THE CHANGING ELDERLY POPULATION AND FUTURE HEALTH CARE NEEDS

DAVID MECHANIC, PHD

ABSTRACT The impending growth of the elderly population requires both fiscal and substantive changes in Medicare and Medicaid that are responsive to cost issues and to changing patterns of need. More emphasis is required on chronic disease management, on meaningful integration between acute and long-term care services, and on improved coordination between Medicare and Medicaid initiatives. This paper reviews various trends, including the growth in managed-care approaches, experience with social health maintenance organizations and Program of All-Inclusive Care for the Elderly demonstrations, and the need for a coherent long-term care policy. Such policies, however, transcend health care and require a broad range of community initiatives.

INTRODUCTION

It is now commonplace to reflect on the fact that the American population, like the populations of other Western developed countries, is aging. It will continue to do so for the next half century because of the extension of life and the reduction of fertility. Although the number of persons over 65 has been growing only modestly by about 6 million people a year, as the baby boomers reach elderly status between 2010 and 2030 the number of persons over age 65 will increase from 39 to 69 million.[1] By the year 2030, there will be fewer people under age 18 than over age 65 unless we elect to change immigration policies radically. Projecting current patterns of expenditure for Social Security, Medicare, and Medicaid for this growing elderly population results in scenarios that many believe are not sustainable over the long course, and these issues will remain high on the national agenda for some years to come.

Pragmatically, the discussion focuses on cost and the expected changing ratios of workers to dependent and retired persons. It requires consideration of impor-

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Dr. Mechanic is René Dubos Professor of Behavioral Science and Director, Institute for Health, Health Care Policy, and Aging Research, Rutgers, the State University, 30 College Avenue, New Brunswick, NJ 08901-1293. (E-mail: mechanic@rci.rutgers.edu)

tant questions of equity among age cohorts, retirement norms, the responsibility of individuals to save for their futures, and the appropriate mix of individual provision and social entitlements. It must take account of the fact that economic circumstances, individual health trajectories, and social norms are changing and will change even more in the future, and that perspectives that served us well in the past may need fine-tuning or even radical modifications. The underlying issues are ideological and contentious and have significant bearing on government expenditures and taxes, with potential for significant conflict among generations. The public power of the elderly, with a growing and well-organized voting block with well-defined interests, makes resolution of distributional issues uncertain.

The issues are interdependent, but here I focus more narrowly on the future of health care and its organization and financing. An extraordinary amount of health care data on the prevalence of illness and disability and patterns of utilization and expenditure are available now. As we confront tough future issues, however, we also require a clear framework of values and priorities that take account of the broad factors that contribute to health and effective function on a population level, the proper balance between preventive and curative health services, the role of chronic versus acute care, and the place of long-term care within our constellation of services.

The US has no coherent long-term care policy, but Medicaid, and more recently Medicare,[2] contribute to a *de facto* long-term care program. Benefit payments to home health care agencies are an impressive example of the inevitable flow of resources into long-term care. While only a tiny component of the program in the early Medicare years, it increased during the decade of the 1980s to the $2 billion mark and then took off, increasing fivefold between 1989 and 1994.[3] This pattern has continued, with home health care benefits increasing from 26.2 to 32.3 billion dollars from fiscal year 1994 to 1997.[4] Although the home care benefit was intended as an acute care service, approximately three-fifths of all such services go to patients receiving services for 6 months or more. The growth of home health costs is a contentious issue, and it commonly is believed that there is significant fraud in billing. Nevertheless, in the absence of long-term care coverage, providers will adapt whatever benefits they can to the long-term care needs of their clients.

Similarly, Medicaid, for which the largest group of enrollees in 1996 was some 18.2 million poor and near-poor dependent children, expended most of its resources on long-term care services for persons with disabilities and for nursing home care for the poor elderly. Individuals with disabilities, for example, who constitute about 15% of all Medicaid enrollees, account for about two-fifths of all Medicaid expenditures.[5] In substance, and to a considerable degree inadvertently, Medicaid has become the nations long-term care program. The central issue we face is not whether to curtail technology at the end of life, as Callahan[6] and others have argued, but the growing challenge of financing and organizing long-term care to maintain a reasonable level of care for persons with serious impairments in the activities of daily living at both younger and older ages. The levels and types of technology necessary to achieve this is debatable, although there is substantial indication that we often misuse expensive technical approaches in many instances for which careful assessment linked with more simple medical and psychosocial interventions might achieve more.[7]

THE ROLE OF TECHNOLOGY

Much of the success of medicine comes through new, useful medical, surgical, and pharmacological interventions. As people age, they have more chronic conditions that can benefit from such technology, and average expenditures increase. Technology often reduces discomfort and repairs function, as persons who have had cataracts removed or hip replacements or many other interventions understand. The public, while encouraged to support medical innovation by the scientific community and medical industries, are vigorous advocates who make possible the strong congressional support for biomedical research and development that has been evident over the past half century. The challenges we face are not with technological innovation, but rather with how we assess and apply it.

Medical innovation diffuses very rapidly, typically before it is evaluated, because those who apply new interventions often find the process challenging, conducive to increased prestige, and remunerative. American medicine, American patients, and perhaps patients everywhere, put greater worth on the performance of technical procedures than on conversation and instruction and are more comfortable paying for an imaging study than for simple talk. This preference is built into most reimbursement systems, and health professionals understand that procedures pay more for less effort. The tendency, thus, is to adopt and use new technology, despite uncertainty about its value, on the notion that perhaps it may do well. Patients, increasingly knowledgeable about new interventions, often demand them because they provide hope of relief of what may be intractable conditions. The tensions are seen easily in the case of highly experimental and unproven treatments for life-threatening conditions. Once claims for a new treatment are made, insurers have a difficult time holding the line on reimbursement, despite the fact that neither efficacy nor effectiveness has been established. There long has been recognition of the need for an impartial expert process for evaluating new technologies, but the abolition of the Office of Science and Technology and the threatened loss, and near elimination, of the Agency for Health Care Policy and Research suggest the difficulty of this role when it opposes strong interest groups.

END-OF-LIFE CARE

As persons age, they require more medical care. Per capita expenditures for Medicare enrollees 65 years or older in 1993, for example, were $3,519, but averages varied from $2,238 among persons aged 65 and 66 to $5,083 among those 85 years or older.[8] Although those 85 and older are a small proportion of the elderly population, this subgroup is increasing substantially and is expected to grow from 3.6 million people in 1995 to 8.5 million in the year 2030.

Observers often draw attention to costs in the last year of life, noting the large proportion of Medicare expenditures accounted for and suggesting some lack of wisdom in this pattern. The report by Lubitz and Prihoda[9] that 1/20 of Medicare enrollees in their last year of life accounted for 28% of expenditures led to much simplistic policy advocacy. It commonly was suggested that we frivolously expend large resources on elderly dying patients. Any reasonable system would expect, however, to expend large resources when people are severely ill and in life-threatening situations, so the pattern really is not surprising. Despite large growth in expenditures and the introduction of new technologies between 1976 and 1990, the proportion of resources expended in the last year of life has remained unchanged. This does not support the frequent contention that our cost problems stem from futile efforts to extend life. Obviously, there is some waste, but the larger argument does not stand up to close inspection.

Futility looks different from a prospective and retrospective view, and clinicians treating desperately ill patients often are unclear as to whether patients can benefit. These instances also are complicated by ethical issues and medical uncertainty. Nevertheless, the expenditure data suggest that physicians do make choices to withhold technology in the case of very old patients. Scitovsky[10] presented Medicare data on expenditures for the year 1988 for persons who survived and died during the year. Average expenditures for persons who died were $13,316, compared with $1,924 for surviving patients. The average cost, however, for those who died was related inversely to age, varying from $15,346 for those aged 65–69 to $8,888 for those 90 years or older. This pattern was evident across a wide variety of causes of death, from cardiovascular disease and cancer to diabetes and pneumonia. Very few elderly persons facing death actually received the intensity of care we commonly associate with medical aggressiveness, such as artificial respiration and intensive care. Scitovsky estimated that such expenditures constituted less than 5% of expenditures. Other researchers who have studied medical expenditures note comparable patterns.

MEDICARE AND MEDICAID

Medicare and Medicaid attract much attention because they constitute large and growing proportions of government budgets and even larger components of budgets under administrative and congressional discretion. Medicare increased from 3.5% to 10.5% of the federal budget between 1970 and 1995,[3(p2)] with expenditures of almost $185 billion.[11] Medicaid expended almost $160 billion in 1995, of which almost $91 billion were federal contributions. These two programs alone account for about a third of all health care expenditures and cover the most vulnerable subgroups in the American population. In 1995, Medicare covered some 37 million elderly and disabled persons; Medicaid covered 36 million individuals. Approximately 6 million individuals were covered by both programs.

The American system of health care is in the process of significant transformation with the rapid growth of managed-care strategies that now affect more than 70% of the population through health maintenance organizations (HMOs) or utilization review. While almost 18% of the population were enrolled in HMOs in 1995, only 8% of Medicare enrollees and 10% of Medicaid enrollees were enrolled. Government has been making efforts to increase HMO enrollment among the elderly because it is believed, on the basis of studies of the general population, that such managed-care organizations can provide a comparable level of care at less cost than the traditional system. Generalization to the elderly population, however, is not yet demonstrated.

HMOs are unfamiliar to many elderly persons, and those with serious illnesses and disabilities usually have established good relationships with their doctors, who they are reluctant to leave. As a consequence, most research studies find that Medicare enrollees in HMOs are more healthy and utilize care less than the Medicare population as a whole. Because of the complex way in which government reimburses HMOs for Medicare enrollees, government presently pays HMOs more for their care than they would if these persons remained in the traditional system. Congress now is reducing payments to HMOs for the elderly, and the HCFA is studying ways of risk adjusting capitation payments to take account of the variability in need among Medicare enrollees, a significant minority of whom in any year use no services at all or require very minimal care. Riskadjusted payment is essential to ensure that HMOs compete on the basis of cost, access, and quality and not on their capacity to enroll healthy individuals, from whose capitation payments they can make large profits. Predicting future need and utilization of care, however, remains a difficult task.

HMOs vary a great deal in organizational and other characteristics, but in the aggregate, they appear to offer services to the general population that are comparable in quality to those of traditional care and perhaps better in some areas, such as prenatal care and other preventive services. It is less clear, however, that HMOs provide high-quality care for persons with complex chronic disease problems, such as those prevalent among elders, or to persons with significant physical and psychiatric disabilities. Although there are only a few well-executed quality-of-care studies that involve large samples and that reasonably allow generalization, there are indications that HMOs perform less well than traditional services in the treatment of chronic disease among the elderly.[12] But, HMO enrollment may be attractive to elders, particularly as cost-sharing obligations increase, because it often provides coverage for services not covered under Medicare (such as drugs) and requires less expenditure out of pocket for gap insurance, cost sharing, or extra-billing allowable in the traditional part of the Medicare program. The HCFA will have to monitor HMO performance very carefully as it proceeds to encourage more Medicare recipients to enroll in HMOs. HMOs, in turn, will have to focus increased attention on effectively providing long-term treatment for chronic disease.

State Medicaid authorities are encouraging or mandating recipients aggressively to enroll in HMOs. Although disabled persons were excluded initially from such efforts, they now are being included in the plans for managed care in a number of states. As of 1996, six states required at least some of their Medicaid clients with disabilities to enroll in prepaid care, but only Arizona's program was more than 3 years old. In 11 other states, enrollees with disabilities are allowed to enroll voluntarily in managed-care plans, but relatively few enrollees have done so. Thus, states have had very little experience in this area or opportunities to learn from one another. An additional 10 states have submitted proposals to the HCFA to make enrollment of the disabled in managed care mandatory; these proposals either have been approved or are pending.[6] The President repeatedly has indicated his intention to make the waiver process easier for the states, and we can expect much more experimentation with alternative managed-care arrangements. The research literature suggests that it is not easy to identify systemic problems in care for persons with complex disorders,[13] but states will have to develop a meaningful process to do so.

States also will have to develop more sophisticated ways to set rates consistent with the magnitude of risk characteristic of varying clients. Oregon, for example, examined 1993 health care costs among its 199 highest-cost children in the Medicaid program and, while the group as a whole averaged 6-month expenditures of $21,472, the range varied from $5,014 to $410,420. Oregon, however, was only paying a 6-month capitation of $3,023 for children in the group in which these children fell.[6(pp49–50)]

It is not difficult, thus, to appreciate why even responsible providers might seek to avoid attracting the most disabled enrollees, whose care is costly and whose capitations might involve significant financial loss or even financial failure. Even more troubling is that health care providers have an incentive not to develop exemplary services for high-cost populations such as persons with acquired immunodeficiency syndrome (AIDS), clients with severe and persistent mental illness, and children with complex disabilities. Managed-care providers with such exemplary programs privately acknowledge that they prefer that their reputation for such services not be known widely to avoid attracting too many high-risk patients. It is alleged that managed-care programs drop from their networks high-quality providers who attract disproportionate numbers of high-risk/high-cost enrollees. While plausible, such practices are difficult to document. The General Accounting Office reports that a health plan official they interviewed whose plan made innovations in managing asthma asked the state to cap its enrollment when the number of asthmatics increased dramatically as the success of the plan became known.[6(pp49–50)]

THE MEDICARE DEBATE

A great deal of attention is focused presently on the depletion of Medicare's Hospital Insurance Trust Fund early in the next century, and proposals abound on how to correct Medicare and ensure its financial stability. In the short run, corrections are relatively easy. The major problem is the unwillingness of both political parties to address the issue in the context of the extreme partisanship that now prevails. There are, in fact, many options, including tax changes, changes in eligibility rules, changes in provider reimbursement, changes in the structure of the program, or some combination. In the short run, some modest adjustments to which both enrollees and providers contribute can provide a temporary fix for another decade. The longer-range issues are more difficult and contentious.

Among the options to be considered are increasing the Medicare tax, advancing eligibility for the program consistent with eligibility changes in the Social Security retirement program, taxing enrollees at higher incomes for some part or all of the value of their Medicare entitlements, revising the premium structure and cost-sharing provisions, encouraging recipients more aggressively to participate in managed care, or reconstituting the program in various ways. Restructuring ideas are most contentious; they range from adapting the program in accord with the Federal Health Benefits Program, in which individuals are given a wide range of insurance options, but have to pay more when they select more expensive health programs, to suggestions that Medicare become a means-tested program.

The idea that beneficiaries be allowed to establish health savings accounts already has received much contentious debate, and the Congress now has authorized a demonstration and evaluation. There are various ways to structure such accounts with different consequences, but in my view the options are undesirable because the risk selection likely to occur would redistribute Medicare resources to the healthy and wealthy rather than to those most in need. This leaves the traditional program with disproportionate numbers of high-cost patients, further threatening its financial viability. Thus far, the elderly have been very slow in enrolling in the savings account program.

Means testing of Medicare simply would turn it into a welfare program with all of such a program's implications. Its public support and quality, which derive from its character as a universal entitlement, certainly would erode. Moreover, such remedies move away from the idea of a community responsibility to provide to all its people a basic minimum of decent health care. We should be examining how to extend universal coverage rather than erode it. The fact that every other developed nation in the world provides such entitlement indicates that this is not an unrealistic goal.

Many of the less-radical solutions, such as extending slowly the age of eligibility, taxing the value of Medicare as income, raising the Medicare tax, and restructuring the program along the lines of the Federal Health Benefits Program each have merits, but also have serious objections. Extending the age of eligibility moves away from the concept of universal coverage and leaves vulnerable retired workers, many of whom may have difficulty in acquiring appropriate substitute insurance. Taxing Medicare health care entitlements seems unfair to many people when we do not tax health care benefits provided by employers to employees; in any case, it would not raise large revenues. While all such benefits perhaps should be taxed, there is a strong political constituency in opposition. Raising the Medicare tax faces the opposition common to most other such increases, and the Medicare tax is already 2.9% of total payroll. Future increases probably will occur to keep up with the growing proportions of eligible persons, but large increases will be resisted strongly.

One option is to restructure Medicare as a multiple-choice insurance program that allows beneficiaries to choose among some wide ranges of certified plans of varying cost and comprehensiveness. The federal government could cover the cost of some average of several plans that meet coverage standards, with opportunities for enrollees to choose enhanced plans if they wish, at their own expense. Such a program would encourage many more elders to join HMOs or other less-expensive insurance plans. Opponents worry that, over time, there would be temptations to erode the Medicare entitlement, and that increasing costs would be shifted to beneficiaries. There is concern also that such a program would distribute the elderly into two tiers of insurance plans, one for those who are poor, and another for the affluent. Further problems involve the capacity of the sick elderly to make informed choices, the difficulty of controlling competing health care plans from risk selection, and the capacity of many plans to provide good chronic disease care. A great deal depends on the specific provisions of such a program, but there is relatively little understanding and trust among the elderly in such proposals, and politicians tread carefully. This proposal, now strongly advocated by conservative Republicans, has many common elements with the Clinton health care reform proposals that were ridiculed by conservative opponents. In short, this area is treacherous politicized terrain.

THE LONG-TERM CARE CHALLENGE

The short-term issues can be resolved readily in a technical sense without imposing a heavy burden on any population group or requiring fundamental change. The long-term issues are far more difficult, not only because of changing demographics, but also because of the need to develop a more integrated approach to long-term care and to align the Medicare and Medicaid programs better. The Medicare program was not constituted to address long-term care needs. However, the realities of illness patterns and need among Medicare enrollees, including the elderly and persons with disabilities who receive Medicare through eligibility in the Social Security Disability Insurance Program, have contributed to large and rapid growth in home health care benefits, which are substantially for long-term care services. Much of the growth has occurred among persons receiving 100 or more visits.[3(p81)] As the health system as a whole moves away from an acute care emphasis, as it should, and gives greater focus to preventing secondary disabilities and promoting function in life activities, our entire health care system will have to take better account of long-term care needs.

The challenge as we move into the next century will be to develop systems of care that provide the kinds of health and social supports in the community that allow people to function, despite serious chronic disease, frailty, and even cognitive impairments, without excessive dependence on institutional care. In the past several decades, approximately 5% of persons over age 65 have been in nursing homes, but the proportion is more than double for persons 75–84 and approximately five times that for persons age 85 and older.[9(Table 91)] We already have tough standards for nursing home admission, and persons usually are not admitted unless they become demented, are incontinent, are too frail to carry out self-maintenance activities, or lose a needed caregiver, but demographics alone will increase demand for long-term care even if later elderly cohorts remain healthy and vigorous for longer periods in their lives.

Social and cultural trends complicate the long-term care issue. As persons now reach the later years, they have more economic security than in the past and elect to maintain single-person households, which can make care provision difficult when problems occur. Moreover, lower rates of marriage and higher rates of divorce[14] also will increase the number of elderly who will enter the later years in single-person households. Even among those who have children, smaller family size, workforce participation of women, geographic mobility, and other factors will make it difficult to sustain traditional caregiving patterns. Informal family caregiving is still a major component of long-term care, but as such supports weaken, alternative community structures will have to be developed further. Because of the longevity differential between men and women and the fact that women typically marry men older than themselves, the average married woman is likely to outlive her husband by a decade or more.

A large variety of alternatives are developing that provide the graduated supports increasingly frail individuals need, such as life care communities, but these remain outside the financial capacities of many people. Long-term care insurance has had a slow gestation and is both expensive and uncertain in many aspects, but an increasing number of options are available, and coverage is growing slowly. Although persons reaching the elder years in the next century will have more savings than earlier cohorts, average savings are modest, and for many are depleted quickly following any extensive long-term care episode. Those who deplete their resources then become eligible for Medicaid long-term care services.

From a public policy standpoint, the challenge is to maintain an appropriate safety net for persons who need care and not to protect the assets of affluent elders. Catastrophic coverage for extraordinary expenses is less costly than front-end coverage because such events are relatively uncommon, but such coverage does little to help elders who are poor and for whom front-end expenses constitute a significant financial burden. The affluent have increasing opportunities to protect their assets through catastrophic health insurance and long-term care coverage, and this seems a proper function for private sector activity. Government may seek to stimulate appropriate insurance products, set insurance standards, and regulate the performance of insurance companies, but to the extent that asset protection is available, government need not focus on this concern.

Government, however, has a stake in maintaining the financial viability and functional capacities of elders with chronic disease who are motivated to retain their independence to the extent possible. This is a frightening area for policymakers because of the potential for new expenditures and the concern that government-sponsored services may replace informal care, but the lack of coherent policies and approaches results in significant unmet needs and the subversion of other programs, such as Medicare, to fill some of the gaps.

There has been long-standing interest in community alternatives to nursing home care. The idea that targeted services to maintain independent functioning in the community can reduce cost has been an intriguing and popular idea. It also has been an idea extraordinarily difficult to demonstrate.[15] Its successful implementation depends on focusing on those who would require nursing homes without community intervention, but such individuals are difficult to identify because they are part of a much larger population of highly frail individuals who have significant care needs. As a consequence, many services inevitably go to individuals who would have managed to hang on in the community despite their frailty. Many elders and their families fear nursing home admission and see this only as a final resort. Thus, they struggle to hang on by marshaling any resources they can, and the discontinuity between community and nursing home has the effect of rationing the use of long-term care services. Predicting who in this population actually will be forced into nursing homes is easier in concept than in reality. Studies show that while elders and their families prefer community alternatives, such alternatives neither reduce costs nor improve longevity.[16]

There are other complications in providing home and community services. Policymakers reasonably worry that if they provide much improved community services to elders, family members and friends will do less, and formal services will replace informal ones. Although some such substitutions are inevitable, research indicates that, for the most part, formal services complement rather than replace those provided by family and friends,[17] and to the extent that they substitute, the respite probably is needed. When elders are sufficiently sick, debilitated, and incapacitated, nursing home care may be less expensive and functionally superior than care in the home, but such decisions should take into account the needs and wishes of elders and their families. The policy climate is focused on cost; as a result, policymakers often give too little attention to patient and family satisfaction as a significant consideration. Enhanced public satisfaction is worthy of some increment of cost, but the proper balance has to be reached through open discussion.

PROGRAMS OF INTEGRATED CARE

As the health of the population has improved and patterns of mortality have changed, our health care system has become substantially a chronic disease care system with an important long-term treatment component. Patterns of insurance, however, often make it difficult to make the transition between acute and chronic care. As capitated practice comes to dominate American health care in the future, it will become more possible to design seamless health care benefits that are more comprehensive than traditional health insurance, that make it easier to integrate varying components of care, and that allow meaningful tradeoffs among different types of service. A fee-for-service system inevitably encourages expensive technical services; capitated systems potentially seek meaningful alternatives to expensive care that commonly might include home care services. The departure from a fee-for-service system removes the incentive to provide these services when they are not needed or are of marginal value. The risk is that too few services will be provided, and this requires sophisticated monitoring and evaluation over time.

Because of the dilemma and potential cost increases involved in expanding medical care to include more home- and community-based services, careful targeting of those most in need and gatekeeping against excessive demand becomes essential. One way to limit use is to have high deductibles and coinsurance, but such disincentives work very imperfectly and keep people, especially the poor, away from needed care. Carefully managing a broader benefit package is an alternative approach, and the HCFA has supported various demonstration initiatives that address this challenge, including the social health maintenance organization (SHMO). The goal of SHMOs is to integrate acute care and necessary long-term care and to provide community-based care as an alternative to nursing homes. Services include homemaking, personal care, case management, meals, home monitoring, counseling, adult day care, and transportation, as well as a broader array of posthospital care than Medicare covers, including some custodial services.

When SHMOs were introduced initially, the new concept was put to a competitive market test in which both impaired and unimpaired elderly would have to pay enhanced premiums to be eligible. Using coordinated case management, need would be assessed by applying various disability criteria, and services would be authorized as deemed necessary. Marketing was initially quite difficult, and the four demonstration projects faced various implementation problems. Evaluation of their performance in the early years showed that the SHMOs could control utilization of expanded services and associated costs; they had high marketing and administrative costs and their acute care costs were higher than anticipated.[18] These difficulties resulted in some policymakers discounting this approach.

Discounting the SHMO concept is premature, however. The health care world is changing radically, and early marketing and implementation experience may not be relevant in an arena that is dominated increasingly by large managed-care providers with sophisticated financial, managerial, and marketing capacities. Similarly, with growing experience in managing high-cost cases in a managed-care context, the ability to target resources effectively is likely to grow. The challenge of dealing with long-term needs only will accelerate, and the SHMO strategy is probably one of the more viable approaches over the long term. We still need much experimentation and evaluation in this area.

In the early 1970s, On-Lok, a capitated senior health services program serving a poor, frail, elderly Chinese population in San Francisco, successfully integrated acute and long-term services (including housing, nutritional, day care, and other needed services) in a seamless way with considerable success. This small program, directed at persons certified as requiring a nursing home level of care, became the model for HCFA's Program of All-Inclusive Care for the Elderly (PACE). In the Omnibus Budget Reconciliation Act of 1986, Congress authorized the PACE program, which currently has 10 sites.[19]

Like On-Lok, PACE targets elderly persons who are eligible for nursing home care, but elect to remain in the community. It seeks to integrate social and medical services using a multidisciplinary geriatric approach through organizations that function somewhat like staff HMOs.[20] Since the program serves the poor elderly who would be in nursing homes, the capitation is constructed largely through an integration of Medicaid and Medicare funding. PACE depends on use of adult day health care and requires elders to change their physicians, features not particularly attractive to many elders. Enrollment has been slow, but once enrolled, few people voluntarily leave the program. Complete evaluations of PACE are in progress. Nevertheless, PACE illustrates possibilities for integrated service approaches in the community for clients who ordinarily would require nursing home care.

SUMMARY

Ball and Bethell[21] have suggested a framework of goals that set a proper context. Among these goals are a universal plan to which everyone contributes to a reasonable extent; coverage of anyone who becomes chronically ill or disabled; coverage of both needed home and nursing home care; services to informal caregivers, as well as patients; emphasis on support for independent functioning; encouragement of alternative long-term care services; and stringent cost and quality controls.

Whatever system we evolve, it is clear that government will have to be the payer of last resort through Medicaid or some other program for those unable to care for themselves. It is less clear how to structure the government role and how to coordinate best government provision with private sector insurance and patient cost sharing. Private insurance with patient cost sharing could cover the front-end risk up to some nonburdensome threshold defined either by a dollar amount or a significant proportion of family income. Such front-end cost sharing helps guard against demand for services overwhelming the system. The extent of cost sharing could be linked to the willingness of patients to accept case management of services. Past the initial threshold, government should play some role in ensuring that persons in need can get care without forcing themselves or their families into poverty. Catastrophic costs are relatively easy to cover, but such coverage is largely asset protection, and except for the poor, should be covered privately. A consensus is yet to evolve on these issues, and we can anticipate a long gestation in arriving at a national long-term care policy.

Dealing with problems of long-term care is a community affair and transcends any narrow medical or long-term care insurance concept. The needs of the elderly and persons with disabilities depend not only on their own capacities and frailties, but also on the organization of communities—how people arrange themselves in households, how they work, the contributions of voluntary organizations, social support structures in families, neighborhoods and churches, and many other arrangements. New technologies provide novel opportunities for linking individuals and monitoring their needs, but we also know that bringing the array of services that individuals might need to isolated households rather than conjoint living arrangements faces significant problems of coordination and supervision, with risks of neglect and victimization. Addressing long-term care needs appropriately requires policies that address the human dimensions that contribute to a patient-oriented perspective, as well as the technical ones.

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