



## Long-Term Care Policy: Its Time Has Come... Once Again

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### Introduction

During the past two decades, advocates and policymakers have attempted to bring long-term care (LTC) to the forefront. The LTC Campaign, a coalition of aging and disability organizations, succeeded in making LTC an issue in the 1988 presidential primary campaigns and subsequent congressional elections. In 1990, the bipartisan Pepper Commission, named in honor of Congressman Claude Pepper, developed a blueprint for long-term care reform.<sup>1</sup> During the early years of his first administration, President Clinton's health reform proposal included a long-term care component. Yet LTC still languishes in the health policy background despite widespread public support for action.

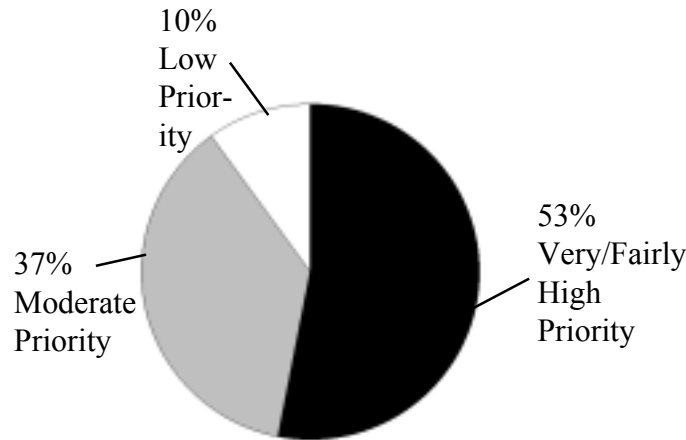
The purpose of this brief is to provide an overview of essential factors that should be considered in developing a long-term care (LTC) policy for the United States. It is not intended to examine in detail the scope of each of the services that comprise the LTC spectrum. The Alliance for Retired Americans Educational Fund (ARAEF) has drawn on a recently released report from the National Academy of Social Insurance, as well as the Georgetown University Long-Term Care Financing Project, for the substantive basis of this brief.<sup>2</sup>

### Public Support for LTC Services/Policy

Baby boomers and the generations before them say they are concerned about paying for LTC and that the current system needs major improvements or overhaul. Nearly three-quarters of Americans over age 40 are concerned either a great deal (54 percent) or a fair amount (18 percent) about paying for LTC. Over half say that addressing LTC costs should be a high priority for the nation, including 34 percent who say it should be a very high priority.<sup>3</sup> (See Figure 1.)

The reasons given why long-term care should be a higher national priority than it is revolve around the increasing numbers of Americans who will need LTC in the future and the costs of such a rise. Additionally, the realization that individuals must deplete their financial resources before they are eligible for government assistance through the Medicaid program, the primary source of public funding for LTC, and the significant expense of LTC insurance adds urgency to addressing LTC as a public policy issue. Consequently, seven in

**Figure 1. Percentage of Americans Over Age 40 Who See LTC as a National Priority**



Source: National Academy of Social Insurance. "Long-Term Care: The Public's View." November 2005

ten baby boomers and seniors feel that the current system of paying for expenses needs a complete overhaul (41 percent) or major improvements (30 percent). The same percentage believe government should do more to help people meet the costs of LTC.<sup>4</sup>

### **What Is Long-Term Care?**

Long-term care refers to an array of services needed by individuals who have lost some capacity for independence because of a chronic illness or condition. It consists of assistance with basic activities and routines of daily living. It may also include skilled and therapeutic care for the treatment and management of chronic conditions. LTC services may be provided in a variety of settings—an individual's home, the community, or an institution.

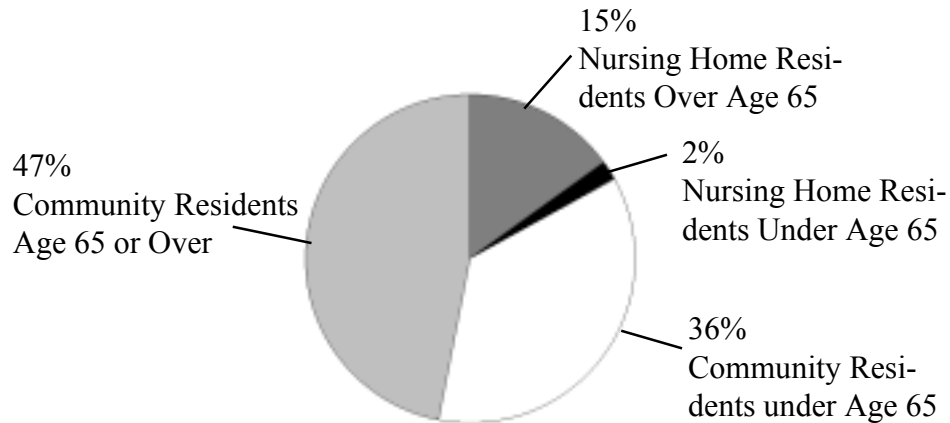
### **Who Needs Long-Term Care?**

The need for LTC ranges from those who use occasional help to those who require intensive or round-the-clock care. Trends indicate that one in four persons over the age of 25 and 40 percent over age 65 will have at least one stay in a nursing home during their lifetime. Yet, the need for LTC is a risk, not a certainty. For those currently age 65, projections indicate that about 31 percent are likely to die without ever needing LTC.<sup>5</sup>

One in five individuals requiring LTC don't get the services they need and nearly 20 percent of family caregivers say they need help with their caregiving responsibilities that they do not receive.<sup>6</sup>

Although the probability of needing LTC increases with age, nearly four in ten (38 percent) of those who need LTC services are under age 65. Over 80 percent of those with long-term care needs live in the community.<sup>7</sup> (See Figure 2.)

**Figure 2. Residence and Age of Individuals Needing Long-Term Care**



Source: Georgetown University Long-Term Care Financing Project: "Who needs long-term care?" Fact Sheet. May 2003.

## Who Provides Long-Term Care?

The vast majority of LTC recipients reside in the community—only 1.6 million of the nearly 10 million who need LTC are in nursing homes. Studies show that if given a choice three out of four Americans age 50 and older prefer to remain in their own homes to receive services.<sup>8</sup> The human component of LTC is very important, most of such care is hands-on and low-tech. Of LTC recipients living in the community, more than three-quarters (78 percent) rely solely on family and friends to provide the assistance they need. Eight percent receive care exclusively from paid staff and 14 percent from both paid and unpaid care.<sup>9</sup> A significant shortage of both paid and unpaid caregivers is projected in the future.

**Family/Informal Caregivers.** Families play a significant role in providing care. There are an estimated 44.4 million individuals—one in five adults—providing health care for adult family members and friends.<sup>10</sup> While the participation of men as family caregivers is higher today (39 percent) than in earlier studies (25 percent), the bulk of caregiving responsibilities still falls on women who spend more hours caregiving per week than men.<sup>11</sup> It is anticipated there will be fewer family caregivers in the future partially because the fertility rate of baby boom women is lower than earlier generations<sup>12</sup> and the very old population needing LTC will increase faster than the population who would traditionally care for them.<sup>13</sup> It is not realistic to continue to depend on family caregivers in the future if caregivers are fewer in number and they do not receive sufficient support.

**Consequences of Caregiving.** Caregiving often takes a toll on the caregiver. In one study of working caregivers, 56 percent have health problems of their own, a third lack health insurance, and three out of five are burdened by medical bills. One-third of employed caregivers miss more than one week of work during the year and employers may lose as much as \$29 billion per year in productivity.<sup>14</sup>

The National Family Caregiver Support program, established by the Older Americans Act

Amendments of 2000, is a federally-funded program that provides grants to states to make information and support services—such as counseling, support groups and training, and respite services—available for family caregivers. However, funding for the program has not increased significantly. Just \$156 million was appropriated in fiscal year 2005. This averages to only about \$1,000 a year for the caregivers who participate.<sup>15</sup>

**Paid Caregivers.** Home health, personal care and nursing home aides are the front line workers in delivering LTC. Yet, LTC workers have few protections in the health field themselves—over half have no health insurance nor pension coverage. Workplace injuries or illnesses for these workers are twice that of workers in all private workplaces (10.1 vs. 5.0 per 100 workers).<sup>16</sup>

The National Governors Association (NGA) acknowledges that these direct-service workers face poor working conditions, earn low wages,<sup>17</sup> receive few benefits and generally lack knowledge about public benefits.<sup>18</sup> As a result, vast numbers of these workers leave their jobs within the first few months of employment. Improvements in these areas are essential not only to the quality of life for the workers but also to the continuity and quality of care for the care receiver.

Who will be the LTC caregivers in the future and where will they come from? Unless aggressive measures are undertaken to recruit and retain LTC workers, substantial shortages of home health aides and nursing aides will occur in the next several years. Between 2002 and 2012, the number of available paid caregiving jobs are projected to increase at a much higher rate than employment in the overall labor market—48 percent increase for home health aides, 25 percent for nursing home aides and 41 percent for personal aides in contrast to a 15 percent increase for all other occupations. Yet the number of workers who fill these jobs is expected to increase only slightly further exacerbating current shortages.<sup>19</sup>

## **Who Pays for LTC?**

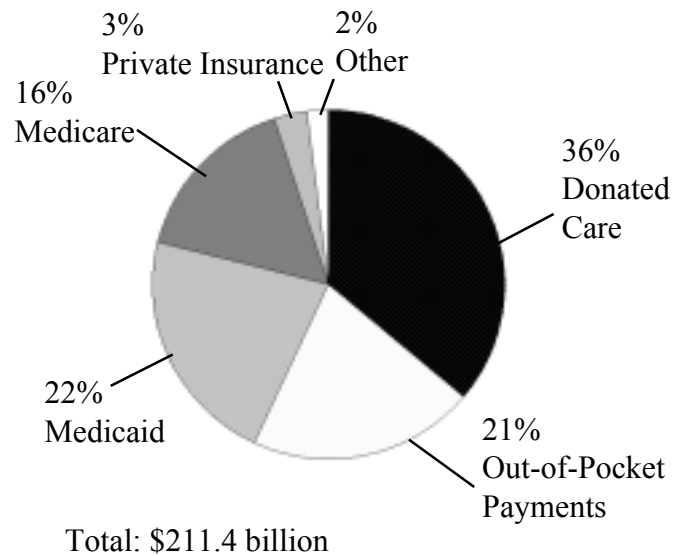
LTC expenditures may be minimal to costly, depending on the setting and extent of care.<sup>20</sup> In Figure 3, national expenditures, including unpaid caregiving and out-of-pocket spending by care receivers and their families, amounted to over \$211 billion in 2004. Costs fall overwhelmingly on recipients and their caregivers who pay 57 percent if donated care and out-of-pocket spending are taken into account. Private insurance pays just 3 percent.<sup>21</sup>

Excluding donated care, which is typically home-based, about two-thirds of expenditures are for institutional care. Public programs such as Medicaid and Medicare pay for two-thirds of formal long-term care; Medicaid alone pays for nearly half.<sup>22</sup>

The majority of Medicaid spending is for nursing home care although Medicaid expenditures for home and community-based services (HCBS) is increasing.<sup>23</sup> Medicaid, however, is not a comprehensive base for LTC protection—recipients must spend down their assets to qualify. Additionally, the NGA emphasizes that states are struggling to bear the primary public role of financing LTC services and stresses that Medicaid cannot continue as the primary funding mechanism.<sup>24</sup> Medicaid also faces significant budget cuts in Congress.

Medicare covers limited nursing home care of up to 100 days following three days of hospitalization or at home for those requiring part-time skilled nursing or therapy services.

**Figure 3. Sources of Spending for LTC for the Elderly, 2004**



Source: Congressional Budget Office. Testimony on the Cost and Financing of Long-Term Care Services by Douglas Holtz-Eakin, Director. April 27, 2005.

Medicare's services are designed to help beneficiaries recover from acute illness rather than provide LTC.

LTC insurance is not a major source of funding for LTC services—only about 6.5 million policies are in effect. Availability and affordability are shortcomings of LTC insurance. It is not available to older, as well as younger, people who already have LTC needs—all policies currently sold exclude those with pre-existing conditions—one in 5 applications overall. Nearly 60 percent of individuals over 80 who apply are declined coverage.<sup>25</sup> The average annual premiums for a 65-year-old are \$2,862, making insurance beyond reach for 80-90 percent of seniors.<sup>26</sup> Despite tax incentives and the limited benefits, public demand for LTC insurance is negligible.<sup>27</sup>

The costs of LTC must be distributed more equitably than today when care recipients and their caregivers shoulder most of the burden.

### **States As Laboratories for Change**

Increased home and community-based care is a major policy goal in most states and states have considerable flexibility to design their HCBS systems either through Medicaid waivers or using state funds. In 2003, the NGA undertook an initiative to bring attention to long-term care and highlight best practices in the states including help for family caregivers.

A major shortfall of state flexibility is lack of benefit uniformity—services and attendant costs vary widely from state to state. The NGA has called upon Congress to partner with states and the private sector to explore innovative funding sources to provide the necessary infrastructure and service options.<sup>28</sup>

In 1999, the Supreme Court held that the anti-discrimination provisions of Title II requires placement of persons with mental disabilities in community settings rather than institutions when certain conditions are met.<sup>29</sup>

To comply with the *Olmstead* decision, and to help states provide community-based options to persons with both mental and physical disabilities, Congress created the Systems Change Grants for Community Living program in 2000, which awards grants to states to test innovative ways to deliver community services to those of any age with a disability or long-term illness and move qualified individuals from nursing homes to community settings. The New Freedom Initiative started by the Bush administration in 2001 is also designed to assist with *Olmstead* implementation through federal agencies. As part of these efforts, the Administration on Aging and the Centers for Medicare and Medicaid Services award competitive grants to states to implement Aging and Disability Resource Centers (ADRCs) as “one-stop shops” for entry points to public long-term support services. These programs, however, are small steps and funds are inadequate for significant impact. In fiscal year 2005, Congress appropriated only \$39 million to the states for System Change grants and \$16 million for the ADRCs.

### **Alliance for Retired Americans Position on Long-Term Care**

The Alliance for Retired Americans supports a social insurance model for a long-term care system that incorporates the following principles:

- A range of quality care services including but not limited to the following services and settings that enhance the physical and mental well-being of recipients and their caregivers:
  - √ Skilled nursing care
  - √ Rehabilitative services
  - √ Respite care
  - √ Personal assistance with activities of daily living
  - √ Congregate living arrangements
  - √ Adult day care services
  - √ Home care
  - √ Hospice care
- Affordable care based on health and physical needs, not income levels;
- An individual’s right to choice of provider and care environment, including one’s own home;
- Enforcement of quality assurance measures;
- Educational efforts to promote informed decision-making by individuals and families including an examination of available options for types of care and settings, as well as financing options and eligibility criteria;
- Recognition of the essential role of front line long-term care workers in ensuring quality care through improvements in nursing home staffing ratios, staff and management training, fair pay, health, pension and other benefits, career advancement and other incentives, and safety protections for all health care workers; and
- The right for all long-term care workers to organize and bargain collectively for better pay, working conditions, benefits and training, along with effective enforcement of those rights.

In addition, the Alliance encourages its state and local affiliate organizations to participate

in the development of state long-term care policies that incorporate the above principles where possible.

The Family Caregiver Support program must have expanded funding to provide authentic respite. The Alliance endorses national enactment of financial and other supports for family caregivers, including but not limited to, affordable health insurance, adequate provisions for respite, expansion of family and medical leave options, and guaranteed retirement security for those who leave the workforce for a loved one.

The Alliance rejects proposals that would divert development of a comprehensive long-term care system by substituting expensive federal tax credits and tax deductions for private long-term care insurance.

## Conclusion

Access to appropriate and affordable long-term care is a right of all individuals. The current long-term care structure has a role for all stakeholders—federal, state and local governments, employers, private programs, and individuals and their families. However, this has resulted in a fractured system. Any LTC policy should concentrate on helping caregivers and those who are not obtaining LTC assistance to ensure that services are available and affordable wherever one lives. A social insurance approach best addresses all of these concerns.

The political will of policymakers to direct public policy is often correlated to self-interest. If members of Congress recognize that resolving the unaddressed needs of millions of caregivers and care recipients is important to the public, they will act. Advocates throughout the country can help move long-term care to the top of the national agenda by raising it as a campaign issue in the 2006 Congressional and gubernatorial elections.

## Endnotes

<sup>1</sup> The Pepper Commission: U.S. Bipartisan Commission on Comprehensive Health Care. “A Call for Action.” September 1990. The strategy approved by the Commission was a partial social insurance approach—social insurance for home and community-based care and for the first three months of nursing home care, regardless of income; and a floor of protection and long-term care insurance for people with long nursing home stays.

<sup>2</sup> National Academy of Social Insurance. “Developing a Better Long-Term Care Policy: A Vision and Strategy for America’s Future.” Report of the Long-Term Care Study Panel. November 2005; Georgetown University Long-Term Care Financing Project, [ltc.georgetown.edu](http://ltc.georgetown.edu).

<sup>3</sup> National Academy of Social Insurance. “Long-Term Care: The Public’s View.” Health and Income Security Brief. November 2005.

<sup>4</sup> Ibid.

<sup>5</sup> Feder, Judith. “Long-Term Care and Medicaid: The Critical Role of Public Financing.” June 2005.

<sup>6</sup> National Academy of Social Insurance. November 2005.

<sup>7</sup> Georgetown University Long-Term Care Financing Project. “Who needs long-term care?” Fact Sheet. May 2003.

<sup>8</sup> AARP. “Beyond 50.02: A Report to the Nation on Independent Living and Disability. 2002.

<sup>9</sup> Georgetown University Long-Term Care Financing Project. May 2003.

<sup>10</sup> National Governors Association. Center for Best Practices Aging Initiative. “State Support for Family Caregivers and Paid Home-Care Workers.” June 25, 2004.

<sup>11</sup> National Alliance for Caregiving and AARP. “Caregiving in the U.S.” 2004.

<sup>12</sup> Mothers of baby boomers had a fertility rate of 3.5 children; today it is about two children.

<sup>13</sup> Between 2000 and 2025 the population age 85 and older will more than double while the traditional caregiving population—women age 20-54—is projected to increase by just 9 percent. Wright, Bernadette. “Direct Care Workers in Long-Term Care.” AARP Public Policy Institute. May 2005

<sup>14</sup> Ho, Alice. et. al. “A Look at Working-Age Caregivers’ Roles, Health Concerns, and Need for Support.” The Commonwealth Fund. August 2005. The Commonwealth study estimates there are 16 million working age caregivers and 2 million are over age 65.

- <sup>15</sup> “Cash and Counseling” demonstrations, which provides allowances to individuals to hire their own caregivers except a spouse, is another approach undergoing evaluation.
- <sup>16</sup> Ninety percent of these workers are women, half are non-white, and one in 3 are unmarried with children. Most intentionally choose direct care work because of a desire to help people and an interest in working in health care. Wright, Bernadette. op. cit.
- <sup>17</sup> The wages for personal and home health aides average between \$8.05 and \$8.75 per hour.
- <sup>18</sup> National Governors Association. June 25, 2004.
- <sup>19</sup> Wright., op. cit.
- <sup>20</sup> According to a survey by MetLife, nursing home costs in 2005 average \$203 per day (\$74,095 annually) or \$177,828 for the average 2.4 years of nursing home stays. Home health care costs average \$19 per hour and personal care is \$17 per hour.
- <sup>21</sup> Congressional Budget Office. Testimony on the Cost and Financing of Long-Term Care Services by Douglas Holtz-Eakin, Director. April 27, 2005.
- <sup>22</sup> Medicaid, a jointly funded federal-state program, is the major source of nursing home payments and increasingly the major source for home and community-based services for low-income individuals or those who become eligible after exhausting their financial resources.
- <sup>23</sup> CBO. 2005. According to the National Academy of Social Insurance report, 75 percent of HCBS spending is for individuals with mental retardation or developmental disabilities with the remaining 25 percent for aged or disabled individuals.
- <sup>24</sup> National Governors Association. Policy Position: Long-Term Care. March 2005.
- <sup>25</sup> “National study reveals: 1 in 5 LTC insurance applicants are declined.” [www.insurancebroadcasting.com](http://www.insurancebroadcasting.com)
- <sup>26</sup> National Academy of Social Insurance. November 2005.
- <sup>27</sup> CBO projects that the proportion of LTC spending that private insurance will pay will rise to only 17 percent in 2020 from 3 percent of total LTC expenditures in 2004.
- <sup>28</sup> National Governors Association. March 2005.
- <sup>29</sup> *Olmstead v. L.C.*, 527U.S. 581 (1999). The *Olmstead* conditions are: 1) the state’s treatment professionals have determined that community placement is appropriate; 2) the transfer to a less restrictive setting is not opposed by the affected individual; and 3) the placement can be reasonably accommodated, taking into account the state’s resources and the needs of others with mental disabilities.

*This is the eighth in a series of issue briefs from the Alliance for Retired Americans Educational Fund on issues and programs that should be considered at the White House Conference on Aging scheduled for December 11-14, 2005 in Washington, D.C.*

*This report was researched and written by Dianna M. Porter, director for policy. This is a publication of the Alliance for Retired Americans Educational Fund (ARAEF), the research and education branch of the Alliance for Retired Americans. ARAEF is a 501(c)(3) organization that focuses primarily on retiree issues. Permission to reproduce all or part of this report is given with following credit line: Reprinted [or excerpted] with permission of the Alliance for Retired Americans Educational Fund.*



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