Defining Common Ground: Long Term Care Financing Reform in 2001

Citizens For Long Term Care

The following organizations are members of Citizens For Long Term Care’s Board of Directors. As the guiding forces behind this paper they actively support and affirm its conclusions.

- AARP
- Aetna Insurance
- Alzheimer’s Association
- American Association of Homes and Services for the Aging
- American Health Care Association
- The Arc of the United States
- National Association for Home Care
- National Committee to Preserve Social Security and Medicare
- Service Employees International Union

BACKGROUND

As a United States Senator from 1978 to 1995 I was privileged to serve for 16 years as a member of the Senate Finance Committee and, for two years in 1989-90, as a Vice Chair of the United States Bipartisan Commission on Comprehensive Health Care, which was tasked with reforming access to acute and long term care for all Americans. Named for Representative Claude Pepper, the nation’s champion for the aged and people with disabilities, the Pepper Commission affirmed the need to use an insurance-based system to reform the financing of long term care.

In the 10 years since the Pepper Commission released its report, A Call to Action, our population has gotten older, disability has increased, and care has become more expensive. Yet no one has responded to A Call to Action. Our national debates over Social Security and Medicare reform ignore long term care financing just as most people ignore it in their private lives until a loved one needs supportive care.

In 2001, a new Congress and a new President provide unprecedented opportunity to make a commitment to reform long term care financing. As is often observed about the election of 2000, “Americans live in times of unprecedented prosperity.” But the election also underlined a sense of unease on the part of our people about the future. The unease comes for many people, in large part, from the knowledge that their economic resources are insufficient to provide extended care in the face of a debilitating incident or health condition. This is best reflected in the generation of Americans born in the years immediately after WWII, referred to as the Baby Boom generation. Most “Boomers” have parents whose retirement savings and security are beyond that of any previous American generation, but whose medical and long term care needs have the potential to eat quickly into the value of that savings and security.

Throughout the last 65 years we have developed a system of social commitments, such as insurances, tax incentives, and health programs which were designed to assist people ensure their financial and retirement security. Unfortunately, long term care, which today poses a real and significant threat to that financial security, has never been integrated into our policy debates on individual financial or national economic security. Ninety percent of Americans are insured against medical expense and only 6% against long term care expenses. In our financing systems, both private and governmental, resource allocations favor acute medical needs over long term disability. Despite more deaths from chronic disease than acute incidents, Medicare still is geared towards providing coverage for acute illness rather than chronic or long term care.

As the great mass of our population ages we are witnessing rising speculation about the nation’s financial security programs’ ability to fulfill their promises. This speculation is the combination of fairly predictable demographic and cost impacts that will severely constrain those public policies built in the 1930’s (Social Security) and 60’s (Medicare/Medicaid) that were meant to help support financial security among our elderly. People living longer with more chronic illnesses, coupled with an increasing number of people under 65 utilizing long term care supports and services, demands we address long term care financing as a key component of the financial security, Medicare and Social Security reform debates.

Given all of this, over sixty of the major national associations of long term care providers, insurers, and patient advocacy groups representing aging and disability concerns began
meeting in 1998–99 in a search for common ground on which to build a national mandate for change. I was asked to chair the effort and together we created Citizens For Long Term Care in April 1999. CLTC began with common ground on a set of principles, which should characterize a system of long term care that would benefit all Americans.

Since July 2000, representative members of CLTC have been meeting together to find common ground on financing policy solutions. We rejected a consolidation of existing long-term care funds into a distinct long-term care program funded either publicly or privately. The delivery system that comes closest to assuring the principles on which we have agreed is one in which goods, services, innovations in professionalism and practice are constantly evolving. Only markets that support people making advanced financing decisions and personal choices in time of need meet these criteria.

The financing system that best optimizes market performance and evolving services while supporting people to make advanced decisions is an elaboration of the employment-based income security system that has evolved in the United States through the 20th century. Not all employment is equal, and as a result, people have different resources and capacities to provide or pay for care. For that reason, CLTC advocates a base of financial support in the social insurance system to which every American contributes with their first paycheck. But with that first job should also come an opportunity and responsibility to invest in private insurance supported by judicious tax incentives to protect both earnings and savings capacity from an early life or aged related disability.

The transition from a Medicaid based assurance for Americans to a social/private insurance security system built over a lifetime will require time. The impact of shifting tens of billions of dollars from the federal/state Medicaid program to a program of social insurance and tax subsidies has intergovernmental consequence. That is why the leaders of America’s long term care associations believe all Americans, not just elected representatives, must be part of the solution; therefore, CLTC calls for a national dialogue to advance this issue led by the President of the United States.

A Congressional commission is not a national dialogue. Not since the Social Security crisis of 1983 has a bipartisan commission’s recommendations been converted to popularly supported legislative actions. For example, the Pepper Commission’s 1990 recommendations were totally bipartisan and nothing happened. The National Bipartisan Commission on Medicare in 1998–1999 was bipartisan and it fell apart—not only failing to enact change but also refusing to include long term care in its recommendations.

The President of the United States must use the powers of the Presidency to focus attention on the need for this critical reform. The power of presidential leadership can be seen in our debate over a prescription drug benefit for Medicare. Only with similar leadership can we expect to help the tens of millions of families that are coping with the devastating costs of long term care.

In releasing this paper Citizens For Long Term Care and its members stand ready to work with our new President, members of the 107th Congress, and with Governors and Legislators from the 50 states. Together we can work to educate and inform America about the need for long term care financing reform. Together we can help to safeguard the financial and retirement security of tens of millions of Americans. Together we can help protect the elderly, people with disabilities and the chronically ill. Together we can find a better way.

Chairman,
Citizens For Long Term Care

INTRODUCTION

Many of life’s most critical hazards are those that unexpectedly reduce the sources of income, significantly strain one’s financial security or greatly affect one’s health. Saving for retirement or protecting one’s financial security during working or younger years is subject to all kinds of events or risks. Many events, like the cost of college tuition, can be planned for. But some risks, like an accident or a birth related impairment or the onset of a chronic disease, which can necessitate years of costly care, are not expected nor very often planned for. During retirement, events such as higher than expected inflation, longer than expected life or the need for long term care can impede the best of plans and threaten financial and retirement security.

What has emerged to help families protect financial security is a base of social insurance, upon which private insurance and publicly encouraged deferred compensation arrangements have been built. For most people, financial security is principally derived from earnings and then Social Security, Medicare, employer-provided pensions and benefits, and savings, all of which seek to help protect individuals and families from unexpected risks associated with health care or loss of income. Most of this structure is for workers and their dependents; however, there is a safety net of public assistance both for those workers who were unable to adequately save or acquire insurance and for those who did not or could not work.

Unfortunately, long term care has never been factored into these programs as a possible threat to financial security. As the numbers of people who are elderly or disabled increase, more people will face greater risks to their financial security from long term care costs. Citizens For Long Term Care believes that this gaping hole in our system of ensuring financial security needs to be addressed.

Of the more than 42 million Americans of all ages who have a disabling condition, over 12 million are dependent upon others for basic tasks such as eating, bathing, toileting, dressing, and getting in and out of bed (Adler, 1995). An estimated 11.5 million Americans perform these daily caregiving services for family members with little financial or community support. Although many people assume that these long term care support services are only required by the elderly, about 45 percent of the long term care population is under age 65.

1The more than 42 million Americans is based on a broad definition of disability, defined as difficulty with certain activities, such as attending school or walking, due to a physical or mental health impairment. The 12 million Americans is based on those who need help with basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs).
People of all ages are at risk for not only having a family member in need of long term care, but also of needing assistance from others themselves as a result of illness or injury. Although the need for health insurance to cover a patient’s medical expenses in case of catastrophic illness is widely recognized, few people are insured against the costs of providing long term support services for that same person.

The current system of financing long term care has not worked well for those who need supportive services, nor for the family members who often act as caregivers. As biomedical advances extend life for the elderly and people with disabilities, the physical and financial burdens of long term care will only increase. In relative terms, there will be fewer adult children to care for elderly parents. Further, employers will see an increasing number of their employees struggle to balance caregiving responsibilities with work.

For the past 60 years, Americans have relied on a combination of social insurance and private means to pool risk and support financial security. The basis for our social insurance programs and most of our private means of pooling risk and enhancing financial security is tied to employment. Social Security, including the life and disability insurance portions of Social Security, and Part A of Medicare are earned rights derived from employment for the worker or the worker’s dependents. Most private insurance is organized through group purchases made by employers on behalf of their employees and their dependents. Relatively common employer-provided benefits include health insurance, disability insurance, and life insurance. Retirement income is also enhanced through employer-provided pensions and deferred compensation plans such as 401(k) type arrangements. These employee benefits as well as many individual savings plans are further encouraged by preferential tax treatment.

Thus, the American approach to pooling insurable risks and protecting financial security has been a combination of social insurance and tax encouraged private insurance. Clearly, there are gaps in these arrangements as well as gaps between these arrangements. Savings are used to bridge these gaps. In the absence of sufficient savings, public assistance is usually available. Public assistance benefits are targeted to those in specific categories with the least financial means.

Unfortunately for those who need extended long term care services, public assistance remains the primary financing mechanism. It is time for a national dialogue on reforming the financing of long term care. Citizens For Long Term Care, representing 63 diverse organizations, has come together in agreement over the need for reform and the principles that must guide reform efforts. The organizations that comprise Citizens For Long Term Care represent insurers, providers of institutional care, providers of home-based and community care, professional caregivers, family caregivers, and people who need long term care, as well as people who do not yet need such care.

**PRINCIPLES TO GUIDE LONG TERM CARE**

Upon its inception in 1999, Citizens For Long Term Care member organizations agreed upon a set of basic principles which would shape the development of an ideal long term care system. We believe that all efforts to enact change must incorporate and reaffirm our basic principles.

**Independence**

Services should promote individual dignity, maximize independence and self-sufficiency, and be provided in the least restrictive setting possible, and reflect the overwhelming preference of individuals to remain at home.

**Choice**

People should be able to choose from a full range of home, community-based, facility-based health and social services so they can get the types of services that will meet their individual needs and preferences.

**Role of Families**

The central role families play in planning for and providing long term care should be recognized and supported.

**Access**

People of all ages and income levels should have access to long term care services and supports.

**Eligibility**

Eligibility for services should be based on functional criteria and social needs that take into account cognitive, physical, and behavioral limitations and the need for support, supervision, or training.

**Financing**

Costs should be spread broadly and progressively, so that out of pocket costs are affordable. This goal may involve tax policy, Social Security, Medicare, Medicaid, private health insurance and pensions, social services and housing policies. Both public and private financing mechanisms should be strengthened toward this goal.

**Accountability**

Systems for assuring the quality of care should be built into all long term care programs. These systems should assure quality and value based on outcomes and consumer protections enforced through appropriate government regulations.

**Standards**

The highest standards of professionalism and quality are essential for caregivers and systems. This must be supported by thorough training, appropriate supervision and fair compensation.
Coordination

Systems should coordinate services for people with multiple needs that change over time, providing a seamless continuum of care.

Efficiency

Incentives and controls in public and private programs must maximize quality and control costs.

I. BACKGROUND

What Is Long Term Care?

Long term care, services, and supports encompass a broad range of assistance to people who need ongoing help to function on a daily basis. These services may range from assistance with daily activities such as bathing, dressing and eating to more complex services such as meal preparation, shopping, money management, medication management, and transportation. Long term care represents the extra set of eyes and hands necessary for dependent persons to function from day to day. Long term care is integral to the lives of those who are frail, cognitively impaired, disabled, or whose chronic illness requires supportive care.

People who need long term care may also require a variety of medical services such as preventative, primary and acute medical care or rehabilitation services, such as occupational, speech and physical therapies.

Long term care cannot be relegated to specific hours or days of the week or to fixed settings. People who need long term care need to receive the care in the setting where they live, and may move frequently between home, hospital and nursing facility while others receive long term care in one place for a long period of time.

Citizens For Long term Care believes that the organization and delivery of long term care must be based on a desire to ensure that those needing assistance can maintain the highest quality of life, according to their preferences, with the greatest degree of independence, autonomy, participation, personal fulfillment, and dignity.

Who Needs Long Term Care?

Over 12 million people of all ages need long term care. The risk of needing long term care increases with age, but 46 percent of the long term care population is under age 65. Children (ages 5–17) who need long term care account for 3 percent of the long term care population (see Figure 1).

The majority—87 percent—of the long term care population resides in the community. The scope and extent of their needs are diverse, however. Among the 10.2 million adults age 18 and older residing in the community, almost 60 percent need help from another person to perform basic activities of daily living (ADLs) including eating, bathing, dressing, toileting, and getting in and out of bed. The remainder of the population residing in the community needs help with instrumental activities of daily living (IADLs) only, such as shopping, managing money, and housekeeping. Almost all of the adults residing in institutions need help with ADLs.

Who Provides Long Term Care?

An entire “community of caregivers” including family and friends, community supports, and paid direct-care professionals struggle to organize, coordinate, and provide long term care. But families are clearly the heart of the long term care system, providing unpaid care to 63 percent of adults needing long term services. About 22 percent of adults receive care from a mixture of unpaid and paid providers, while 7 percent of the long term care population age 18 and older rely exclusively on paid assistance. (see Figure 2). The task of caring for

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*In an effort to move away from the “care” model and towards one that emphasizes independence, the disability community uses the phrase “long term services and supports” instead of long term care.

*People with long term care needs receive or need help from another person with one or more of the following activities of daily living (ADLS): walking, getting in or out of bed or a chair, bathing, using a toilet, dressing, and eating; and/or people who because of a health or physical condition have difficulty with and receive need help from another person with at least one of the following instrumental activities of daily living (IADLS): preparing meals, shopping, managing medication, using the phone, light housework, and getting outside of walking distance.

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Fig. 1. The Long Term Care Population, 1995.

Fig. 2. Percent of adults age 18 and older receiving long-term care assistance in the community, by paid and unpaid providers, 1994.
a person with a disability, the frail elderly, or someone who is chronically ill is an emotionally and physically challenging job. In addition to the skills necessary to complete one’s job, the caregiver must possess a level of patience and understanding that helps them treat society’s most vulnerable with the dignity and respect they deserve. For parents in some states, the challenge of providing care is magnified when they find that they must give up custody of their children in order to obtain assistance for them.

**Families and Friends Are Critical**

Family members provide most long term care, particularly spouses, daughters, and daughters-in-law (see Figure 3). Most people who need long term care rely on one or two key family caregivers, but there are often other family members involved in ancillary aspects of caregiving. In 1997, the value of informal caregiving was estimated at $196 billion, compared to $83 billion for nursing home care and $32 billion for home health care.6

Among the long term care population age 15 or older living in the community, spouses and adult children were the key caregivers, providing some 65 percent of the unpaid care received by those in the community. In 1994, an estimated 120 million hours of care were provided by more than 7 million family members to elderly people that need long term care (R. Stone 2000). More than 3.9 million family members provided assistance to people under the age of 65 who need long term care.

One-third to one-half of primary family caregivers are also employed outside the home. Working family caregivers provide care an average of 18 hours a week, while struggling to meet the demands of their work and other family obligations.7

**Paid Professionals**

Direct-care workers provide the majority of paid long term care. Paid workers include registered nurses, licensed practical nurses, as well as certified nursing assistants, qualified medical aids, personal assistants and other direct support professionals who deliver care and assistance in facilities and as at home care workers. Of the 2.2 million workers in long term care, some 1.9 million are women, which often makes them more susceptible to injury from the physical rigors of providing care.

In addition, professionals that provide skilled care often do not receive the same status or value as professionals in acute care medical professional-patient relationships. The American medical model, which favors acute care and sub-specialty emphasis, prioritizes technological and professional values in ways that are detrimental to the values and the professional skills required for long-term care. Too often, patients needing long term care develop relationships with institutions instead of medical professionals.

Some groups are concerned that improved financing of professional caregiving will crowd out family members’ unpaid caregiving, and increase the strain on an already overloaded system. Evidence shows that although public financing does change how unpaid caregiving is organized, families tend not to decrease the amount of care they provide. Furthermore, even though current public financing of home and community-based long term care is greater than it has ever been, family members today are providing more care for longer than families have ever needed to in the past (Tennstedt, 1999; D. Stone, 2000; and R. Stone, 2000).

**How Is Long Term Care Financed?**

Long term care, which includes nursing home and other facility based care, home health care, home and community-based waiver services, and personal care, is financed through a wide mix of public and private sources (see Figure 4). Public financing, which funds 62 percent of all services, is delivered through Medicaid, Medicare, state programs, the Veterans Administration, and the Administration on Aging. Private financing includes private insurance, philanthropy and out-of-pocket payments by individuals and families in need of care.8

Medicaid, the largest public payer of long term care services, accounted for 45 percent of all long term care expenditures, 46 percent of nursing home revenues and 38 percent of home care revenues in 1998. Some 73 percent of Medicaid’s long term care expenditures, however, are for nursing home care. Medicaid expenditures for long term care have

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6(Arno et al., 1999).
7The NAC/AARP Family Caregiving Survey (1997) found that 54 percent of employed family caregivers have made changes at work to meet their caregiving responsibilities.
8National income estimates of private expenditures include home health care only. Excluding the value of personal or custodial care at home dramatically understates individual out-of-pocket expenditures, since it is personal care that is the bulk of paid long term care provided in the community.

**Fig. 3.** Relationship of the care provider to people age 15 and older receiving personal assistance.
grown substantially in recent years, largely due to a growing elderly population.\(^9\)

Medicare is often described as the second largest public payer of long term care, financing 16 percent overall. Medicare finances 12 percent of all nursing home care and 27 percent of all home (health) care. Medicare's coverage of long term care, however, is tied to a patient's need for skilled services which only covers care in a licensed skilled nursing facility subsequent to a hospital discharge. These payments are limited by law to short term post acute and rehabilitative services. In the strictest sense they do not truly represent long term care because they are time limited as opposed to ongoing. When a person living at home requires skilled service, Medicare covers only chronic care and supportive services incidental to the need for a skilled service.

The largest source of private financing and the second largest source overall are the individuals' families. Families financed 27 percent of long term care out of pocket in 1998. Altogether, payments from families account for 15 percent of home care revenues and 32 percent of nursing home revenues.\(^10\) Private long term care insurance finances less than 7 percent of long term care.

### II. WHY FINANCING REFORM IS NECESSARY

At a national average cost of more than $4,500 a month, the cost of a short stay in a nursing home or other facility exceeds the monthly income of most Americans, especially those no longer able to work. A long stay in a nursing home, other facility or a similar period of in-home care can easily consume a lifetime of savings or prevent the accumulation of savings in the case of families where a child has a significant disability. Extensive use of home and community-based services can easily rival the cost of care in a nursing facility. Families exhaust themselves physically, mentally and financially to provide care at home often turning to a nursing or other facility when they are no longer able to provide at home care. As a result, more than 85 percent of long term care is either publicly financed through public assistance, primarily Medicaid, or directly out of the pockets of those who need help and their families (Feder et al., 2000). As our population rapidly ages, we are faced with the potential for long term care costs to explode. We must act now to help protect the financial security of families and the economic security of the federal and state governments. Additionally, financing reform will dramatically improve the delivery and quality of care.

#### The Consequences of Fragmented Financing

The current system of financing long term care through a blend of public, private and out-of-pocket payments is inefficient and inequitable. Financial assistance is often contingent upon impoverishment, but not every American who is impoverished is eligible for assistance. Furthermore, the type and amount of assistance varies. Someone eligible for Medicaid in one state may not be eligible in another, and two people eligible for Medicaid in the same state with the same level of functional impairment may not be eligible for the same services. Extensive use of home and community-based services can easily rival the cost of care in a nursing facility.

Another consequence of this fragmented system is that one in five adults with long term care needs—about 2 million people—report that their needs are unmet, often with serious consequences (Feder et al., 2000). Although over 361,000 people with mental retardation or developmental disabilities are receiving residential services, there are about 66,250 people on a waiting list for these services (Prouty and Lakin, 2000).

Our patchwork long term care system has resulted in a confusing array of choices that rarely match families' needs. Families are forced to do the best they can with poor information and often-imperfect sources of professional assistance. In addition to shouldering a heavy financial and emotional burden, families must undertake a massive on-the-job education in organizing and delivering long term care to their loved one.

#### Impoverishment Bias

With individuals paying such a large portion of long term care costs, it is not surprising that many people are nearly impoverished by the health care needs of a family member. About one-third of discharged nursing home residents and one-half of current nursing home residents entered as private pay residents but spent down to Medicaid (Weiner et al., 1996). Individuals who are eligible for Medicaid are forced into a lifetime of impoverishment in order to continue receiv-

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\(^9\)The elderly population has more than doubled since the time Medicaid was first enacted.

\(^10\)Some of this out-pocket spending may be attributable to those on Medicaid. Medicaid beneficiaries in nursing and other facilities are able to retain about $30 a month for their personal needs. The rest of their income, including Social Security and Supplemental Security Income, is turned over to the facility.
Fig. 5. Medicaid spending for long term care, 1990 and 1997.

ing assistance. This double-bind leaves families in an extremely difficult position, especially families with a younger disabled person.

Institutional Care

While Medicaid must cover nursing home care, states are not required to provide home or community-based care (other than home health care). State Medicaid programs can choose to provide personal care as a statewide benefit or to establish a home and community-based program under a Medicaid “waiver.” A waiver allows a state to experiment with specific program designs and also target assistance to either a particular category of Medicaid eligibility or a limited area in the state, or both. All states have one or more Medicaid waiver programs, but only 30 states and the District of Columbia have elected to provide statewide personal care to their Medicaid beneficiaries (Doty, 2000). Coverage under the personal care benefit is often limited and insufficient to remain in the community.

Nevertheless, Medicaid spending on home and community-based care services has increased substantially since 1990. Most of the growth has been directed at younger persons with disabilities, especially those with mental retardation or developmental disabilities (Wiener et al., 2000). In 1997, some 77 percent of total spending for Medicaid home and community-based waivers was for people with mental retardation or developmental disabilities, compared to 21 percent for the aged and elderly disabled populations (Harrington et al., 2000). As a result, the proportion of total Medicaid spending for intermediate care facilities for people with mental retardation or related conditions (ICFs/MR) has declined substantially (Figure 5).11 For the elderly, however, more than half of the growth in home and community-based expenditures occurred in four states. (Wiener et al., 2000). Thus, for people who need long term care, the one option that is available through Medicaid in all states is nursing home care.

III. THE DEMOGRAPHIC IMPERATIVE

Demographic trends indicate that in the future more people will need long term care, and that relatively fewer people will be available to provide this care. Longer life expectancies have resulted in the need for long term care at all ages for longer periods of time. Current difficulties in locating, organizing, and paying for long term care will only be exacerbated by the aging of our society.

Disability Rates

The Elderly Population

Disability rates among the elderly have declined.12 However, a growing absolute number of elderly people, coupled with increasing life expectancy, means that the number of people who need assistance is expected to increase. Projections of the number of elderly persons needing long term care by 2030 range from 10.8 million to almost 14 million (Friedland and Summer, 1999).

The Non-Elderly Population

On the other hand, disability rates for children and young adults have risen considerably since 1990. Before 1990, however, disability rates for both groups remained steady for two decades. Among children under age 18, disability rates increased from 5.6 percent to 7.9 percent for boys, and from 4.2 percent to 5.6 percent for girls between 1990 and 1994. These changes can be partially attributed to the increase in the prevalence of asthma, mental disorders, mental retardation, and learning disabilities (Kaye et al., 1996). Among younger adults, ages 18 to 44, disability rates increased slightly for both men and women between 1990 and 1994, in part due to the increase in orthopedic impairments and mental disorders.

Among adults age 45 to 64, disability rates remained fairly constant from the 1970s through the early-1990s.13 Work disability rates have also remained fairly constant; some 11 percent were unable to work and 7 percent were limited in the type or amount of work they can do (1994). Work disability rates are much lower for adults age 18 to 44, but have been increasing. Between 1990 and 1994, for example, the proportion of those unable to work increased from 2.9 to 3.7 percent (Kaye et al., 1996).

The Impact of the Aging Population

The aging of our population will have a significant impact on the demand for care and hence, the future of both paid and unpaid caregiving. The relative size of the paid long term care workforce in the future is uncertain. The overwhelming prefer-

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11The trend toward deinstitutionalization of persons with mental retardation and developmental disabilities in favor of care in community-based settings began in the 1970s. In 1982, for example, the number of Medicaid beneficiaries with MR/DD in a waiver program was 1,381. In 1999, that number had increased to 261,930. And in that same period the number of beneficiaries in an ICF/MR decreased from 140,682 to 117,917 (Prouty and Lakin, 2000).

12From the National Long term Care Survey (NLTCs), the annual rate of decline in disability between 1982 and 1994 was about 1.3 percent per year among people age 65 and older. This resulted in 1.2 million fewer elderly persons with disabilities in 1994 than if the disability rate had not declined.

13The rates were about 25 percent for men and 23 percent for women before 1982, and 22 percent for men and 23 percent for women after 1982. (In 1982, however, the NHIS question on disability was changed substantially.)
ence for home care by people with disabilities and the elderly population has greatly increased the demand for paid professionals, but the number of people choosing this type of work is not increasing as quickly as the demand for their services.

Changes in family structure will also affect the pool of potential unpaid caregivers. The elderly of today have fewer adult children than did previous generations and the elderly of tomorrow will have even fewer children upon which to depend. Adding to the complexity is the fact that adult children are increasingly less likely to live near their parents. Furthermore, the population most likely to require long term support services, age 85 and over, is growing faster than any other age group. Thus, the elderly needing care in the future will be among the “oldest old,” and hence their caregivers, primarily spouses and adult children, may also be elderly.

The Paid Long Term Care Workforce Is Declining

It is clear the size of the paid long term care workforce will not be able to keep up with the anticipated demand for workers unless the system changes. The recruitment and retention problems that providers face, primarily due to the low-wage rates that are being offered in today’s competitive labor market, will only be exacerbated as our population ages. High turnover rates in facilities and in the home care industry, exacerbated by insufficient government reimbursement rates are a major concern because they create an unstable workforce and are a barrier to high-quality care. The Institute of Medicine (IOM) reported that nursing home caregivers average turnover rates of 105 percent per year (1994). Turnover rates for home care workers, however, are generally lower (Wilner and Wyatt, 1998).

Growth in Long Term Care Expenditures

As our population ages, long term care expenditures are expected to increase dramatically. Estimates by the Congressional Budget Office (Hagen, 1999) suggest that for the elderly alone, long term care expenditures are expected to increase from $123 billion now to $346 billion in 2040 (in 2000 dollars) (see Figure 6). Given the relative newness of the long term care insurance market, the impact of private insurance on the financing of these costs remains uncertain. The Congressional Budget Office, however, estimates that regardless of how much private long term care insurance expands between now and 2020, Medicaid spending will still increase substantially. Assuming an increase in private long term care insurance spending, Medicaid spending would have to increase from $43 billion today to $75 billion in 2020 (in 2000 dollars) to maintain current levels of service to low and middle-income elderly people. If there is no appreciable expansion in private insurance spending, Medicaid long term care expenditures for the elderly is estimated to increase to $88 billion by 2020 (Hagen, 1999).

Increasing Demand on States

Most publicly financed long term care services and supports are funded through the federal-state Medicaid program. Recently, a number of state-funded long term care programs have been developed to supplement the public funding provided by Medicaid. The establishment and expansion of such programs demonstrates a response to unmet need by states. More than $1.2 billion was spent on state-funded long term care programs for the elderly in 1996 (Kassner and Williams, 1997). Today, 36 states report that they have state-funded multi-service programs that provide home and community-based care to people of all ages in 2000 (Summer, forthcoming).

It is unclear how much the demand for Medicaid long term care services will increase as our population ages. It is clear, however, that in the absence of long term care financing reform, states’ roles in providing long term care services and supports will expand. As Medicaid competes with Social Security and Medicare, which are also affected by the aging of the population, there is likely to be pressure to restrain growth in Medicaid spending (Merlis, 1999). Thus, the burden of long term care financing will increasingly be placed upon states and local communities.

IV. A CALL FOR A NATIONAL DIALOGUE

Pillars of Reform

Citizens For Long Term Care’s Principles of Reform, which described a set of basic principles that would shape the development of an ideal long term care system have served as an important point of reference in discussions. From the Principles of Reform, Citizens sought to be more specific and develop the Eight Pillars of Financing Reform, which would help guide the national dialogue on long term care financing reform.

- Every American must be assured access to needed long term care services.
- A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.
- The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.
The New Social Insurance Benefit

- Eligibility for the social insurance benefit should be based on functional limitations as an entitlement benefit.
- Private and public policies should be developed to educate and encourage individuals and families to plan for the financing of care before the onset of disability.
- Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.
- Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.
- The financing system must support choices across the continuum of care and help maximize personal independence, self determination, dignity and fulfillment.

Motivated by concerns over the current state of long term care and in agreement on the need to pool long term care risk, Citizens For Long Term Care calls for a national dialogue on reforming the financing of long term care. To help guide that dialogue Citizens For Long Term Care developed a set of goals for new system. The system must: be a public/private long term care system; it must assure access to care; support individual preferences and family caregivers, and build on the current financial security framework; and, the system must be financed by a clear national commitment based on principles of social and private insurance.

Most specifically, Citizens For Long Term Care agreed that there must be a new social insurance benefit that finances a minimum floor of financial protection. This benefit will be based on functional need with appropriate eligibility and benefit level qualification standards. The new social benefit is to be combined with a program of tax incentives for the purchase of private insurance earlier in one’s life. Citizens also strongly believes that public assistance must be available to those whose needs exceed all other public and private resources. The member organizations agreed that certain key elements should be a part of long term care financing reform. They are:

The New Social Insurance Benefit

- A new social insurance benefit with appropriate eligibility and benefit level qualification standards must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.
- The financing system should be as flexible as possible, not only to meet different and changing needs of individuals, but also to accommodate regional variations and to assure appropriate consumer choice in settings across the continuum of care. Two people with the same level of functional need should receive the same level of assistance but be able to use that assistance differently.
- There needs to be a new publicly financed program that provides a national, uniform system of disability assessment and assistance, which offers both information and assistance in arranging for appropriate services.
- There needs to be a critical examination of the definition of guidelines for disability and long term care to help ensure integrated coverage for supportive services over the course of one’s lifetime.

Private Insurance and Employers

- The acquisition of private insurance, especially at a younger age, for those for whom it is most appropriate must be encouraged and supported through publicly supported tax incentives.
- Insurers have a responsibility to help educate consumers and work with employers, the government, and consumer groups to develop ways to expand the pool of privately insured risks and to ensure that private resources are used to improve the organization and delivery of long term care.
- Employers have a critical role to play. Employers, working with government, have a responsibility for helping people to better understand the financial consequences of long term care and their options to plan for this risk. Employers are also in a better position than individuals to choose and organize disability and/or long term care insurance options.
- Individuals and their families have a responsibility to plan for the financial consequences of needing long term care. For some people, at various stages of their lives, the only effective way to plan for the future will be by working and paying taxes. Others, however, will have the opportunity to build on the protections provided by the social commitment and use tax incentives to purchase private insurance or to finance other options that insure long term care needs.

Medicare

- Medicare needs to be reformed to cover the most appropriate level of support for health care needs of those with chronic illness and disabling conditions.
- Medicare needs to be reformed in ways that ensure more beneficiaries are able to either avoid or delay the onset of chronic and disabling conditions and to better define the separation between chronic health care and long term care services so that the health needs of those with chronic conditions are better met.

Medicaid

- Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.

This approach to reform establishes a national framework to improve the financing, organization, and delivery of long term care. It offers the potential to pool public and private resources towards the development of an efficient and equitable market of long term care providers, and provides the potential to help families better organize, coordinate, and integrate needed care with their own efforts. As outlined, individuals are encouraged to take responsibility for their
future long term care needs while the government provides necessary consumer protections, a base social insurance program that can be built upon, and long term care for those whose needs exceed their resources.

While often not recognized as a key element of financing reform, the intergovernmental aspect of the Medicaid program dictates that reform of the financial, regulatory and oversight interchange between local, state, and federal governments will be an integral aspect of long term care financing reform. To solve long term care financing reform will require an intensive re-examination of the intergovernmental relationships that currently govern long term care financing. These include:

**Intergovernmental**

- The federal government must be responsible for establishing the operating principles; policies and public financing for the national long term care system.
- State and local governments have a responsibility to work with the federal government to design and implement measures of quality outcomes.
- State and local governments have a responsibility to work with the federal government to encourage the development of local capacity to help people based on national standards of care.
- The federal, state, and local government must share responsibility for educating consumers about long term care risks, helping them make informed choices about insuring those risks and making sure long term care insurance has adequate consumer protections.

There are still many critical questions for which Citizens For Long Term Care did not reach agreement. First and foremost is the question of the size and scope of the floor of financial protection. Others include appropriate levels of support for tax incentives for the purchase of long term care insurance or necessary changes to Medicare and Medicaid. The answer to these questions will require a national dialogue about long term care.

**The Road to Reform**

The need for long term care is an emotionally and financially draining experience that can affect a family through the birth of a child with developmental disabilities, accident, chronic disease or as the result of the frailties of old age. People of all ages and economic stratum are at risk of being impoverished by its expense. For the last sixty years we have developed and refined a combination of social insurance and necessary consumer protections, a base social insurance provision that can mean impoverished golden years. For the states and federal governments it will mean long term care costs will crowd out other priorities. For America it means we must begin addressing long term care financing reform now to prevent these possibilities.

The transition from the current welfare-based system of financing long term care to a new national public/private system will be slow and difficult. It will not happen overnight, but fortunately we have several years to begin the process before the full force of the retiring Baby Boomers is upon us. In order to begin the transition our country’s highest leaders must take the initiative. We need, and expect, the President of the United States, with help and support from business and elected leaders, to begin a national dialogue on long term care financing reform. We have started the dialogue on the other aspects of financial security; Medicare, Social Security and tax reforms: long term care financing reform must now be part of the dialogue. To ignore this threat imperils the financial security of every American and the economic prosperity and security of our nation.

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**REFERENCES**


Kassner E, and Williams L. Taking Care of Their Own: State-Funded Home and Community-Based Care Programs for Older Persons. AARP PPI: Washington, D.C 1997;


