A Call for Action

THE PEPPER COMMISSION

U.S. Bipartisan Commission on Comprehensive Health Care

Final Report

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Executive Summary

Our health care system still inspires awe—and rightly so. Americans should be proud of a system that can provide the best care in the world.

But our system also creates fear—among the millions already excluded from it and the increasing numbers at risk of exclusion:

- Uninsured pregnant women, without the resources to seek prenatal care;
- Workers who are ill, with preexisting conditions that may cost them their health insurance if they change jobs;
- Workers in small businesses, for whom a sudden illness can put insurance premiums out of reach for the entire firm;
- Workers with good coverage, who see their benefits threatened each time they go to the bargaining table;
- Families whose emotional and financial resources are exhausted from providing long-term care to frail parents or disabled children.

Finally, our system breeds frustration—among the many who seek ways to reform it and resolve its problems.

Most reformers agree that our health care system should cover all Americans. But to do so, some would replace the system. Others would reshape it, often in dramatically different ways. People and institutions criticize and ultimately reject initiatives that differ from their ideal or that—in their view—move too fast or too slowly. If their first choice is unattainable, the second choice for many is to do nothing.

Public policy is paralyzed. The fear and the flaws continue.

The Pepper Commission calls for action to end that paralysis with recommendations for legislation that would guarantee all Americans coverage for health and long-term care within a system that both ensures quality and contains costs.

To develop these recommendations, the Commission intensively investigated the problems and alternative actions to address them. It listened to numerous witnesses in public hearings held in the nation's capital and around the country. It heard from experts in health and long-term care. In the process the Commission gathered a wide range of views from consumers, employers, workers, providers, insurers, and numerous organizations and groups. Then its members met in a series of working sessions to consider all these views, clarify their own objectives, and develop recommendations to achieve them.

Based on a shared view that current conditions are unconscionable and that public action is urgent, the Commission unanimously agreed that all Americans should have access to affordable health and long-term care coverage in an efficient and effective system.

"Allowing these health and long-term care problems to persist not only deprives millions of Americans of what they ought to be able to have . . . it diminishes our economy. . . . [and] . . . the United States of America. I don't think it's possible to say . . . that we are a civilized nation when so many of our people . . . do not have long-term care, do not have health insurance."

—Senator John D. Rockefeller IV

After further intense debate, the majority of the Commission adopted specific recommendations to achieve this goal. These recommendations reflect the view that we must begin to build universal health care coverage now. We must pursue the workable rather than the ideal. We must secure and improve the health care system for all Americans, including those currently left out. And we must create a long-term care system that serves our nation's severely disabled and addresses the deepest fears of Americans—elderly and nonelderly—about their future should they become disabled and need long-term care.

This report lays out the problems the Commission believes the nation must solve and the Commission's blueprint to guarantee all Americans affordable, high-quality health care and long-term care when they need it. With this blueprint before us, we can build universal coverage a step at a time.

Because today's system works differently for health care (primarily physician and hospital services) than for long-term care, the discussion and the recommendations address each separately. Although health problems cannot be so neatly segmented, this is simply the most pragmatic way to discuss building a system based on what we now have.

WHY DO WE NEED HEALTH CARE REFORM?

The American health care system is approaching a breaking point. Rapidly rising medical costs are increasing the numbers of people without health coverage and straining the system's capacity to provide care for those who cannot pay. The gap is widening between the majority of Americans, who can take advantage of the best medical services in the world, and the rest, who find it hard to get even basic needed care. As the gap increases, the weight of financing care for those without adequate coverage is undermining the stability of our health institutions. Even for the majority, the explosive growth in health care costs is steadily eroding the private insurance system—the bulwark they count on as their defense against financial risk in case of illness.

"[The] American health care system . . . [is] a paradox of plenty and of want, a system where some receive the benefit of the most advanced medical technologies in the world, yet many poor women can't get decent prenatal care and families can't get help to keep a frail parent from having to go into a nursing home."

—Senator Dave Durenberger

Who Is Uninsured and Why?

Most Americans of working age get insurance for themselves and their dependents through their jobs. But not all of us work—and not all employers provide insurance. People who fail to obtain job-based coverage may also be excluded from Medicaid and other public programs because of restrictive eligibility rules. Consequently, almost 32 million Americans under 65 lack health care coverage of any kind. That's nearly 15 percent of our nonelderly population. Another 20 million have inadequate coverage. And the proportion who are uninsured was 20 percent greater in the 1980s than in the 1970s.

Anyone can become uninsured—regardless of age, income, or employment status. A close look at the problem shows what kinds of people are falling through the cracks (see Figures 1 and 2):

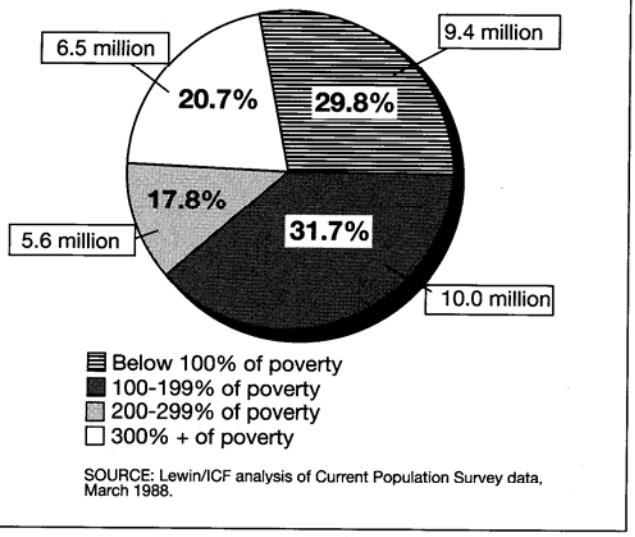
- Many of the uninsured are young. In 1987, nearly half were under 25, and more than 28 percent were under 18.
- Most of the uninsured are poor or near-poor. In 1987, one-third were in families with incomes below the federal poverty level ($11,611 for a family of four). Two-thirds were in families with incomes below twice the poverty level.
- Most of the uninsured are directly or indirectly attached to the work force. Three-quarters of the uninsured are workers or their dependents.

These characteristics of the uninsured raise two key questions about our country's health care coverage.

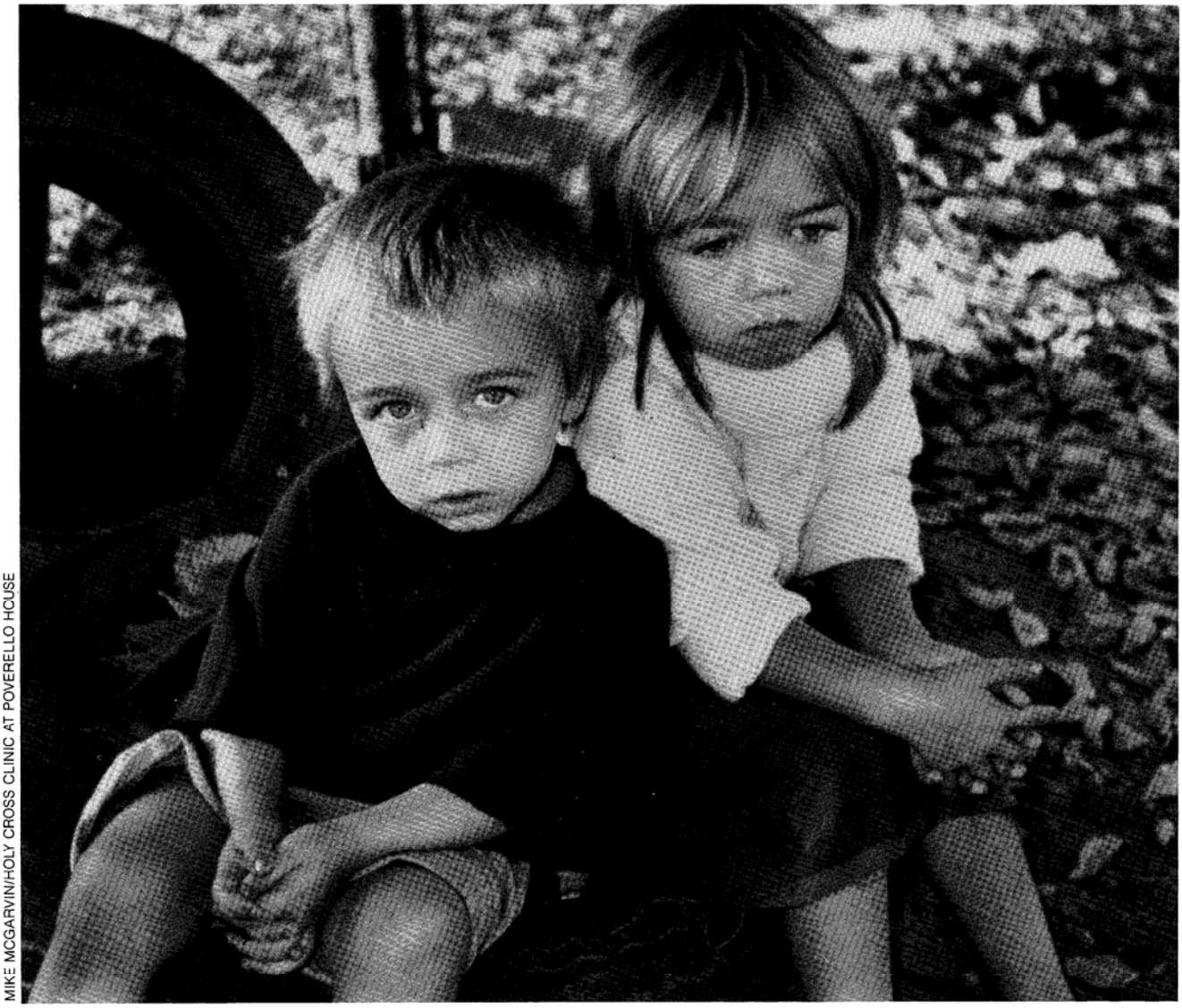
- Why doesn't job-based health insurance reach all workers and their families?
- Why does the public safety net fail to protect the poor?

Uninsured Workers—Firms of all sizes have uninsured workers, but workers in smaller firms are much less likely to get insurance through their jobs (see Figure 3). In 1987, just over half of uninsured

Figure 1 Distribution of Nonelderly Uninsured, by Family Income as a Percentage of Poverty, 1987



SOURCE: Lewin/ICF analysis of Current Population Survey data, March 1988.



MIKE MCGARVIN/HOLY CROSS CLINIC AT POVERELLO HOUSE

Almost 9 million children are uninsured—more than one- quarter of all those without public or private protection.

workers were in firms with fewer than 25 employees. Even though most small firms provide insurance to their workers, large numbers do not—increasingly because they are disadvantaged in the insurance market.

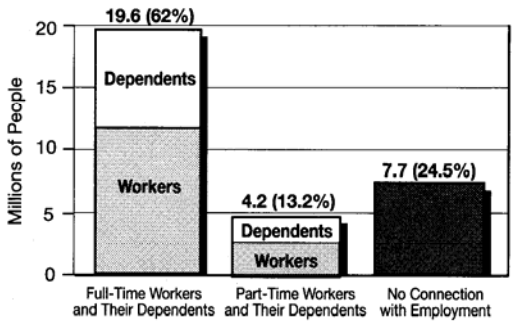
Small firms must pay more for insurance than large firms because they have fewer employees among whom to spread administrative costs and any losses for extremely costly enrollees. Small firms thought to present high risks pay even higher rates, and are often forced to exclude certain employees or certain conditions. They are sometimes unable to obtain coverage at any price.

Insurance practices that make it hard for small employers to obtain coverage are the byproduct of today's competitive market. So long as any insurer engages in assessing the risks of each individual in a group (medical underwriting) and group-specific rating, others must follow suit or risk losing all but the highest-cost groups. Without reform of the insurance market, the problem will only get worse.

Coverage of the Poor—Coverage for the nation's poor is largely the responsibility of the Medicaid program, a federal/state entitlement program administered by the states under broad federal guidelines. Medicaid has accomplished a great deal. But Medicaid does not reach more than a fraction of the low-income population. In 1987, the program assisted only 42 percent of those with incomes below the poverty line. Even among the extremely poor (family incomes below 25 percent of poverty) nearly a quarter are not covered by Medicaid or any other program.

The poor must meet two kinds of tests to receive Medicaid assistance. First, they must fall into one of the categories of persons traditionally eligible for cash

Figure 2 Work Force Connections of the Uninsured and Their Dependents, 1987*



*Under 65 Population

SOURCE: Lewin/ICF analysis of Current Population Survey data, March 1988.

assistance or welfare: the aged, disabled, or members of families with children. Completely omitted from the program, even if they are literally penniless, are single people and childless couples under 65 who do not meet disability tests. Second, applicants must meet financial standards imposed by the states. For many covered groups there are no federal requirements to prevent states from setting shockingly low standards. In Alabama, for example, a family of three qualified for Medicaid in 1990 only if its income was less than 13 percent of the federal poverty guidelines.

Moreover, because states have failed to increase their income eligibility levels to keep pace with inflation, Medicaid programs are covering smaller proportions of the poor. Even recent congressional efforts to expand coverage for pregnant women and young children—severing eligibility for Medicaid from eligibility for cash welfare—appear to have been largely offset by declining coverage among older children and other groups. Finally, in an effort to control costs, states frequently limit both the services covered and the payments made to providers for covered services. The result: inadequate access to service.

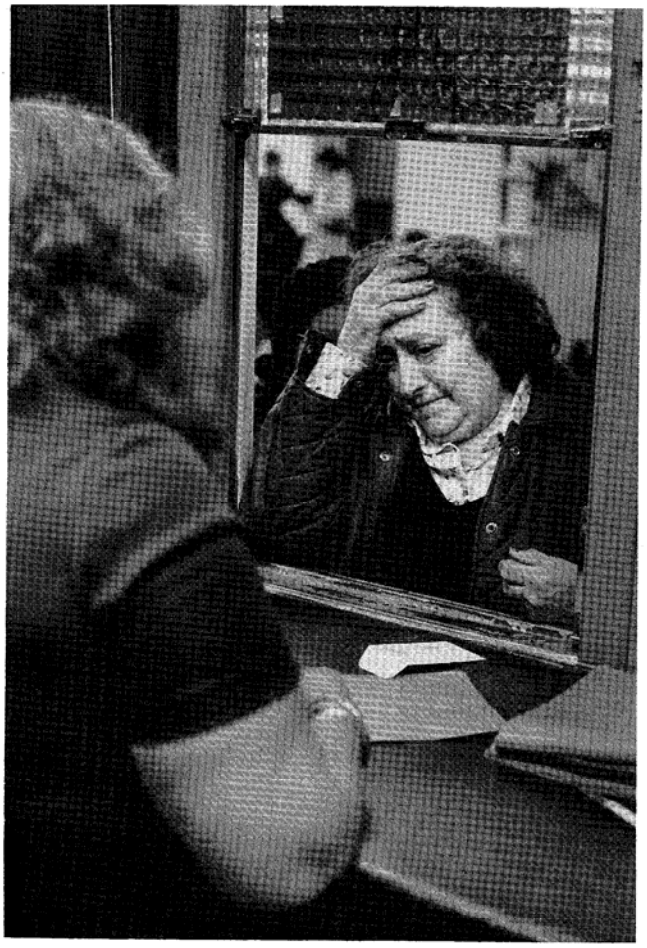
Some states have tried to fill in with programs of their own. But funding limitations and other problems have prevented these programs from reaching more than a few of the millions of poor people lacking health coverage.

Without major changes in public policy, Medicaid and supplemental programs will never reach all the poor. Protection will vary considerably from state to state. And many low-income Americans will go without health care coverage even in the more generous states.

Who Cares for the Uninsured?

Care for the uninsured poses two fundamental problems. First, people lacking insurance may go without care when they need it. Second, the costs for the care they do receive are unfairly distributed among other groups, straining critical elements of the nation's health care system.

Barriers to Care—The Commission heard heartbreaking testimony about care foregone or delayed; a substantial body of evidence demonstrates that the witnesses were not presenting isolated or unique cases. A 1986 nationwide survey found that uninsured people with serious symptoms saw physicians only half as often as similarly ill people who had insurance. Other studies show comparable results.



EARL DOTTER

Faced with costs they cannot pay, the uninsured delay or do not get medical care.

Often the uninsured delay care for minor or chronic problems until those problems become serious or acute. To the human costs of being uninsured, then, must be added the economic costs of the patterns of care that result.

Financing Care for the Uninsured—Who pays for this care? Although government programs provide some help for people who cannot afford to pay, the insured population foots much of the bill. Providers of care cover their losses on uninsured patients from their charges to those who can pay—primarily the privately insured. For hospitals this cost shifting totaled $8.3 billion in 1988.

Cost shifting has long been regarded as a hidden tax on those with insurance, much of which is paid by the employers who offer insurance, in effect, to pay for the workers of employers who do not.

Increasingly, employers and insurers are finding ways to avoid this hidden tax at the same time as the need for care is rising. Along with a greater number of uninsured people, the nation is experiencing a rise in costly social problems like drug abuse, AIDS, violent crime, and low birthweight babies—problems that require expensive care. Some hospitals are responding to squeezed resources by eliminating trauma centers and emergency rooms, which are most likely to attract those who cannot pay. These services are then lost to the entire community, causing everyone to travel farther for urgent care.

Is Health Care for the Insured In Jeopardy?

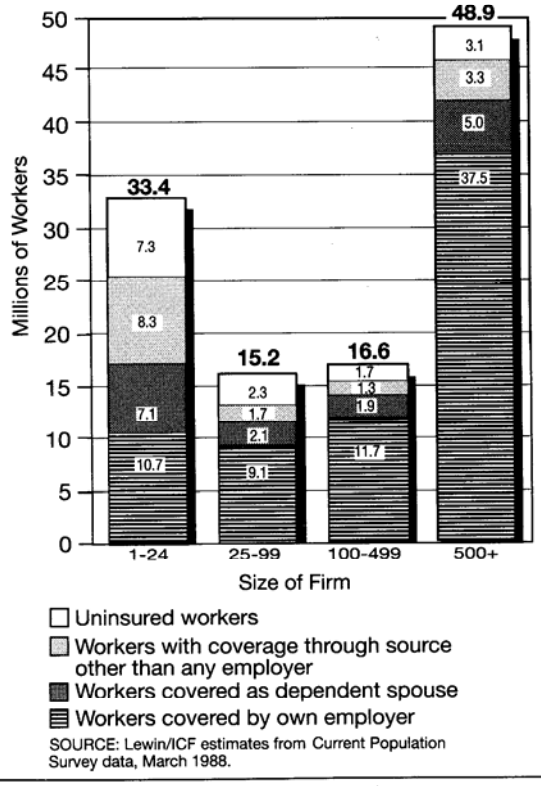
For the majority of Americans with health insurance, the problem of care for the uninsured may seem remote. This is a shortsighted view. As the strains on the system grow, those who depend on job-based coverage face an increasing risk of joining the ranks of the uninsured.

"Health insurance is supposed to be a bridge to security . . . [but] we have a system that's falling apart. The 'on-ramp' has collapsed and a lot of children are having difficulty, uninsured because of the income level of who they're born to. The [Medicare catastrophic] 'off-ramp' has collapsed. . . . The long-term care off ramp has never been open. And the group insurance concept is beginning to break apart, which has been sort of the main body of the bridge. . . . [This Commission] has the responsibility to be the safety engineers and architects and we need a review of the entire system."

—J. Robert Hunter, president, National Insurance Consumers Organization

Especially threatened are workers in smaller firms. Almost half of the smallest firms still offer insurance to their workers. But their ability to do so is jeopardized by the growing competition among insurers to avoid poor risks. A whole company may lose coverage or see its premiums skyrocket because of the experience of a single individual. Some of these workers may be able to find coverage on their own. But those in poor health may not find coverage at any price, or may only find coverage that excludes the precise condition for which they need care. It makes little sense that hard-working Americans, able and willing to pay, cannot find an insurer that will cover them.

Figure 3 Workers and Source of Health Insurance, by Firm Size, 1987



SOURCE: Lewin/ICF estimates from Current Population Survey data, March 1988.

While poor Americans typically face the greatest barriers to insurance coverage, the specter of inadequate insurance and catastrophic medical expenses threatens middle-income Americans as well.

Larger firms do not face problems in the insurance market. Yet their workers, too, are not entirely secure. Their coverage is jeopardized by continuously escalating health care costs. For the country as a whole, health care spending now absorbs 11 percent of the gross national product (GNP) and is projected to absorb 15 percent by the year 2000. For employers, health benefits are equivalent to more than 90 percent of after-tax profits, compared with 74 percent in 1984 and only 14 percent in 1965. Such dramatic increases

not only impede efforts to improve access to health care; they are bound to erode the access we now have as employers cut back on coverage. Employees increasingly are paying more of the premium for themselves and their dependents, causing growing numbers to drop coverage.

And as costs continue to rise, Americans are questioning whether we are getting our money's worth. Concerns about the appropriateness and effectiveness of medical procedures, the quality of health care providers, and the problems related to our approach to medical malpractice add to the crisis caused by the burden of unfinanced care. Unless these concerns are addressed, even those who are now well-insured may find their health coverage in jeopardy.

"I view health care finance in this country as a house of cards. You can add cards at the bottom: Medicaid expansions. You can add cards at the top: Medicare catastrophic. It is still a house of cards. A house of cards can stand in a quiet room, but it cannot stand when there is wind. [And] we have the wind of unmet need. . . the wind of public dissatisfaction. . . the wind of demographic change. . . the wind of cost. . . . This house of cards cannot stand in this wind."

—Deborah Steelman, chairman, Advisory Council on Social Security

BLUEPRINT FOR HEALTH CARE REFORM

The Commission concludes that, in the absence of systemwide reform, the proportion of Americans without adequate health care coverage will grow. The burden of caring for those who cannot pay will overwhelm the system, putting us all at risk of inadequate access to care. As costs continue to rise, more and more dollars will go to services of uncertain value, while millions of people will go without basic and necessary care.

To prevent such a disaster, the Commission unanimously adopted the following goal:

> The Commission is committed to the development of recommendations for public policies that will assure all Americans access to affordable health care coverage that allows them to obtain necessary care and assures them adequate financial protection; that will promote quality care and address the problem of health care costs; and that will provide the financing required to assure access.

Before selecting its preferred course of action, the Commission explored two major alternative strategies to achieve this goal. The first was an expansion of the Medicaid program to cover all the poor plus subsidies to help the near-poor purchase private health insurance. The Commission believes that such an approach would be an inadequate response to the crisis. Even the substantial expansion of public support the Commission considered would leave some 14 million Americans—almost half the uninsured population—without access to affordable coverage. Further, it would fail to provide help to additional millions whose coverage is inadequate. With so many remaining uninsured, cost shifting and the burden of uncompensated care would still mean inequity and instability in the system as a whole. Finally, broadening the public program for the poor but making no requirements on employers would allow employers who do not now provide coverage to continue to shift responsibilities to others. This approach could also reduce employers' willingness to cover low-income employees who are now protected—shifting substantial costs from employers to taxpayers.

The second major alternative the Commission considered was replacing of the current combined job-based and public approach with national health insurance. The Commission is convinced, however, that such a drastic departure from our current system would be controversial and disruptive to the majority of Americans—for whom insurance still works. It would also totally shift fiscal responsibility from employers to taxpayers. Furthermore, movement to a single federal system would eliminate the diversity and choice that many believe, appropriately guided, can increase the strength and flexibility of our health care system.

In order to act now, as we must, the Commission recommends that we build upon and strengthen the existing system of job-based and public coverage to create universal health care coverage. This is, in the Commission's judgment, the most pragmatic strategy for securing adequate health coverage for all Americans.

Combining universal coverage with other federal initiatives to strengthen the health care system can ensure the value for the health dollar and access to quality service, efficiently delivered, that the nation so sorely needs.

Building Universal Coverage

The Commission's blueprint for building a universal job-based/public system of health care coverage has five parts.

1. The Commission believes that employers and the government together should provide a minimum level of health care coverage for workers and nonworkers who, in turn, should be expected to accept that coverage.

Small employers face considerable and increasing obstacles to purchasing affordable health insurance policies for their employees. Other Commission recommendations address the problems of the insurance market (see below). Because of these obstacles, and because it would take time for the insurance market recommendations to take effect, *the Commission recommends that small employers be encouraged through tax credits/subsidies to provide coverage for their employees.*

Large employers do not face such obstacles. *The Commission recommends that, after a period for adjustment, they be required to provide coverage for their employees.*

The subsidies and the insurance market reform should allow small employers to purchase affordable insurance for their workers. If sufficient progress has not been made after several years, *the Commission recommends that small employers become subject to the same requirements as large employers.*

Even if job-based insurance becomes much more widely available, it will never be enough. The unemployed and the poor will need public protection. *The Commission recommends that the federal government provide coverage for these groups by replacing and expanding the role currently performed by states through the Medicaid program.*

When job-based coverage and the federal program are fully implemented and in place, *the Commission recommends that all individuals be required to obtain health care coverage from their employer or from the public program.*

2. The Commission believes that all parties—employers, individuals, and government—should share in financing health care coverage. Requirements for financial participation should not impose excessive burdens on individuals or employers. It is the federal government's responsibility to establish a ceiling on obligations related to ability to pay, and to provide the additional necessary financing. Therefore, *the Commission recommends that the small employers encouraged to provide coverage receive tax credits/subsidies to reduce the costs of private insurance; that employers required to provide coverage be able to obtain it from a federal program for a contribution set at a fixed share of their payroll expenses; and that low-income workers and nonworkers receive subsidies to keep their contributions within reasonable bounds.*

3. The Commission believes that private insurers and government should each play a role in administering health care coverage. But there is a critical need for reforms to strengthen both private and public performance, making coverage not only available but also adequate to ensure access to care. In order to preserve and expand private insurance as the primary source of job-based coverage, *the Commission recommends requirements that would bring an end to the underwriting, rating, and marketing practices that are unraveling private insurance protection for small employers.* At the same time, *the Commission recommends that responsibility for providing public coverage be shifted from states to the federal government, be severed from the welfare system, be uniform across the country, and pay providers at rates determined by Medicare rules.*

4. The Commission believes that universal health care coverage that ensures people access to necessary care must meet an adequate minimum standard. That standard should establish basic protection for the currently uninsured and underinsured and preserve protection for the currently insured into the future. For public and private coverage, *the Commission recommends a federally specified minimum benefit package that includes preventive and primary care as well as other physician and hospital care.* Individuals would be responsible for a share of premiums and service costs—on all but preventive services—up to a maximum and subject to their ability to pay.

5. The Commission believes that action cannot come too soon for the millions without coverage and millions more who see their coverage threatened. However, an effective system cannot be put into place overnight. It will take time to develop and implement.

To balance these concerns, the Commission recommends that the system be put in place a step at a time. The first and most critical step in expanding coverage is to ensure protection for pregnant women and children who are now uninsured and to initiate reforms that reverse the disintegration of the private insurance market for small employers. This would create an environment in which employers would have an op-

portunity to provide the coverage the Commission expects. The second step, to take place in years two through five of implementation, is to effect a series of incentives and requirements for employer coverage, giving employers time to adjust to their new obligations. The final step, to occur in year five, is to extend the federal government's coverage for all nonworkers.

The Commission believes this sequence of steps allows immediate action to address the most urgent problems and provides an orderly transition to universal health coverage.

Strengthening the Health Care System

The Commission recognizes that universal health care coverage can only be as sound as the health care system itself. Coverage that buys unnecessary or inappropriate care, that pays for poor quality, that fails to promote efficient delivery, or that shifts costs from some purchasers to others, wastes private and public dollars that could be used elsewhere.

The Commission disagrees strongly with the view that we cannot extend coverage to the uninsured until we control health care costs and reform the health care system.

The Commission believes, on the contrary, that expanding access to quality care and containing costs through increased efficiency are equally urgent and fundamentally intertwined goals. Ultimate success in reaching either goal can be achieved only through an integrated strategy of system reform. The Commission's recommended strategy has six parts.

1. The Commission believes that the nation needs a national system of quality assurance aimed at defining appropriate or necessary services and ensuring that patients receive these services.

The Commission recommends that national practice guidelines and standards of care be developed and implemented; that a uniform data system on all health care services, regardless of payment source or setting, be developed and implemented to support research on treatment outcomes and assessment of provider performance; that new methods of quality assessment and assurance be developed and tested; and that local organizations be developed and held accountable for effective quality assurance.

It is also imperative that we find a better way to deal with the problem of malpractice. Because there is, at present, insufficient evidence to support specific reforms, *the Commission recommends that the Physician Payment Review Commission and congressional committees study and explore the issue of malpractice and propose legislative remedies.*

The Commission believes that universal coverage should be designed in a way that promotes efficiency in service use and delivery of care. Several of its recommendations pursue this goal.

2. *The Commission recommends a minimum benefit package that, except for preventive services, includes significant consumer cost sharing (subject to ability to pay and an out-of-pocket maximum), so that consumers recognize and are sensitive to costs as they consume services.*

3. The Commission recognizes the efforts of employers and their private insurers to manage their health care expenses by encouraging appropriate use of services and negotiating appropriate payment rates with providers. *Accordingly, its recommendations include managed care as an appropriate means of service delivery for employers as well as the federal government. Insurers offering managed care to large employers would be required to extend that option to small employers as well.* The Commission's recommendations for insurance reform, if implemented, would further encourage managed care and other cost management innovations because insurers could no longer profit simply by avoiding the "poor" risks. Competition would have to be based on efficient service and health care expenditures management.

4. *The Commission recommends also that the newly established federal program adopt and extend Medicare's increasingly effective payment mechanisms.* Initially for hospitals and more recently for physicians, Medicare's payment rules have been refined to reward providers for delivering services efficiently. Applying these rules in the new federal program would extend their scope for publicly financed patients as well as provide a model for private insurers seeking new ways to control their costs.

5. The Commission recognizes that universal coverage in an efficient health care system is necessary but not sufficient to ensure all persons access to the care they need. People in isolated rural areas and inner cities, and particular segments of the population—minorities and the poor, pregnant teenagers, the physically or mentally disabled—would still face difficulties finding and getting the care they need.

The Commission recommends that expanded public coverage reinforce but not replace primary care delivery systems that are subsidized to serve these populations. It also recommends federal support to promote and extend systems that provide and coordinate a broad array of

social and health services. Moreover, it recommends provider payment methods and other mechanisms to ensure the general availability of health providers adequate to serve these most vulnerable citizens.

6. The Commission's commitment to universal coverage in an efficient and effective health care system goes beyond ensuring access to treatment. Preventing the *need* for treatment ensures Americans the most secure and productive lives, and uses the nation's resources most efficiently.

The Commission therefore recommends federal support for programs of health promotion, disease prevention, risk reduction, and health education toward the reduction of excess morbidity and mortality, and toward the increase of healthy lifestyles.

Beneficiaries and Costs of the Commission's Health Care Recommendations

Building universal coverage in the way the Commission recommends would extend coverage to almost 32 million Americans under 65 who are now uninsured. It would also ensure adequate health insurance coverage for the 20 million under 65 who have some insurance, but are still exposed to catastrophic costs if major illness strikes. All Americans would be guaranteed affordable protection that ensures access to care when they need it.

"I think these are the two words that [characterize what's going on in our country in health care]. The first one is 'wrong.' And the second one is 'stupid'. . . . [People] say South African apartheid [is] . . . wrong. . . . It's immoral. . . . The kind of suffering we have heard about here today is just wrong. . . . On the stupid side, we have already heard about the death, the suffering, the expense, the loss of productivity."

—Luanne Nyberg, director, Childrens' Defense Fund–Minnesota

The Commission's strategy for ensuring adequate access to health care for everyone is achievable for less than 2 percent more than the nation spends for health care under current law. If the recommendations were implemented in 1990, the projected increase in total health care expenditures would amount to $12 billion, raising total current health care expenditures from $647 billion to $659 billion in 1990. (All cost estimates are for 1990.)

Table 1 Impact of Commission Plan on Health Care Spending, by Source

(In Billions, 1990)

Federal spending		$24.0
State and local spending		(7.4)
Employer spending (after taxes)		14.7
Employers who now insure	(12.8)	
Employers who do not now insure	27.5	
Household expenditures		(19.3)
Net new spending		$12.0

SOURCE: Lewin/ICF estimates using the Health Benefits Simulation Model.

Not all sectors of society would be required to pay more, however (see Table 1). Employers who now offer health insurance to workers and their dependents are projected to save almost $13 billion because they would no longer bear the cost shift by insuring (as dependents) individuals who work for other firms or by paying for uncompensated care. Individuals and families are projected to save over $19 billion, as employers and government share their insurance and health care costs. State and local governments are projected to save more than $7 billion in payments now made for the uninsured, over and above Medicaid. Because states' contributions to expenditures under the recommendations would be limited in real terms to their current Medicaid contribution, they would also get some relief from the growing burden of financing care for the medically indigent.

Those employers who do not now provide health insurance for their workers and the federal government would share the new costs. Newly insuring employers would face a total of about $27.5 billion in increased payroll costs, less than 4 percent of payroll after taxes, on average. For a single employer, the increase could not exceed a specified percentage of payroll. This is because the Commission's recommendation allowing employers to choose a public health insurance program would effectively cap an employer's risk. The new federal costs of guaranteeing universal coverage would be $24 billion—to support adequate coverage for nonworkers and affordable coverage for workers and employers.

Some say we cannot afford universal coverage. The Commission believes that a decision *not* to make this investment would cost the country incomparably more: the disintegration of our health care system and

the waste of our most precious resource, the health and human potential of our people.

Improving Protection for People 65 and Over

The above recommendations apply primarily to Americans under age 65. Nearly all elderly Americans receive their basic health insurance protection from Medicare. Nonetheless, gaps in Medicare protection expose the elderly to considerable financial risk. To address these gaps, the Commission recommends three actions, consistent with recommendations for younger Americans.

1. The Commission is concerned about protecting the elderly against excessive financial burdens in obtaining health coverage or health care. *The Commission therefore recommends that Medicare, or the public plan that replaces Medicaid at the federal level, provide assistance with the Medicare premium, deductibles, and cost sharing to all elderly people with incomes below 200 percent of poverty and undertake strong outreach efforts to ensure participation.*

2. Consistent with the insurance benefits provided to the under-65 population, *the Commission recommends that Medicare be expanded to provide selected preventive services. Preventive services to be added include mammography and colorectal and prostate screening services.* As with the under-65 population, other preventive services should be added when they are determined to be effective relative to costs.

3. Private insurance (usually termed Medigap) supplements Medicare for four out of five nonpoor elderly people. However, continued congressional oversight has documented that the Medigap market has historically been subject to considerable abuse and inadequacy.

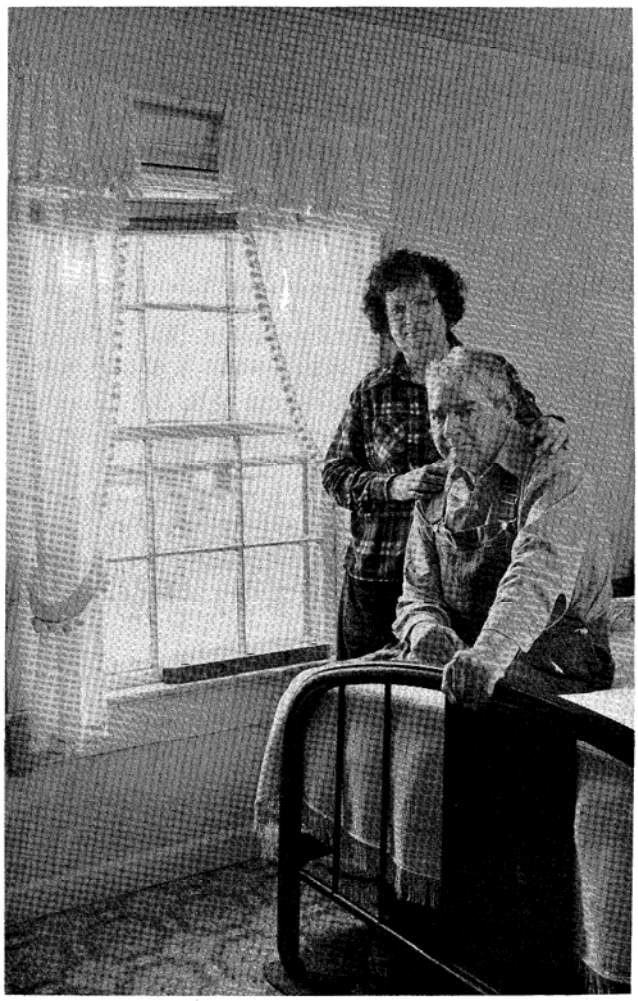
The Commission recommends federal action to ensure the nonpoor elderly access to adequate coverage through insurance reforms that are generally consistent with reforms the Commission recommends for other health insurance plans. Recommended action includes support for state or local counseling efforts and legislation to extend federal Medigap standards. Proposed standards would ensure policies of adequate value; allow consumers to compare policies and prices; and prevent sales abuses, duplication of coverage, and discrimination on the basis of health status.

These recommendations would, in combination, benefit 30 million Americans over the age of 65 at a total new federal cost of $2.8 billion.

WHY DO WE NEED LONG-TERM CARE REFORM?

Between 9 million and 11 million Americans of all ages are chronically disabled, dependent on others for help in the basic tasks of daily living that we call long-term care. As many as 4 million people are so severely disabled they cannot survive without substantial help from others. Millions more know the physical, emotional, and financial burdens of caring for relatives of friends who need such care—a mother with Alzheimer's disease, a child with cerebral palsy, a husband paralyzed from an automobile accident.

Yet in contrast to health care—for which most Americans have insurance, even if inadequate—there is almost no public or private insurance for in-home or nursing home care. Public support, primarily through the welfare-based Medicaid program, comes only after people have exhausted their own resources. Consequently, most Americans face the risk of impoverishment should they need long-term care.



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Without adequate public or private insurance, Americans who need long-term care are at risk of impoverishment.

At more than $2,500 a month, on average, the cost for even a short stay in a nursing home exceeds most Americans' incomes. At a national average cost exceeding $60 per visit, extensive home care is not far behind. Families exhaust themselves and their resources to provide care at home; long stays in a nursing home consume the savings of a lifetime. As the population ages and technology extends life for young and old disabled Americans alike, these burdens will only increase.

Who Needs Long-Term Care?

Two-thirds of the long-term care population are elderly; the rest are under 65.

The vast majority of people of all ages who need long-term care live in the community (see Figure 4). More than 5 million disabled elderly and over 3 million disabled younger people live at home (or in non-nursing residences). Nearly 2 million people live in nursing homes—1.5 million elderly and 0.2 million people under 65.

During their lifetimes, 36 percent to 45 percent of persons reaching age 65 in 1990 are expected to spend time in a nursing home before they die. A minority of 65-year-olds (about one in five) can expect to receive a year or more of nursing home care. But many nursing home users do not end their days in nursing homes after long stays. Between 26 percent and 45 percent of nursing home stays last fewer than three months, and half these "short stayers" are able to return to their homes.

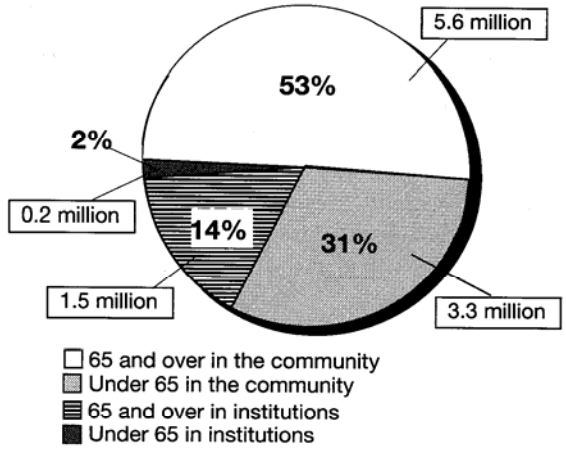
How People Get and Pay for Care

In 1988, the nation spent $53 billion on long-term care. Only 18 percent of these expenditures went to home care—despite that fact that four out of five disabled and almost three out of five severely disabled live at home. Most home care is provided by relatives and friends. And when people do buy home care, they get little help from public programs.

Public spending on nursing home care, by contrast, is substantial. Almost all of the private share is paid for, without the benefit of insurance, by the individuals and families who need the care. Public support for nursing home care is largely available only *after* people experience financial catastrophe. Consequently, most people who need nursing home care face enormous financial risk.

Caring for People at Home—Almost three-quarters of severely disabled elderly—and two-thirds of the most severely disabled elderly—in 1989 relied solely on family members or other unpaid help.

Figure 4 Residence of People Needing Long-Term Care



SOURCE: Lewin/ICF estimates using the Brookings/ICF Long-Term Care Financing Model.

More than 7 million spouses, adult children, other relatives, friends, and neighbors provided unpaid assistance to disabled elderly in 1984. Most of these caregivers are women. Four out of five caregivers average four hours a day, seven days a week. Many caregivers who make this extraordinary effort are vulnerable themselves. One-third are older people, have incomes below or near the poverty level, or are in poor health. More than one in 10 of all caregivers report leaving their jobs to provide care.

That families devote such effort to caring for disabled relatives is moving testimony to the strength of the human spirit. But the scale of their sacrifice suggests there may be objective barriers to purchasing help. For the minority who purchase long-term care services in the home, costs can be substantial. The most severely disabled spent an estimated $439 per month in 1982. And even people willing to pay face difficulty in finding the services they need and doubts about the quality of those services if they find them.

In 1988, federal and state governments spent about $7 billion on in-home services—about 37 percent through Medicare, 47 percent through Medicaid, and 16 percent through federal grant or state-funded programs. The programs differ in significant ways, but all are limited in their capacity to finance long-term care.

Eligibility for Medicare is limited to people who are unable to leave their homes (homebound) *and* who require skilled or professional service. Most

people who need long-term care do not need skilled services, so Medicare is of little help. And few states rely on Medicaid to provide substantial long-term care to disabled people living at home. As with other Medicaid benefits, states control service and spending by limiting amount, duration, and scope of services; payment rates for providers; and eligibility. And the special waiver programs serve very few.

Two other major federal programs—the Social Services Block Grant program under Title XX of the Social Security Act and the Older Americans Act—do not carry stringent restrictions on eligibility, but provide only limited funding for in-home and community-based care. They are fixed-dollar allotments that states can use for many purposes besides long-term care.

A few states are investing substantial resources of their own in designing innovative in-home and community services programs. These initiatives provide models for broader coverage of care for disabled people at home. They are, however, the exception rather than the norm in the nation's effort to provide home and community-based care. Unless frail elderly and disabled Americans need skilled care and qualify for Medicare, or are poor *and* in a generous state, they must depend on their own resources and on relatives and friends to provide care.

Nursing Home Care—Despite the enormous efforts of disabled persons and their families to manage at home, nursing home care sometimes becomes inevitable. At this point, they face both emotional and financial devastation. Among elderly people with at least $3,000 in out-of-pocket spending annually, 83 percent of that spending goes for nursing home care. This fact reflects not only the absence until recently of private long-term care insurance (described below), but also the limits to public programs.

Medicare covers nursing home care only as a limited extension of its health care coverage. It does not cover the extended personal care that is the bulk of nursing home service.

Medicaid, on the other hand, provides almost 90 percent of the public financing for nursing home care and more than 40 percent of all nursing home revenues. But people receive Medicaid nursing home benefits only if they are, or have become, virtually destitute. In addition, Medicaid payment rates are so low in many areas that Medicaid patients—particularly those needing extensive care—may have problems finding care at all.

The Emergence of Private Long-Term Care Insurance

Private insurance to protect against financial losses from long-term care has only recently become available. Private insurers historically have been reluctant to offer such policies since it is so hard to predict the number of policyholders who will make claims and the cost of the services they will use. Although general health insurance entails similar risks, they are greater with long-term care. Services are harder to define, and there may be no need for care until decades after the policy is purchased.

Insurers have nevertheless begun to offer long-term care policies, and their availability has grown rapidly. The number of policies sold since 1987 has more than doubled. This does not mean that insurers no longer face risks, but that they have designed and marketed policies to limit their financial liability, thereby protecting their solvency.

Protection for insurers limits benefits to consumers. Insurers do not sell policies to people who are already disabled. Policies that provide some coverage may still leave consumers at risk of substantial expense when they need care.

Creativity and competition among insurers, along with regulatory requirements, have expanded benefits policies offer. But even in most improved policies, benefit levels do not keep pace with increases in service costs. Insurers can raise premiums or cancel policies, even after policyholders have paid substantial premiums.

And decent protection is expensive. The Health Insurance Association of America reports that for a 65-year-old, a relatively comprehensive policy costs about $1,400 in 1990; for a 79-year-old, the price is $4,000.

Some argue that more and more elderly will purchase long-term care policies, reducing the need for government protection. The fact is, only about 3 percent to 5 percent of the elderly currently own long-term care insurance. And for many elderly, the financial burden of these policies is patently prohibitive. Only about 6 percent of today's elderly could purchase the relatively comprehensive long-term care policy for as little as 5 percent of their annual income.

The emergence of job-based long-term care insurance, combined with anticipated increases in the elderly's income, makes some observers optimistic that private insurance will fill a considerable part of

the need by the year 2020. But even if private insurance protection grows substantially, critical questions will remain:

- How to protect the currently disabled population as private insurance expands,
- How to ensure that the privately insured receive adequate protection and value for the dollar, and
- How to protect the population that private insurance will inevitably leave out.

Prospects for the Future

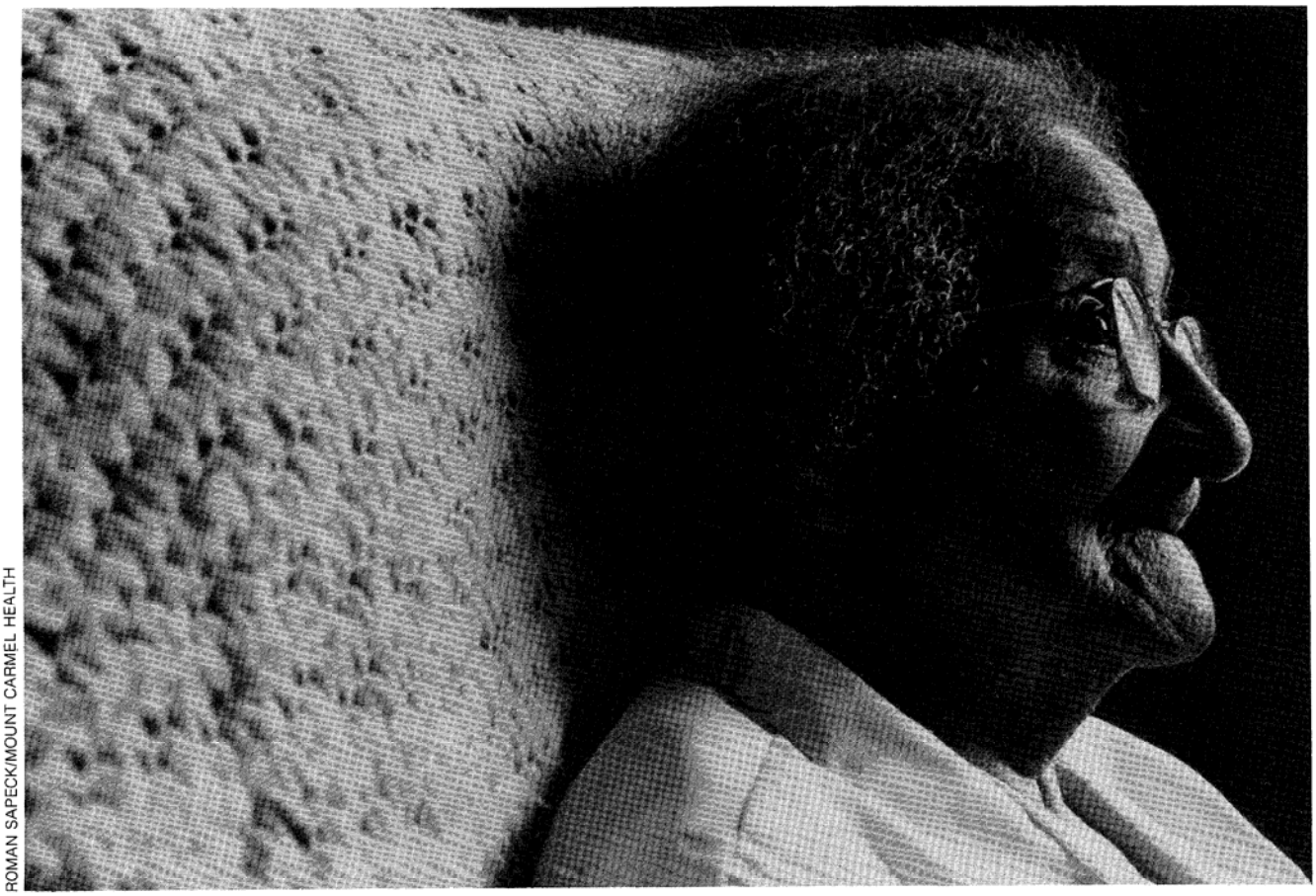
Growth in the numbers of people likely to need long-term care makes improvements in the nation's financing of this care imperative for the well-being of all Americans. If disability rates remain what they are today, the number of elderly persons needing help with basic tasks is expected to double between 1990 and 2030—increasing from about 7 million to almost 14 million. The number of elderly requiring nursing home care will more than triple—rising from about 1.5 million to over 5 million (see Figure 5). And the use of high-technology and new medical breakthroughs may continue to extend the lives of disabled people of all ages.

It is highly unlikely that service availability will keep up with these growing needs. Demographic trends predict that fewer family members will be available to care for their disabled relatives. The private marketplace seems unable to develop an adequate home care delivery system even for those who can pay. The two major public programs—Medicare and Medicaid—have structural limitations that prevent them from meeting the projected need.

Without a change in public policy, more and more Americans will have difficulty getting the care they need in nursing homes as well as at home.

BLUEPRINT FOR LONG-TERM CARE REFORM

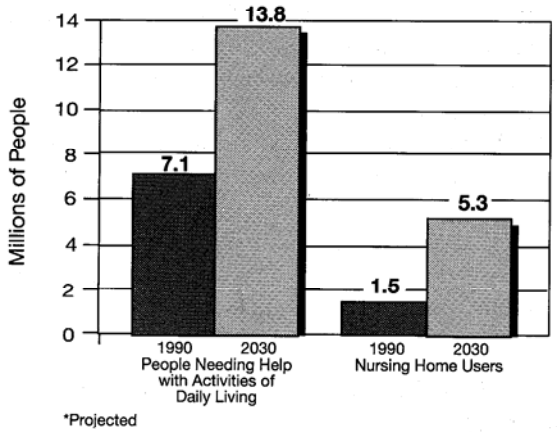
The Commission concludes that federal action is essential to change the nation's fundamentally flawed approach to long-term care financing, and that such action should follow an insurance strategy (public or private or both). The Commission rejects the alternative of encouraging private savings to cover long-term care costs. Depending on private savings concentrates the financial burden of severe impairment—an expensive and largely unpredictable event—



ROMAN SAPECK/MOUNT CARMEL HEALTH

By 2030, the number of elderly people requiring nursing home care will more than triple.

Figure 5 Number of Elderly Needing Long-Term Care, 1990 and 2030



*Projected

SOURCE: For 1990, Lewin/ICF estimates using the Brookings/ICF Long-Term Care Financing Model; for 2030, Shelia Zedlewski, et al., *The Needs of the Elderly in the 21st Century* (Washington, D.C.: The Urban Institute, 1990).

on the unlucky few who experience it, rather than spreading it among the many who are at risk of impairment. Failure to reform the system on an insurance basis is not only to abandon today's elderly and disabled but also to condemn growing numbers of Americans to inadequate access to care in the future.

To prevent this outcome, the Commission unanimously adopted the following goal:

> The Pepper Commission is committed to the development of recommendations for public policies that give Americans of all ages access to coverage that provides them necessary long-term care and adequate financial protection; that will assure quality care and choice of setting and will control costs; that will provide the financing required to assure access; and that will support research to prevent the need for long-term care.

The Commission explored a range of possible strategies to achieve this objective. One strategy would be to enhance government protection for the low-income population and promote adequate private insurance protection for the better-off. The Commission believes, however, that to build such a two-tiered system would be to repeat the nation's unfortunate experience in health care. Too many people would continue to face impoverishment or find themselves dependent on a welfare-based system, a system unable to ensure access to quality care.

Another strategy would be to develop a comprehensive public insurance program for all long-term care services. The Commission believes that public or social insurance has considerable merit in guaranteeing adequate protection to all Americans, regardless of income. However, the Commission is concerned that applying this strategy to all nursing home care, as well as to home care, has disadvantages. Namely, it would require substantial public resources and would provide unlimited protection of assets for people who could well afford to protect themselves through private insurance.

To target public resources most effectively, guarantee Americans of all incomes adequate protection, and achieve an appropriate balance between public and private insurance, the Commission recommends a limited social insurance approach. The Commission believes that federal social insurance for home- and community-based care is essential to ensure the development of an adequate and efficient delivery system for these services and that priority in the use of public resources should go to disabled people at home or able to come home after short nursing home stays. People in nursing homes should be guaranteed an ample floor of protection, ensuring that no one—regardless of length of stay in the nursing home—will become impoverished. All but the poorest should contribute to the costs of their care.

Building a Long-Term Care System

Based on these principles, the Commission recommends developing an integrated public program that would meet the diverse needs of severely disabled people and support private insurance for those seeking broader protection. The blueprint has nine parts.

1. *The Commission recommends social insurance for home and community-based care and for the first three months of nursing home care, for all Americans, regardless of income.* Individuals would be required to contribute to the costs of care, with subsidies for people with low incomes. This protection would sustain resources and standard of living when people need long-term care, just as Medicare or private health insurance does when they need physician or hospital services.

2. *For people with long nursing home stays, few of whom return home, the Commission recommends a floor of protection against impoverishment—protection of $30,000 in assets (excluding homes) for individuals and $60,000 for couples—and protection of income for spouses, home maintenance, and a decent allowance for personal needs.* Protected assets are approximately equal to the life savings of three out of five elderly people. People whose assets exceed the floor would not receive benefits until their unprotected assets were depleted. Income above protected amounts would be applied toward the cost of nursing home care.

3. Recognizing that many people will want additional protection for assets and income above levels protected for long stays—as well as for cost sharing obligations associated with other benefits—*the Commission recommends measures to promote private long-term care insurance, subject to federal and state oversight.* Promotion would involve clarifying the tax code to give long-term care insurance the same preferential tax treatment health insurance now receives. Oversight would entail standards for insurance policies, consumer counseling to evaluate policies, and penalties on insurers for failure to comply.

4. The Commission believes that all severely disabled persons—regardless of age, underlying disease or disabling condition—be eligible for public benefits, at home or in a nursing home. To qualify for long-term care benefits at home or in a nursing home, *the Commission recommends that individuals meet at least one of the three following disability criteria:* (a) *need hands-on or supervisory assistance with three out of five activities of daily living;* (b) *need constant supervision because of cognitive impairment that impedes ability to function;* or (c) *need constant supervision because of behaviors that are dangerous, disruptive, or difficult to manage.* Individuals assessed as severely disabled would be directed to a case manager for help in obtaining home care or assisted in obtaining a nursing home placement.

5. To ensure that home care services support but do not replace family caregiving and are managed in a fiscally responsible manner, *the Commission recommends relying on case managers to develop and oversee individual care plans.* Within a federally determined budget, case managers would be free to allocate a broad array of services, tailored to people's needs and preferences. *The Commission recommends that benefits include personal care, homemaker/chore services, shopping and other support services, day care (for disabled adults and children), respite services, and training for family caregivers, as well as skilled nursing and rehabilitative care.*

6. Under the recommended plan, both federal and state governments would be responsible for financing and administering public benefits. *The Commission recommends that the social insurance portions of the public program be fully financed by the federal government. The federal government and the states would share financial responsibility for long nursing home stays.*

In administering benefits, the Commission seeks a balance between ensuring equal and adequate protection for all severely disabled, regardless of the state in which they live, and allowing flexibility to tailor services to diverse populations and communities. *The Commission therefore recommends that the federal government contract with the states to administer the plan. The federal government would be responsible for setting guidelines and adequate standards for this administration.* The federal government would certify assessment agencies and develop standardized assessment criteria, set guidelines for certifying case managers and establish their budgets (described below), set guidelines for quality assurance and appeals procedures, and determine provider payment rates. Within federal guidelines, states would develop and certify case management and delivery systems, certify providers, establish review and appeals procedures, and enforce quality standards.

7. The Commission recognizes that financial support for long-term care can be effective only if it promotes and ensures quality of care. Furthermore, to be sustainable over the long term, a program must be designed in a way that controls expenditures. The recommended plan therefore includes several measures to ensure quality and control costs.

The recently enacted nursing home requirements would apply to the recommended nursing home coverage, and standards would be developed for care in the home.

Alongside these standards, the Commission believes that case management, an integral part of its recommended home care benefits, plays a critical role in ensuring quality and managing costs. *The Commission recommends that case managers allocate services and monitor service delivery within a budget set by the federal government.* This approach would ensure fiscal constraint and the capacity to tailor services to individual needs and preferences.

The Commission further recommends that the federal government establish provider payment mechanisms and determine appropriate rates. Prospective payment systems can be used to ensure access to quality care, efficiently delivered, and to control spending for care.

8. The Commission recognizes both the urgent needs of the currently disabled and their families for public support and the time it will take to build a long-term care system. *The Commission therefore recommends that the plan be put into place a step at a time over a four-year period.* The program would begin with limited home care benefits to relieve the burdens on family caregivers. Benefits would be expanded over the next four years, until full coverage is reached. Nursing home coverage would begin in year two. Payment rates would be increased gradually over the subsequent two years to ensure adequate supply and quality of service.

9. In establishing a long-term care system, the Commission believes it essential to assess the effectiveness of treatment, delivery, and management of services, and to explore means to prevent the need for long-term care services.

The Commission recommends that the federal government move aggressively to contain costs and mitigate human suffering by funding a research and development program aimed at preventing, delaying, and dealing with long-term illnesses and disabilities.

Research should encompass special problems of minorities; the development of outcome measures and practice guidelines; and evaluation and innovation in assessment, quality assurance, and service delivery mechanisms, especially in care at home.

Beneficiaries and Costs of the Commission's Long-Term Care Recommendations

The Commission's recommendations provide a blueprint for developing a national long-term care system. Home and community-based care would be available and affordable. People who need nursing home care for short periods would have their resources preserved intact to return home. And no one would have to fear impoverishment if they end their lives in a nursing home. People would contribute to the costs of care for all services subject to their ability to pay. They would also have broader access to private insurance to cover these costs. All Americans would benefit from the new public program, for it provides everyone peace of mind in the face of long-term care needs.

But long-term care is expensive—averaging more than $2,500 per month for nursing home care and over $60 a visit for in-home support. We cannot build a system that ensures adequate service to people who need it merely by shifting around the dollars we spend today. New expenditures are required.

If the program were in place today, it would serve 4.4 million people at a net new federal cost of $42.8 billion—$24 billion for care at home and $18.8 billion for nursing home care. About three-quarters of total spending would go to the elderly and about a quarter to people under 65 (see Table 2).

For the severely disabled elderly, new federal spending would be split almost evenly between home care and nursing home care ($15 billion and $16.8 billion, respectively). For nursing home care, the floor of protection against impoverishment would cost about $11.3 billion; broader protection for short stays would cost another $5.5 billion. For younger severely disabled, most of whom live in the community, almost all new spending ($9 billion out of a total $11 billion) would go to home and community-based care.

The new program would serve some 2 million severely disabled elderly people at home every year, doubling the number who now receive paid support. For the 1 million people who would have purchased their own care in the absence of the public program, out-of-pocket savings in 1990 are estimated to be $900 million—about $1,000 per user.

Because more people would have access to better nursing home care under the Commission's program, nursing home use is also expected to increase. Under the recommended program, about 1.2 million people a year are expected to enter nursing homes. All would receive some public support. People who would have used the nursing home at their own expense or spent down to Medicaid in the absence of the new program would save $6.9 billion in out-of-pocket expenses, or about $3,000 per user. Under the recommended new public program, all 1.2 million nursing home entrants would receive coverage for the first three months of nursing home care. For almost half of all entrants, or 528,000 people, the three-month social insurance bene-

Table 2 **Beneficiaries and Net Federal Costs of Commission Long-Term Care Recommendations, by Age Group and Type of Service**

	Home Care	Nursing Home Care	Total
Total Beneficiaries (In Millions)			
Elderly	2.0	1.2	3.2
Nonelderly	1.0	.2	1.2
Total	3.0	1.4	4.4
New Federal Costs (In Billions, 1990)			
Elderly	$15.0	$16.8	$31.8
Nonelderly	9.0	2.0	11.0
Total	$24.0	$18.8	$42.8

SOURCE: For elderly, Lewin/ICF estimates using the Brookings/ICF Long-Term Care Financing Model; for nonelderly, Commission staff estimates.

fit would cover their entire nursing home stay. The majority of "long stayers" (425,000 entrants) would have their assets fully protected. A minority (79,000 people) would acquire asset protection during their stay.

Although people would no longer be expected to devote all their resources to long-term care before they could receive public support, all but the poorest would be expected to contribute to the costs of care. Under the Commission's recommendations, individuals could be responsible for cost sharing equivalent to as much as $12 per home care visit or—for short stays—$15 per nursing home day. For long nursing home stays, they would contribute assets and income above protected levels. The Commission recommendations would facilitate the purchase of private insurance to cover these expenses, through both assistance and oversight to ensure adequate policies and favorable tax treatment for policies purchased.

This count of people and dollars significantly understates the benefits long-term care coverage would bring. Families of the severely disabled would receive badly needed help in caring for their impaired loved ones. Employed caregivers, or caregivers who could be employed, would be better able to balance responsibilities at home and on the job. Employers would reap the benefits of a more secure and productive work force.

Finally, and perhaps most important, all Americans would benefit from the security of knowing that if the need for long-term care should arise—for themselves, their parents, or their children—they would not be left to cope on their own. The nation would have a system to which everyone in need could turn for help.

REVENUES TO FINANCE COMMISSION RECOMMENDATIONS

The estimated new federal cost of the Commission's recommendations—health care plus long-term care for people of all ages—would be about $69.6 billion if fully implemented in 1990. Although some of these funds could be raised from reductions elsewhere in the federal budget, the Commission recognizes that new revenues will be necessary. To finance the new costs of the program entirely through new taxes in 1990 would require about $430, on average, from each nonpoor American adult. Various tax packages would spread the burden in different ways.

The Commission recommends that three criteria guide the selection of options for raising these revenues:

- *Taxes should be progressive, requiring a higher contribution from those most able to bear increased tax burdens.*
- *Revenues should be able to grow fast enough to keep up with benefit growth.*
- *Contributions should come from people of all ages.*

A CALL FOR ACTION

Congress called upon the Commission to recommend legislation to ensure all Americans coverage for health and long-term care. With this report, the Commission fulfills its task. Now the Commission calls for action from the Congress and the President to turn its recommendations into law.

The Commission's investigations leave no doubt that Americans' fears about their health care system are well founded. Without action, people cannot rely on coverage they can afford or care when they need it.

The Commission not only documents the problems our citizens face; it puts forward workable solutions. In health care, we can build upon and strengthen the coverage we now have. In long-term care, we can identify priorities and build the coverage we now lack. We can build carefully and deliberately, one step leading to the next.

Universal coverage in an effective, efficient system is within our reach. We must act now.