Replacing the nursing home

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The term “nursing home” hardly fits the American institution that houses 1.7 million feeble old people. First, no one who lives in a nursing home could possibly confuse it with a home. Sharing a bedroom with a sick stranger, being served institutional food on a fixed schedule, having no control over the design and furnishing of your room, and being cared for by indifferent aides contradicts the idea of home. Second, these institutions provide little professional nursing care for their residents. Residents in nursing homes receive attention from registered nurses for an average of nine minutes per day. The basic problem with nursing homes, however, is not the misleading name. Changing the name from nursing home to something else, as some institutions have done in recent years, does not change the experience of those forced to live in them. The fundamental problem is much deeper and more resistant to change. These institutions are costly, inhospitable structures, failing to meet the needs of the persons who must spend their last weeks or years
of life in them because better alternatives are not available.

Rather than continuing down the path of trying to reform nursing homes through ever greater governmental regulation, it is time to phase out public support of the nursing-home industry. The 50 billion dollar annual subsidy of nursing homes coming from government could be redirected to support alternative arrangements that better meet the needs of the disabled elderly. A bold move to end government support of nursing homes could profoundly improve the quality of life for several million older Americans.

**Who created the nursing home?**

The modern nursing-home industry, involving the construction and operation of profit-making, medical-type facilities, was developed after World War II. In the mid 1940s, fewer than 200,000 persons resided in institutions of this type, but warnings about depersonalization occurring in nursing-home environments were already being sounded. Despite persistent criticism of conditions, however, the number of residents in these facilities continued to grow, in large measure due to perverse government incentives. Expansion of the nursing-home industry in the 1950s was encouraged by the Hill-Burton Act that provided public money for construction of non-profit nursing homes and by the Federal Housing Administration's guarantee of mortgage loans to proprietary nursing homes.

More rapid growth occurred after Medicaid was enacted in 1965. Medicaid regulations signaled the willingness of government to pay the full cost of long-term care for poor older persons in nursing homes, but not in other settings. The infusion of this new source of money provided a tremendous boost to the nursing-home industry; and government regulations that accompanied it set the model that nursing homes had to adopt. In addition, the deinstitutionalization of residents of mental hospitals, which began in the 1960s, further increased the supply of older persons who were candidates for nursing-home admission. Thus by the early 1970s, more than one million older persons were residing in nursing homes, and large-scale government support of the industry was firmly in place.
Cost and quality

Three big problems of nursing homes will not go away: excessive cost, poor quality of care, and dehumanization. Nursing homes are an expensive way to care for frail, older persons. The cost of residing in a middle-range nursing home for a year now exceeds $45,000. Because very few individuals have private insurance to cover long-term care, nursing-home expenses are paid out-of-pocket or through governmental funds. Nursing-home residents who are poor (or who can appear poor through deceptive Medicaid estate-planning techniques) qualify for Medicaid support. Those who do not must pay their own bills until they have spent down their savings and assets. Thus all but the very wealthy face the threat in old age of having to transfer their life savings to a nursing home and becoming wards of the state.

Nursing homes threaten the general public with financial disaster as well. The total cost of caring for the nearly two million persons now living in nursing homes is $80 billion annually. The government pays about 60 percent of this bill, which is increasing each year. From 1990 to 1994, while the size of the older population was growing at 1.6 percent per year, government spending on nursing homes (adjusted for inflation) was growing at 9 percent per year. But the older population in need of care will grow far more rapidly in the future, as the baby-boom generation grows older. Projections by the Urban Institute, using current nursing-home admission patterns, indicate that the number of persons in nursing homes could nearly triple between 1990 and 2030. If per-capita nursing-home costs continue to grow more rapidly over this period than the economy, as they have done for some time, society will face an immense economic burden.

Cost, however, is not the only reason why alternatives to nursing-home care must be found. A second problem plaguing the nursing-home industry is the poor quality of care provided. At the extreme are instances of physical abuse and theft of property. Of greater concern, however, is the routine experience of receiving what Bruce Vladeck, Administrator of Health Care Finance Administration, terms "unloving care."

Residents of nursing homes tend to be highly dependent
upon others for care. A majority suffer from dementia, most cannot walk or bathe themselves without assistance, many are incontinent. Who in the nursing home is entrusted with the task of caring for these vulnerable and challenging patients? This responsibility falls upon aides, who typically have little training and little motivation for the difficult work assigned to them. Studies of daily life in nursing homes find that, in performing the bathing, toileting, transferring, and feeding of patients, aides often treat them as work objects. That is, the work is done without meaningful social interaction and without respect for the patients.

An obvious response to this situation would be to upgrade the quality of care provided by aides. Unfortunately, structural constraints limit the feasibility of this solution. The job of a nursing-home aide is poorly rewarded and difficult. Salary and fringe benefits are low, prospects for advancement are nil, and relationships with supervisors are often antagonistic. The work is difficult, both physically and emotionally. Aides who stay for long (most do not) will see their patients deteriorate and die. Given these work conditions, aides seldom are attracted to these positions for positive reasons. Rather, aides tend to lack skills that would make them competitive for more financially rewarding and less emotionally draining jobs.

By increasing salaries, reducing work loads, and providing more training, it would be possible to improve the quality of care in nursing homes. But these are costly changes. Profit-making nursing homes must keep costs below the level that they charge patients or Medicaid in order to stay in business. Without greatly increasing the cost, it is not likely that meaningful improvement in quality of care is possible for the nursing-home industry. Without solving the quality-of-care problem, nursing homes cannot be anything but miserable institutions for unfortunate persons waiting to die.

Perhaps the most poignant aspect of the nursing home is the dehumanization that it brings about. The deleterious effects of institutionalization on individuals have repeatedly been documented and discussed since they were first elucidated in Erving Goffman's 1961 classic, *Asylums*. Those forced to reside in nursing homes inevitably experience an erosion of autonomy and a loss of privacy. The decisions of daily living—
how to furnish their rooms, when to eat and bathe, where to go, whom to socialize with, what medical treatment to receive—are all made for them by administrators. Loss of privacy occurs in many ways: Rooms are shared with strangers, doors are left ajar, and almost anyone has access to the patient’s space. Privacy of information, privacy of property, and privacy of body are routinely violated by staff. No one intentionally designs nursing homes to destroy the spirit of the frail and disabled, but the institutional environment produces this outcome.

No place like home

But there are cost-effective, noninstitutional alternatives to the nursing home. Consider the following five arrangements which, due to misguided public policy, are not in sufficient supply: home care, assisted living, group homes, hospices, and rehabilitation.

As in the past, most old people with disabilities live at home, not in an institution. Approximately 80 percent of all older persons who must depend on others for assistance in the activities of daily living (e.g., dressing, eating, toileting, getting out of bed) reside in their own homes. They are able to avoid institutionalization because they obtain assistance from others in a community setting. A majority (over 70 percent) of the home-based care received by dependent elders is provided by informal helpers—spouses, adult children, other family members, friends, and volunteers. But home care also can be purchased from service providers. Expenditures for home-care services have been growing at a brisk 20 percent per year recently. The rapid expansion of home-care services reflects demographic change (increasing number of disabled persons), technological change (increasing feasibility of delivering services within the home), and public-policy changes (increasing willingness of Medicare and Medicaid to pay for home health care—Medicare expenditure on home health care grew from $1.9 billion in 1988 to $9.7 billion in 1994).

Few disagree that older persons should be allowed to live at home whenever possible. The important questions, therefore, relate to what is possible and whether the need for nursing homes could be reduced by delivering more care-
giving services in home settings. Is it cost-effective to reallocate some of the $50 billion of public resources going to nursing homes to support home care and community-based services (such as adult day care, respite care, transportation services, and meals-on-wheels)? Is it possible to exercise adequate quality control over services delivered to persons at home? Would increasing home care place unreasonable burdens and stress on the informal care givers? Fortunately, a great deal of research has been directed to these questions, and enough answers are in to justify transferring significant resources from support of nursing homes to home care.

Now it is true that some very disabled persons, particularly when they do not have access to informal care givers, must be institutionalized. When a person is comatose or has an unstable medical condition that requires around-the-clock monitoring, for example, the cost of providing home care may be excessive. However, a number of studies demonstrate that providing shelter, food, personal assistance, and medical care at home generally costs less than the $45,000 or more per year required to provide these things in a nursing home. And rarely is no informal care available. Thus policy makers should rewrite Medicare and Medicaid regulations to provide more flexible funding of home care. A major reordering of long-term-care strategy from institutional care to home- and community-based support of frail elderly persons would meet needs in a more humane way and at a lower total cost.

Concern over monitoring the quality of home-based care is legitimate. It may seem obvious that there is greater potential for supervising and monitoring nursing-home care than that which is home based. Yet the quality of care provided in institutions is not superior to that being provided by home-care and home health-care agencies; in fact, it is worse. In home environments, the individuals receiving care or their family members have greater control over who provides the care and how well the care is provided. In addition, morale problems and conflict with supervising staff are likely to be less common in home settings than in institutions.

Another concern is that expanding home care might create unreasonable burdens on family members. Although gerontologists, in recent years, have gone overboard in writing about
“the burden of care giving,” it is important to consider how informal caregivers might be supported. Expanding the supply of community-based support to supplement the care provided by family and friends is one way to help out. In order to prevent institutionalization, family members are usually willing to provide care for a loved one, so long as the responsibilities are manageable. Adult day care and respite care can provide relief for family caregivers, as can access to assistance from home health aides and personal-care attendants. Rather than cutting off informal care by institutionalizing an older person, we should provide outside assistance that enables many dependent older persons to remain at home where they will continue to receive care from family and friends.

Overregulation of home care, however, is a problem. While the intention may be to protect consumers, regulations restricting who can give medications, change catheters, monitor respirators, or take vital signs may do more harm than good. Millions of parents with no special training now administer prescription drugs and give basic medical care to their children. With minimal training, the average person can monitor respirators, change dressings, and give shots. The risks associated with empowering common people to perform basic medical procedures are relatively small; and the adverse consequences of unnecessary regulation are significant (excessive cost, inconvenience, and loss of patient autonomy).

A helping hand

Assisted living provides an attractive alternative to nursing homes for those who are unable to live independently. A wide range of facilities provides assisted living, but all embrace the value of personal control for older, frail residents within a home-like environment. Residents in assisted-living facilities, in contrast to those in nursing homes, experience autonomy, responsibility, and privacy, and their needs for health care and personal assistance are arranged on a personalized basis. Assisted living is distinguished from simple congregate housing by the level of assistance available to residents needing help with personal care and by the protective oversight and around-the-clock emergency help that is available. Recent estimates indicate that over one million older persons live in
what legitimately could be called assisted-living facilities. A much larger number of disabled older Americans, many of whom now are in nursing homes, could benefit from this type of living arrangement if more were available.

A basic feature of assisted living is the independent and private living arrangement it provides for older persons who require assistance because of frailty. Each resident typically has a private room, a bathroom, a kitchenette, and doors that lock. Various design features that increase safety and promote independence (grab bars in bathrooms, emergency-call systems, door levers rather than knobs, counters at convenient heights, good lighting) can be built into these facilities. It is the responsibility of each resident (or guardian) to decide upon the furnishing and decor of the apartment. In this environment, individuals can take care of themselves as they are able; family and friends can help as they are able; and professional help can be purchased as necessary.

The nursing and health-care needs of residents in assisted-living facilities are planned and provided for on an individual basis. In some cases, personal assistance is purchased from home health agencies that are independent of the assisted-living facility; in other cases, the services are available from the facility. In either case, residents are free to choose what help they want to purchase and to use as much informal care giving as they are able to obtain.

As with every other arrangement, financing is a critical issue. Thus far, a majority of assisted-living facilities have been developed by the private sector and marketed to affluent older consumers. A large proportion of the older population has significant assets (e.g., homes with no mortgage) and substantial incomes (Social Security, private pensions, interest from investments), so the potential market for private-sector development of assisted living is large. For many frail elderly, however, public assistance is needed to make assisted living possible. As experiments in Oregon have demonstrated, it is feasible and cost-effective to subsidize assisted living for low-income people who qualify for nursing homes. By increasing the flexibility of Medicare and Medicaid guidelines for supporting persons in assisted living, it would be possible to facilitate expansion of this alternative to nursing homes. Equally
important, however, is the fact that the government has the power to impede the growth of assisted living through enacting bureaucratic requirements that interfere with its development. Efforts to force a medical model upon assisted living and to increase government control will discourage the growth of this promising alternative.

**The group home**

Approximately one-half of the persons admitted to nursing homes suffer from dementia, and over 60 percent of all nursing-home residents are cognitively impaired. Some Alzheimer (and other dementia) patients in nursing homes also have serious medical problems, but many do not. Placing relatively healthy people with dementia in a typical nursing home makes little sense.

In recent years, a growing number of nursing homes have created special Alzheimer Units for their patients with dementia. These units, especially the better designed ones, offer a more appropriate environment for meeting the needs of persons with Alzheimer's disease. Advantages for patients include greater privacy, a more homelike setting, staff trained for meeting their special needs, avoidance of distracting and confusing stimuli, and services designed for meeting needs of memory-impaired individuals. While this represents an improvement, it would be better if such units existed completely apart from standard nursing homes.

Consider, for example, the group-home approach developed in Sweden. These group homes, located in the community and typically accommodating 10 residents, are organized on a social, rather than a medical, model. Each person is provided a small, private apartment with a living area, bathroom, and small kitchen. There is also a common area and grounds that provide opportunities for social interaction. Appropriate security prevents the residents from wandering away from the home. Each resident, with the assistance of family or other helpers, creates a homelike setting by providing his own furniture, pictures, memorabilia, and other personal belongings.

Staff for these group homes are trained to engage the residents in familiar household activities, such as cleaning, food preparation, laundry, gardening, and shopping. Staff and resi-
dents eat, have coffee, and discuss issues together. Use of psychotropic medicine is kept to a minimum. Not surprisingly, evaluations of these homes found that staff were generally positive about their work, and that staff turnover was low. And family members were highly satisfied with the homes, and residents experienced better outcomes than comparable dementia patients in other settings. Further, the cost of care in group homes was less than in nursing homes.

The development and expansion of group homes does not require a Swedish style welfare state. Much of the cost should be paid by the residents who, like other old people in our society, typically have personal resources to support their housing and living expenses. The government can, nevertheless, facilitate movement in this direction by avoiding excessive regulation and by avoiding irrational control over how public-health-care dollars are spent. Why should Medicare and Medicaid pay for the care of a person with Alzheimer's disease in a nursing home while refusing to assist the same person to live in a much more appropriate environment at lower cost?

Hospices and rehab

A nursing home is the final residence for most old people who enter it, many of whom die within a few months of moving in. Some are placed in a nursing home because they are dying; but conditions in the nursing home hasten the demise of others. It is difficult to see why terminally ill persons should live out their last weeks or days in these institutions. Surveys of what people would like their last days of life to be like find that they prefer to be in a comfortable, familiar environment with access to family and friends. Further, they would like to be free from pain and to have as much control as possible over what happens to them. Such is not to be found in the nursing home.

The recent spread of the hospice movement has provided a humane alternative to the hospital or nursing home for thousands of terminally ill persons. Analgesic medication and social support provide comfort while use of high-technology equipment that prolongs death is avoided. Family members, friends, and volunteers are able to provide much of the care, with a supportive team of physicians, nurses, social workers, and pas-
 tors. Although hospice care does not transform dying into a painless experience for the dying person or those emotionally tied to him, the contrast with death in a nursing home is stark. The dying person retains dignity and contact with loved ones; and family and friends know that their loved one was not abandoned to institutional care.

The humaneness of hospice care is sufficient reason to support the expansion of this alternative to nursing homes. But, in addition, studies show that hospice care is cost-effective relative to conventional care in a hospital or nursing home. Evaluations of the Medicare Hospice Benefit found that every dollar spent on hospice care saved Medicare $1.26.

Given that the probability of experiencing a disability greatly increases in later life, one might expect that rehabilitation programs would target older persons. This is not the case. The old are frequently viewed as poor candidates for rehabilitation, either because their prospects for improvement are considered weak or because work with younger persons is considered more cost effective. Such reasoning often is based on stereotypes of aging. Many of the functional problems of older persons can in fact be improved through rehabilitation programs. Studies of rehabilitation efforts directed to older persons experiencing stroke, hip fracture, and urinary incontinence confirm that geriatric rehabilitation can save money, increase independent living, and improve the quality of life. Among other things, appropriate interventions can reduce the number of candidates for admission to nursing homes where they would receive custodial care.

Nursing homes frequently offer rehabilitation services and, in an effort to avoid stigma, some have even changed their name to "rehabilitation center." However, an inspection of such centers reveals a serious truth-in-labeling problem. Offering token rehabilitation efforts, while continuing to operate as a long-term-care institution, does not accomplish the goals of real rehabilitation. Persons with disabilities who enter nursing homes are more likely to experience an increase in disabilities than to experience rehabilitation and greater independent living. How many current residents of nursing homes have the potential for significant improvement from rehabilitation therapy is unknown. But Peter Shaughnessy, Director
of the Center for Health Services Research at the University of Colorado, is surely correct when he writes: "Too often patients [in nursing homes] with weak to moderate rehabilitation potential are treated as chronic-care patients in something of a dependence-fostering rather than independence-fostering manner."

**Defund the nursing home**

The dehumanization of patients in nursing homes is nothing new. Ever increasing legislation passed by state and federal governments to improve conditions have made nursing homes safer but have failed to correct the fundamental problem—nursing homes are authoritarian institutions. Moreover, it is projected that if current policies persist, more than 40 percent of those reaching age 65 now will face the risk of entering a nursing home before they die. Many of these persons will experience financial catastrophe as a result of being institutionalized, and they will end their lives dependent upon welfare. The cost to tax payers of supporting the nursing-home industry is already burdensome. Maintaining the status quo over the next several decades would produce a large increase in the size of the nursing-home population and would require huge increases in government spending.

It is a mistake, however, to view nursing homes as either a natural or necessary way to care for dependent older persons. The nursing-home industry took its current form largely because of government support. The industry is sustained through lobbying efforts of the nursing-home industry and by our failure to explore the full range of possible options.

The time has come to pull the plug on nursing homes. Reform efforts have failed, and the human and economic costs of preserving these institutions are too great. The government need not pass legislation forbidding the construction and operation of nursing homes; if it would simply withdraw its support from them and transfer the savings gained to various alternatives, the nursing-home industry would die. Who would choose to pay $45,000 or more per year to live in a nursing home, or to put a parent in one, if the humane alternatives outlined above were available at no greater expense?