, individuals with hypertension, arthritis, any history of heart disease, diabetes or recent hospitalizations may be screened out. As yet, there is little evidence that such factors are actually good indicators of later need for long term care, but nonetheless individuals with such medical histories are unlikely to be able to purchase individual long term care insurance policies.

Thus, there will always be gaps left by private insurance approaches. Even if tax benefits are added to encourage purchase of insurance, many moderate income families cannot and should not purchase such coverage. Assets are low and they would effectively be lowering their standards of living for many years to purchase benefits that may not protect them over time. Further, since such insurance is of most value to protecting assets, then those with few assets to protect will likely find becoming eligible for Medicaid a reasonable alternative. Thus if we wish to expand the

availability of long term care services for low and moderate income individuals, a public component must be at least part of the solution. The Medicaid approach, which is not insurance, but rather support after individuals have depleted their resources, is widely disliked. It offers help, but too late to provide the same type of protection offered by insurance. At a minimum, considerable expansions of Medicaid would be necessary to fill in gaps with a private insurance approach.

There does not appear to be a "solution" to the problem of long term care on the horizon, but some expansion of public support (either direct and/or through tax relief) could help to ease some of the most egregious hardships that our current system imposes. The lack of a commitment to public financing means that we will retain a patchwork approach that leaves serious gaps and inequities. And if Medicaid becomes a block granted program subsisting on even more limited federal contributions, unmet need for long term care services will grow—particularly in some states. Nonetheless, some expansions of long term care should be possible, financed in part by some economies in other programs even in this era of fiscal austerity.

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ENDNOTES

[1] This is an estimate of the number of policies purchased to date, some of which undoubtedly have lapsed.

[2] This assumes a $100/day nursing home, $50/day home heath care policy with 5 percent inflation protection and a nonforfeiture benefit.

[3] Other public programs offer more modest coverage. Medicare, the acute care program for the aged and disabled, covers less than 5 percent of long term care expenses. Indeed, many elderly persons are surprised to discover how little Medicare covers when they are in need of long term care. Skilled nursing facility benefits and home health care services are offered by Medicare, but are limited to those with acute medical problems. They provide for transition care for persons after acute episodes. Social Services Block Grants and elderly nutrition programs of the Administration on Aging also offer limited benefits to those in need. But these are appropriated programs, and not very generously funded. Moreover, the Social Services Block Grants cover a variety of services and long term care must compete for a share of the total.

[4] In practice, most states do not seek to take the home even after the death of a surviving spouse. This has proven to be a politically unpopular means for limiting the costs of Medicaid nursing home care.