



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



LONG-TERM CARE FOR THE BOOMERS:

A PUBLIC POLICY CHALLENGE FOR THE TWENTY-FIRST CENTURY

February 1991

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared under grant #87ASPE1821 between HHS's Office of Family, Community and Long-Term Care Policy and Miami University of Ohio. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The email address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Paul Gayer.

LONG-TERM CARE FOR THE BOOMERS: A Public Policy Challenge for the Twenty-first Century

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February 1991

Prepared for
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Grant #87ASPE1821

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

TABLE OF CONTENTS

ABSTRACT	ii
LONG-TERM CARE DISABILITY.....	1
PROJECTION MODEL.....	2
POLICY IMPLICATIONS	3
LONG-TERM CARE SYSTEM.....	4
TECHNOLOGY AND LONG-TERM CARE	8
ETHICAL ISSUES SURROUNDING THE DELIVERY OF LONG-TERM CARE	8
DEVELOPMENT OF FAMILY POLICY	9
THE ROAD TO THE FUTURE.....	10
BIBLIOGRAPHY.....	12

ABSTRACT

Although the current difficulties in developing an adequate system of long-term care are extensive, they pale in comparison to the challenges ahead as the "baby boomers" come of age. To explore these issues this paper reports the results of research predicting disability among older people through the year 2020, focusing on the policy issues and challenges that will be associated with providing long-term care in the twenty-first century. Topics addressed include system structure and financing, the service and technology interface, the role of family, and ethical issues in the provision and allocation of long-term care.

Determining how best to meet the long-term care needs of an aging America has become a lively topic in aging and health policy circles. Ever increasing costs, concerns about quality of care, and the rising population in need of long-term care have clearly brought this issue to the forefront of public policy debate. A bipartisan commission, numerous legislative bills, considerable mass media attention and volumes of policy and research articles attest to the widespread concern about the long-term care difficulties in the U.S. Although the current problems faced in developing an adequate system of long-term care are extensive, they pale in comparison to the challenges ahead, as the "baby boomers come of age". To explore these challenges, this paper briefly reviews the results of research predicting disability among older persons up through the year 2040, then focuses on the policy issues and challenges that will be associated with providing long-term care in the twenty-first century.

LONG-TERM CARE DISABILITY

On any given day, the average person performs countless activities of daily life. From the morning shower to the midnight snack, our days are typically filled with tasks of life. Most of us rarely think about the effort required to complete these activities. Yet it is precisely these areas that constantly challenge those with long-term care needs. Research studies have consistently shown that the majority of long-term care services are provided to assist with tasks of daily living (Kemper et al, 1987). The ability to perform these functional tasks has been consistently identified as a critical factor affecting the need for long-term care (Branch, 1977; Greenberg et al, 1980; Applebaum and Harrigan, 1986). Thus, any discussion of future long-term care policy issues needs to begin with an understanding of the demographic changes that are anticipated to shape the care delivery system.

To project the size of the over 65 population expected to have long-term disability, a simulation model was developed (Kunkel and Applebaum, 1989). This work attempted to build on the estimation models developed in several previous studies (Manton and Liu, 1984; Rivlin et al, 1988; McBride, 1989). Each of these studies attempted to develop a baseline disability level for the over 65 population and then a projection model to estimate the size of future populations. This study varies from the previous works by combining two changes in approach. First, this study employs a model in which life expectancy and rates of disability can be altered over time, rather than using a constant model where the rates of disability and mortality are assumed to remain the same throughout the projection period. Second, this research treats the projection of long-term care needs as an issue related to, but separate from, where people live (whether in an institution or at home in community). Since the residential mix may change in the future, projections of need for long-term care should be separate from the issue of where and what type of care is currently provided. These estimates will then provide the basis for a policy discussion concerning the structure and delivery of long-term care in future decades.

PROJECTION MODEL

Estimating future rates of disability and mortality is unquestionably a speculative process. Numerous societal changes in a range of areas such as public health, medical technology, the environment, social structure, and the economy cannot be predicted, yet will clearly affect rates of disability and mortality.

Our assumptions for mortality used three of the Bureau of the Census assumptions about longevity patterns: a rapid improvement in life expectancy, a middle mortality assumption, and a slow improvement in life expectancy (Spencer, 1989). However, no such source was available for the estimation of future rates of disability. To develop estimates of future disability rates we completed a review focusing on the longitudinal studies of disability conducted in the United States and Canada (Verbrugge, 1984; Wilkins & Adams, 1983). Based on this review we identified three generic scenarios in predicting future rates of disability. First, there could be an Increase in the rate of disability, anticipated to occur as a negative by-product of increased longevity. A second scenario predicts a decrease in the rate of disability, anticipated as a result of effective preventive health practices, and technological advances in medicine and public health. A third scenario anticipates that future disability rates for the over 65 population would remain essentially the same.

Combining mortality and disability assumptions creates a number of possible scenarios that can be used to generate projections. This work reports on three diverse scenarios: 1) a constant model--with mortality and disability trends continuing under current rates; 2) a longer life/lower disability model--assuming faster improvement in mortality and lower levels of disability; 3) a longer life/higher disability model--assuming faster improvements in mortality and higher levels of disability.

Results of the model estimates are presented in Table 1. Numbers for 1986 indicate that about 2.6 million older people had a moderate disability and about 2.5 million were severely disabled. In the constant model, with no changes in current disability or mortality rates, the sheer force of population aging will result in 4.9 million older people estimated to have a severe disability by 2020; with another 4.8 million having a moderate disability. The longer life/lower disability model generates the lowest estimates of disability for 2020, predicting 4.8 million severely disabled older people and 4.6 million with moderate levels of disability. This represents an increase of about 84 percent, from the current 5.1 million to 9.4 million.

Estimates of the over 65 population expected to have a long-term disability in 2040 range from 14.8 to 22.6 million people. This compares to 5.1 million older people in that category today, (an increase ranging from 190 to 343 percent). Although the differences in the estimates generated by the models are considerable, what is most interesting is that the numbers generated under any of the models represent substantial increases. Regardless of the scenario projected, by the year 2040 when the baby boomers reach their 80's and 90's, there will be a massive number of older Americans with long-term care disabilities.

TABLE 1. Estimated Number (in millions) of Older People at Different Levels of Disability in 1986, 2000, 2020, and 2040 for Four Projection Scenarios				
Projected Year	Little or No Disability	Moderate Disability	Severe Disability	*Total Population
CONSTANT				
1986	24.1	2.6	2.5	29.2
2000	28.1	3.4	3.4	34.8
2020	42.4	4.8	4.9	52.1
2040	53.3	7.2	7.6	68.1
LONGER LIFE/LOWER DISABILITY				
1986	24.1	2.6	2.5	29.2
2000	29.7	3.1	3.2	36.0
2020	48.1	4.6	4.8	57.5
2040	64.1	7.5	8.5	80.1
LONGER LIFE/HIGHER DISABILITY				
1986	24.1	2.6	2.5	29.2
2000	28.1	3.9	4.0	36.0
2020	43.9	6.6	7.0	57.5
2040	57.5	10.6	12.0	80.1

* Due to rounding errors total may not match the sum of individual disability categories.

POLICY IMPLICATIONS

These projections present a critical challenge for a long-term care system that has already been subject to considerable scrutiny, particularly concerning financing and quality. When combined with other social and demographic trends, such as lower fertility rates and changes in the family structure, these estimates suggest that the challenges of providing adequate long-term care to an aging America are truly monumental. Given this scenario, what then are the policy issues that need to be addressed as the long-term care needs of the nation expand?

We have identified a series of critical policy issues that the system will face as the size of the population with long-term care needs continues to grow. Our discussion of these issues is organized according to the following major topics: 1) the long-term care system itself, including its current structure, methods of financing, availability of personnel, and regulatory and quality assurance efforts within the system; 2) the interface of long-term care needs with technology; 3) the role of family in the provision of long-term care services; and 4) ethical considerations. Although these issues are not new to the long-term care policy arena, they are magnified and reshaped by the projected demographic changes. This paper seeks to go beyond highlighting the importance of each of these issues by focusing on the need for a creative solution to the challenges of long-term care in the twenty-first century. Innovation and new ways of thinking about long-term care are absolutely necessary. Extrapolating from a cogent summary of problems in the financing of long-term care, we clearly see that "the fundamental policy question is whether we can come up with a system ... that is better than just multiplying the current unsatisfactory system by three or four" (Weiner, 1990).

LONG-TERM CARE SYSTEM

LTC System Structure and Financing. It has become almost a cliché to talk about the system of long-term care as an irrational "non-system" of care delivery. Although the current approach to delivering long-term care may not be rational, it is costly. With over 40 billion dollars spent on institutional long-term care and an estimated 8 billion on community based long-term care, long-term care expenditures have clearly become a primary component of federal, state and local budgets (Sabatino, 1989). The multiplicity of funding streams, administrative and regulatory agencies, and service providers means that is difficult for both the consumers and funders alike to master the system. Critics of the current structure consistently focus on the lack of service coordination.

Although there are a number of delivery system issues that arise when thinking about providing long-term care in the future, perhaps the most fundamental questions focus on the nature of the service delivery system itself. For example, what does adequate long-term care assistance to those in need actually look like? Do we provide care primarily in institutional or community settings? And how is this balance determined? How should accessibility to and receipt of a long-term care benefit be determined? How does the delivery of long-term care interface with the provision of acute health care? Despite numerous long-term care demonstrations and research projects, we know very little about how to deliver and allocate long-term care services. Although the answers to these questions are not clear cut, it is clear that such issues need to be addressed prior to the tremendous expansion of the population expected to experience long-term care needs. As the number of older people in need of long-term care doubles and then triples, and possibly quadruples, the development of a coherent system of care will be essential.

The limitations of simply multiplying our current system to account for the growth of the disabled older population is well illustrated by looking at nursing home utilization. In 1986, approximately 1.3 million older persons were residents of nursing homes (Schick, 1986). Considering that there were 2.5 million severely disabled older people in 1986, the nursing home figure roughly represents one nursing home bed for every two severely disabled older persons. Put another way, there were enough nursing homes beds for approximately 52% of the severely disabled older population. Use of such figures is somewhat limited, since not all nursing home beds are occupied by severely disabled older people; some moderately disabled older persons, and some younger people live in nursing homes. Despite the limits of such calculations, it is instructive to note that, in order to simply continue current nursing-home utilization ratios, we would need about 2.8 million nursing home beds by the year 2020, and 4.4 million by 2040. Keep in mind that the "1 for 2" ratio used in these calculations does not include the

moderately disabled older persons who might need institutionally based long-term care.¹

Financing institutional-based care for 1.3 million older persons is a problem today; it is painfully clear that current financing strategies and the current system of long-term care delivery will not be adequate for the approximately 8 million severely disabled older persons projected to need care in 2040. Without question the financing issue has dominated the recent long-term care policy debate. Continually escalating long-term care costs coupled with rising deficits have placed long-term care financing issues on the national agenda. At the heart of the debate is the ideological issue of who should be responsible for those with chronic disabilities? Is ensuring that each individual has proper long-term care an individual's responsibility or is it the responsibility of government? Clearly the same philosophical debate exists for acute health care as well.

The current long-term care system has used a mixed approach, relying first on the individual and then, following depletion of resources, the Medicaid program. Although debating the pros and cons of any health or long-term care funding strategy is common practice among policy analysts, there is little disagreement that the current funding mechanism is flawed, criticized for being both ineffective, and inequitable. The "all or nothing" system of support for institutional care, which requires individuals to spend almost all of their resources before governments' responsibility begins, is the source of concern. The system thus ensures that many older people live their final years as dependents of the state, despite the values and preference for independence, or at least shared independence expressed by the majority of the population, (GAO, 1977; Weiner, 1990; McConnell, 1990). The nature of this eligibility process encourages inequity. Some decide that since they will require Medicaid support they should transfer or shield assets, while others use all of their resources prior to Medicaid utilization. In fact an army of attorneys and financial planners have appeared as more and more of the population understands the nature of the current system of funding long-term care. Other typical financing horror stories have focused on the restrictive nature of Medicaid, which prior to recent legislation required spouses in some states to divorce their dependent spouse in order to avoid poverty.

Although there is wide agreement that the current system is not acceptable, there is a lack of consensus on solutions. Proponents of an increased national role have proposed expanded long-term care coverage, financed by the federal government. Critics of this approach believe that such a plan is too expensive and would add more expenditures to an already costly system. Thus, the suggestion that the development of private insurance coverage is the appropriate response. The policy challenge is compounded by the need to not only develop a system for today, but for tomorrow's needs as well. Given the budgetary struggles of 1990 this may be an insurmountable task for the current polity.

¹ These figures are based on the "best guess" assumption of improved life expectancy and moderate increases in disability levels.

LTC Personnel. Current providers of long-term care have begun to discuss a growing service delivery problem: a shortage in the supply of paraprofessional workers. Both nursing homes and home health providers have identified difficulties in the recruitment and retention of those individuals responsible for providing the personal care to those with long-term care needs. Because personal care assistance dominates the long-term care needs of the chronically disabled person, staffing challenges have serious implications for both quality and cost of care.

As is the case with employees in any area, the supply of workers is affected by two major factors: 1) the demography of the labor force, and 2) the nature of the economy and the work environments it engenders. Brannon and Smyer (1990) describe the changing labor force as older and more diverse. "Over 80% of the net labor force growth during the next 10 years is projected to come from three sources: women, minority youth, and immigrants" (Brannon and Smyer, 1990:64). Clearly long-term care employers must face the challenge of attracting and retaining employees from among these groups.

One of the factors that will influence the competitiveness of long-term care employers is the nature of other employment opportunities. In a service economy with increasing competition for skilled workers, long-term care employers have an opportunity to provide an appealing work setting for non-skilled workers (Brannon and Smyer, 1990). In order to realize such an opportunity, long-term care employers must enhance several aspects of work life, including wages and benefits, working conditions, the nature of the work, status of the job, ability to advance, opportunity for other jobs, and the intrinsic value of performing the work task. Many of the factors affecting long-term care workers and the workplace are influenced by long-term care policy. For example, reimbursement rates have a direct effect on salary and benefits. Regulatory requirements affect the tasks, activities, levels of supervision, and work load of long-term care employees. Opportunities to advance and perform new and varied tasks are also affected by regulatory activities.

Critics of the existing system suggest that efforts to enhance the quality of work-life is minimally emphasized in the long-term care field. For example, wages for nursing home and home health aides are low. A recent study commissioned by the Older Women's League, indicated that the median wage for home health aides in the U.S. was four dollars per hour (OWL, 1988). Employee benefits such as health insurance, vacation or sick time, and training support are typically not available for paraprofessional long-term care workers. Workers also report a number of on-the-job frustrations; a lack of control over rules, staffing shortages, poor training, resistive or hard-to-care-for clients, and an unsafe work environment (Canalis, 1987).

Thus, in looking at the provision of long-term care we see that the work of the paraprofessionals, while a key component in delivering successful long-term care, has not been highly valued. Combining these employment conditions with a reduction in the fertility rate and more competition for service industry employees has resulted in reported shortages of long-term care workers. States with low unemployment rates

appear particularly challenged by recruitment and retention problems. Given the projected rates of disability and projected changes in the labor force, it is clear that issues of personnel supply will accompany the policy issue of financing as a dominant future issue. A number of public policy issues ranging from long-term care reimbursement and regulation to immigration policy will influence personnel needs in the future. Once again, exactly how these public policies should be shaped is not clear; however, it is clear that the projected size of the disabled population, combined with anticipated shortages of workers, will necessitate a coherent policy.

Quality Assurance and Regulation. Efforts to regulate and ensure the quality of care have become a dominant theme in long-term care service delivery. Independent quality commissions, revised survey and certification procedures, new training and regulatory requirements, and alternative reimbursement approaches have all received considerable attention in recent years. For those working in long-term care, the term "OBRA regulations" have become the most widely spoken words in the field. Despite this keen interest in assuring quality, the provision of long-term care, particularly institutional care, remains subject to a substantial amount of criticism. Responses to concerns about quality have resulted in increased regulatory activity in the long-term care arena. Coupling the current regulatory environment with the projected increase in those needing long-term care creates some interesting questions concerning future quality assurance efforts.

The current approach to assuring the quality of long-term care has been characterized by a hierarchical strategy, dominated by a series of structural regulations developed and enforced at the federal and state levels. Under this approach, a series of rules and regulations have been developed as the primary mechanism to ensure that care is of high quality. In both institutional and home health care an annual survey, designed to enforce the array of regulations, has been the cornerstone of the quality assurance strategy.

Our efforts to regulate nursing homes provide the bulk of experience on this approach. Despite the intense regulatory environment, criticism of the quality of nursing home care is considerable. Changes in structural areas, such as fire safety and personnel training have contributed to some industry-wide improvement in conditions. However, these efforts do not seem to address many other aspects of long-term care that are important to the quality of the care recipient's life. Thus, we are left with a highly regulated system that remains the subject of almost daily criticism from consumers, advocates and regulators themselves.

As we look to the future it is clear the number of older people receiving formal long-term care services, whether in an institutional or community setting will continue to increase. Given current difficulties in the states' ability to adequately staff such regulatory efforts, questions about future capacity are certainly appropriate. For example, a study of the home health regulatory system in California reported that in 1988, only 7 percent of currently licensed home health agencies received their annual surveys (Harrington & Grant 1990). As more providers are added to the system and if

improvements in staffing are made to address the personnel shortages currently experienced, it will be necessary to add a large number of new workers to sustain the regulatory system as it now stands. However, experience suggests that such a regulatory strategy, while costly, does not appear to assure quality of care for long-term care service recipients. Thus, it is clear that the expansion of the long-term care delivery system will need to be accompanied by an alternative view of how to provide and ensure the quality of care provided.

TECHNOLOGY AND LONG-TERM CARE

Although the increase in the proportion of the over 65 population experiencing a disability is substantial, it is likely that in the future technological advances will help provide some of the long-term care assistance needed. Robotics, "smart houses", continued refinement of prosthesis, specialized medical equipment, and other such developments are appearing on the scene in 1990. For example, combining voice-activated personal computers with robotics has been a recent development that is allowing disabled people to complete many functions of daily life without assistance. One can only imagine innovations that could exist by the year 2020 and beyond when George Jetson needs long-term care.

The development of new technology has both potential benefits and limitations. If technology can be developed to maximize independence and enhance individual and family interactions, it could provide a key element of the solution to the long-term care challenges. If, however, mechanical support and interaction becomes a substitute for human interactions, such innovations could serve to further isolate the population experiencing disabilities. The increase in the proportion of older people expected to need long-term care assistance will create an environment in which we are likely to attempt to reduce the number of personnel needed to deliver long-term care. Whether long-term care can be restructured such that technology can support the key elements of good care, rather than substitute for it, will be the key policy challenge in this area. Thus, it is clear that a practice and policy interface with those developing new long-term care technology will be essential.

ETHICAL ISSUES SURROUNDING THE DELIVERY OF LONG-TERM CARE

Spurred on by major changes in medical technology and increases in life expectancy, ethical issues surrounding the provision of care have come to the forefront of health and long-term care policy. Ethical debates initially focused on whether terminally ill individuals should have the right to refuse medications or resuscitation assistance. This issue was then extended to question whether life support or life sustaining nutrition could be removed. Recently, the ethical dilemma has moved to a

new plane; should individuals have the right to take their own life or the life of a physically ill or cognitively disabled loved one? Cases of mercy killings and the more recent "suicide machine" are examples of this next level of end-of-life ethical issues.

In addition to individual or case-by-case ethical issues, a series of policy questions addressing the delivery of health resources have been raised. For example, the book Setting Limits (Callahan 1987) received considerable attention because of its suggestion that a mechanism for rationing the resources allocated to health care should be implemented. The book suggests that age should be used as the primary criterion to allocate health resources and benefits. Recent policies in the state of Oregon, which attempt to control high cost benefits such as organ transplants for the medically indigent under the Medicaid program, have shifted the rationing debate to the state policy arena. High resource expenditures occurring near the end of life, coupled with concerns about inadequate funding for health coverage for all age groups, particularly children, have created the impetus for this rationing-of-care debate.

The ethical discussion in 2020 may move to a different level. It is quite possible that our ethics debate of the future will focus on whether the receipt of long-term care is an individual's right. Rather than the current debate about whether and when we should limit life-saving or life-sustaining acute care, the issue may very well be whether we should limit the receipt of long-term care. Based on 1990 philosophy, the "ethical" question of 2020 might be: Can we afford to provide long-term care to this large number of older people when other age groups of the society are facing serious resource constraints?

DEVELOPMENT OF FAMILY POLICY

Research has identified the critical role that families play in the provision of long-term care. Described in a number of state and national surveys and demonstrations (Applebaum 1988) data indicate that families and other informal caregivers provide a considerable amount of care to older people experiencing chronic disabilities. For example, about three quarters of the 5.1 million older persons with a chronic disability reside in the community, and approximately half of the 2.5 million severely disabled older people reside in the community. With a level of disability that is similar to those residing in nursing homes, these severely disabled older people are able to remain in the community through a combination of family caregiving and formal services.

Family and friends provide a considerable amount of care, but this delivery of long-term care also presents major challenges and costs for the family. Women, who have provided the majority of long-term care in this country, are now more likely than ever to work outside the home. Discussions concerning the sandwich generation--women caught between jobs, children, and older parents--have become common in both the gerontological literature and the mass media (Brody, 1987; Newsweek, 1990). Adult children provide a significant amount of caregiving; spouses and adult children combined provide approximately 80% of the daily care received by older adults.

Seventy-five percent of family caregivers are women, and these women often find themselves in precarious financial and health situations. An estimated one-third of women caregivers are categorically poor, and about one-half are in poor health (Shields and Summers, 1988). The tremendous burden of unrelieved caregiving is clear from such statistics, and is painfully illustrated by the testimony of women who are in these situations. It is obvious that any long-term care system must find a way to support family caregivers in their efforts. Beyond the difficulties of fulfilling that role on a day-to-day basis, the health and financial deficits that caregivers bring into their own old age are of enormous consequence for our long-term care system. Women who have forfeited financial resources and health in order to provide care will themselves have great long-term care needs.

In the future, families will likely remain heavily involved in long-term caring. However, several social and demographic factors will continue to place pressure on family care-giving. It appears that the trend of two-worker households will continue. This development will increase pressure on both families and employers to develop a work style and benefit packages that allow for the longer time commitment that long-term care for an older family member may represent. Compounding this challenge are reduced fertility rates. In the 1970's and 80's; for example, the 1984 total fertility rate of 1.8 children per woman was half of the 1955 figure of 3.6 children per woman (Weeks, 1989). Obviously these fertility changes will result in a smaller pool of potential family caregivers. Combining these factors with continued expectations about longevity and disability suggests that the sandwich generation may become the pancake generation; flattened by the pressures from both sides.

Recent discussion surrounding family policy has become prominent public policy debate. Issues such as leaves for family members to deal with caregiving at both ends of the age spectrum, employer flexibility in the structure of the work place, employer day care for a range of ages, tax credits or incentives for caregiving, and expanded community service coverage for respite and home care, are all examples of proposed policy recommendations. Questions surrounding both specific policies and the proper role of government in the development of these policies will continue. Although the options are varied, the need to develop a coherent policy to support family involvement in long-term care is quite clear.

THE ROAD TO THE FUTURE

Policy analysts have discussed repeatedly the incremental nature of public policy development in the United States. We are continually reminded that the U.S. has lagged behind the rest of the industrial world in its efforts to develop public policy on retirement, health care, and other critical policy areas. Unfortunately, there is no evidence to suggest that long-term care challenges will inspire an alternative policy development process. However, if there is one consistent theme of this analysis, it is that the demographic challenges are so critical that the need for a coherent and long range policy is paramount. The projections, which call for a doubling of the long-term care

population by 2020 and a tripling or quadrupling by 2040, are quite real. In fact, all of the people included in these projections have already been born. The question that we now need to ask is whether the incremental system can develop a policy strategy with a time line that extends beyond the next congressional election. The irony is that future long-term care needs for the generation of boomers, who are accustomed to immediate gratification, will rely on a longer range planning process than we have ever been able to implement or even conceptualize as a nation.

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