



# Consumer-Preparedness for Long-Term Care

## Introduction

As Baby Boomers (those born between 1946 and 1964) age and medical advances result in more people living longer with chronic, often disabling, medical conditions, the need for long-term care services in America is growing. The U.S. Census Bureau predicts that the population over age 65 will double from 36 million in 2003 to 72 million in 2030, increasing from 12 percent to 20 percent of the population.<sup>1</sup> Eighty percent of seniors have at least one chronic health condition and 50 percent have at least two.<sup>2</sup> Chronic and disabling conditions often lead to declines in independent living and quality of life, imposing an economic burden on those requiring long-term care services.<sup>3,4</sup> Long-term care services are provided through a variety of care arrangements, including community-based paid or unpaid care, institutional care, self-care using assistive devices, or a combination of these. The majority of older adults with functional disabilities receive long-term care services in the community (71%), primarily from family and friends.<sup>5</sup>

Unfortunately, despite the population trends and the growing need for long-term care services, there is a significant discrepancy between consumer expectations and their actual long-term care needs. As a result, there is inadequate planning by many. To address

this issue, the Commonwealth Fund and AcademyHealth brought together a panel of experts who have been thinking about the issues involved with long-term care planning to participate in the June 2007 colloquium on long-term care, *BuildingBridges: Making a Difference in Long-Term Care*. Panelists included Lisa Alecxih, The Lewin Group, Brian Burwell, Thomson Healthcare, Robert Kane, M.D., University of Minnesota, and Brenda Spillman, Ph.D., Urban Institute. With the assistance of a facilitator, Len Fishman, Hebrew SeniorLife, the panelists shared their perspectives about issues of concern to policymakers and practitioners. Panelists addressed the current state of long-term care needs awareness and planning, barriers that dissuade individuals from adequate preparation (with the lack of practical financial planning options one of the greatest challenges), and possible strategies to encourage consumers to better prepare for their future long-term care needs.

## Current Awareness of Long-Term Care Needs

Setting the tone for the dialogue, Len Fishman reported that polling by the Long-Term Care Study Panel of the National Academy of Social Insurance found that 63 percent of respondents had personal experience with long-term care, most gained through a parent or spouse's parent, or a grandparent or spouse's grandparent. In



AcademyHealth

addition, one-third indicated that they would rely on long-term care insurance, far more than actually have such insurance.<sup>6</sup> Fifty-three percent of respondents indicated that long-term care should be a high priority for the nation, with 34 percent indicating that it should be a very high priority.<sup>7</sup> More than 70 percent favored a larger role for the federal government in meeting the costs of long-term care.<sup>8</sup> Personal experience with long-term care was not necessary for concern about the issue.<sup>9</sup> Interestingly, the pollsters conclude that while many find increased policy focus on meeting individuals' long-term care needs important, "after listening to an extensive case for doing more to help people meet long-term care costs, the proportion that are concerned a great deal or fair amount...remains virtually unchanged from the outset of the survey." Fishman noted that this is an indicator of challenges ahead for public education about this issue.

### **Making the Case for Long-Term Care Planning**

The probability of needing assistance with activities of daily living<sup>10</sup> and instrumental activities of daily living<sup>11</sup> increases with age. As a result, an increasing proportion of elderly individuals require long-term care services. As noted above, the majority of those people receive services while continuing to live in the community, primarily through unpaid care from family and friends. Others in the community benefit from home and community based services, such as home health care, personal care, or adult day services. Still others receive care in institutional settings, including nursing homes, assisted living facilities, or other residential care facilities.<sup>12</sup>

Costs of long-term care services can be significant. As Alexih notes, even when care is provided by family and friends there is a commitment of time and money for which they are often not prepared. For those relying on professional services in the community or in institutions, information from a Genworth Financial survey for 2007 shows that costs are substantial and vary widely. The average annual cost of nursing home care was

\$74,806, which varied from a low of \$43,435 in Louisiana to a high of \$196,735 in Alaska. Likewise average annual costs for assisted living were \$32,573, ranging from \$19,308 in Montana to \$57,036 in Massachusetts. The average hourly rate for a home health aide from an agency was \$25.47.<sup>13</sup> Someone turning 65 today can expect to need long-term care for three years prior to death. However, the amount that a specific individual will need for long-term care services over the course of his or her life varies widely, with 26 percent needing more than \$100,000 in paid assistance and 31 percent needing no long-term care services at all.<sup>14</sup>

There are a variety of sources of financial support for long-term care services. Medicaid is the largest source of financing (37%), followed by family resources (36%). While Medicare covers limited time in a skilled nursing facility following a hospitalization, it does not cover long-term care services. Long-term care insurance covers costs for some individuals (4%). Alexih notes that even those with Medicaid coverage also incur out-of-pocket costs for long-term care. Those in nursing homes contribute the vast majority of their income to the facility, and some states also require cost-sharing under their Home and Community-Based Services waivers.<sup>15</sup>

### **Planning for Long-Term Care is Inadequate**

Unfortunately, despite the likelihood of requiring long-term services and the significant costs of obtaining them, Alexih concludes that few Americans plan ahead to meet these needs. Fewer than 10 percent of those over 65 years old own a long-term care insurance policy, and while older adults have a significant investment in home equity, few use it as a resource for obtaining long-term care services.

Agreeing with Alexih that too few plan adequately, if at all, for their long-term care needs, Kane posited this was due to factors beyond poor financing options. He noted peoples' experience or exposure to long-term care is often negative. They associate the

care with cognitive or physical declines in the person receiving services. In addition, they may have experienced services being provided in a negative, usually institutional, environment. In addition, people find confronting issues of long-term care forces them to face their own mortality, never an easy thing to do. Further, some individuals consider the prospect of needing long-term care services and being dependent on others worse than death. For these reasons, they avoid planning for their long-term care needs. Others, who are able to overcome the emotional barriers to adequate planning, may understand that long-term care is necessary but not find it worth the investment or they may believe all long-term care is the same, not understanding that there is variation in quality, as well in the location of service provision, which can make a difference.<sup>16</sup>

Burwell noted that poor planning for long-term care raises concern among policymakers and others that pressure on Medicaid and other publicly-financed systems may become overwhelming. As a result, there is increased interest in better understanding planning behavior among Americans, as well as motivators that would encourage better planning. Research and focus groups on long-term care planning have found variation in the propensity to plan for the future aligning with basic personality traits. To adequately plan for long-term care, one must accept the possibility of future functional decline and believe that one can exercise some control over future events. Failing this leads to denial or fatalism and ultimately to lack of future planning.<sup>17</sup>

Understanding that long-term care was perceived negatively, that there was denial about the possibility of the need for long-term care, and that dignity and control were major motivators for planning, the federal government launched the Long-Term Care Awareness Campaign, *Own Your Future* in 2005. This national initiative<sup>18</sup> is designed to increase consumer awareness about planning for

long-term care. Core activities include using the governor as a “trusted source” in state-based direct mail campaigns. Households with members between the ages of 45 and 70 are targeted and encouraged to consider long-term care needs in their overall retirement planning. They are provided with a planning guide that includes an audio CD with anecdotes about individuals’ experiences with long-term care, as well as shopping tips for long-term care insurance. As of March 2007, 15 states had participated in the *Own Your Future* campaign.<sup>19,20</sup>

### Options for Better Long-Term Care Financial Planning

Recognizing the growing need for long-term care services, as well as consumers’ lack of preparation for financing them, Brenda Spillman highlighted current options for long-term care financing, as well as barriers limiting their feasibility.<sup>21</sup> She noted that the policy concern over long-term care financing emanates from a fear of rising Medicaid costs on the part of states and the federal government, as well as the long time horizon and complexity that make personal planning difficult.

She stated that there are currently two primary approaches individuals can take to financial planning for long-term care: 1) pre-funded options, including long-term care insurance, hybrid products combining annuities or life insurance with long-term care benefits, accelerated death benefits as a life insurance option, and continuing care retirement communities; and 2) self-insurance and ad hoc solutions, including personal savings, life annuities, and reverse mortgages.

Each of these options has significant barriers. Long-term care insurance is relatively expensive, the cost rises with age, and affordable coverage may have benefits that provide insufficient protection. In addition, medical underwriting often precludes the purchase of long-term care insurance, either because the insurer excludes the individual or because risk-rated policies are too costly. While fewer younger individuals would be subject to

medical underwriting exclusions, younger individuals typically have other spending and savings priorities. The difficulty in understanding the complex array of options for long-term care insurance may inhibit some individuals from purchasing it, since knowing whether the decision is the “right” one may not be obvious for twenty years after the purchase is made. The long-term care shopper’s guide disseminated by the National Association of Insurance Commissioners suggests that buyers’ have a high level of fore-knowledge before purchasing a policy. For example, it mentions the importance of knowing whether your policy will cover new kinds of facilities that may be developed in the future and suggests one be aware of how much facilities and home health agencies will charge.<sup>22</sup>

Describing his elderly, financially independent (although not wealthy) mother’s experience, Kane noted that when she was approached by a long-term care insurance salesperson, he advised her against purchasing the policy.<sup>23</sup> Citing its limited coverage (nursing home and formal home care) and the low statistical probability of her needing prolonged long-term care, he recommended that she invest her money instead. Five years later, Kane’s mother had a stroke resulting in her spending 3.5 years in an assisted living facility with additional aides, followed by three months in a nursing home, prior to her death. The total cost of Kane’s mother’s care was \$330,125. Four years of premiums for the long-term care insurance policy she was offered would have been \$96,000 and Kane calculates that the policy would have covered only \$90,500 of the costs incurred. Kane acknowledges that if she had purchased the policy at age 55, rather than at age 80, the premiums would have been significantly lower. However, it would have been impossible to estimate costs 25 years into the future, even with an inflation adjuster, and having invested the premiums for 30 years would have resulted in more funds available for long-term care services than purchasing the long-term care coverage.<sup>24</sup>

Kane concludes that if professionals working within the health care and long-term care systems are having serious problems getting desired care even when they can pay for it for themselves and their families, the system is failing. If the infrastructure is missing why would one save for such care? Noting that there is no advocacy group to support the needs of the elderly or those with chronic illness, Kane has taken the lead in forming the group Professionals with Personal Experience in Chronic Care (PPECC), whose mission is to draw upon the credentials of health care professionals as both recipients (directly or indirectly) and subject matter experts to promote the changes needed for aligning the medical system to better provide chronic illness care.<sup>25</sup>

Spillman notes that several policy approaches exist or have been proposed to address issues of long-term care financing, including incentives for increased private support and social insurance approaches.<sup>26</sup> Policy initiatives or proposals designed to provide incentives for private financing include:

*Partnership for Long-Term Care:* This initiative, originally limited to four states but available to more under the Deficit Reduction Act (DRA), allows purchasers to become Medicaid eligible when their private benefits (meeting program standards) have been exhausted, while retaining some or all of their remaining assets.

*Tightening of Medicaid Eligibility:* The DRA makes it more difficult to gain Medicaid eligibility through financial manipulations by lengthening the “look back” period for asset transfers. The DRA also requires disclosure of all annuities with the state named as remainder beneficiary to preclude the use of annuities to shelter assets.

*Federalizing Medicaid Long-Term Care Benefits:* Standardized federal Medicaid long-term care benefits would make it easier to understand what can be expected from Medicaid and might encourage offerings of private, portable long-term care insurance product innovations for those with modest means.

*Tax Incentives:* The Pension Protection Act of 2006 extended tax deductibility to include long-term care benefits offered as part of an annuity or life insurance contract. Policymakers have also discussed extending deductions to all taxpayers and using other tax-related vehicles, such as medical savings accounts or tax-free withdrawals from retirement accounts, for the purchase of long-term care insurance.

Social insurance options that have been discussed as tools for meeting the long-term care needs of Americans include:

- Linking a long-term care benefit to Social Security;
- Universal premium-funded federal social insurance with a cash benefit (automatic enrollment requiring enrollees to “opt out”); and
- The Community Living Assistance Services and Supports Act (CLASS Act) to establish a national long-term care benefit for workers and their dependents, introduced originally by Senator Edward Kennedy in 2005 and reintroduced in 2007.

## What Does the Future Hold?

As Baby Boomers age and the long-term care needs of society place increased stress on both private and public sources of funding, the challenges are great and their impact is widespread. There are no magic bullets to address the issues of long-term care provision or financing, but it is clear that as more individuals are affected it will become an increasingly important issue for society. Consumers need to continue to receive reliable information about available long-term care services, as well as alternative financing mechanisms. As Spillman concludes, the challenge for policymakers is deciding how important long-term care is and who will pay for it, while researchers continue to provide the evidence to support informed debate of the options.<sup>27</sup>

## About the Authors

Deborah L. Rogal is a director at AcademyHealth and can be reached at 202.292.6700 or [deborah.rogal@academyhealth.org](mailto:deborah.rogal@academyhealth.org). Rachel Shiffrin co-authored the brief while she was an intern with AcademyHealth.

## Endnotes

- 1 He, et al. U.S. Census Bureau, Current Population Reports, P23-209, 65+ in the United States: 2005, U.S. Government Printing Office, Washington, DC, 2005.
- 2 Centers for Disease Control, *Healthy Aging: Preventing Disease and Improving Quality of Life Among Older Americans 2003, At a Glance*, Department of Health and Human Services, 2003, as cited in He, et al. U.S. Census Bureau, Current Population Reports, P23-209, 65+ in the United States: 2005, U.S. Government Printing Office, Washington, DC, 2005.
- 3 Ibid.
- 4 National Center for Health Statistics, *Health, United States, 1999, with Health and Aging Chartbook*, Centers for Disease Control and Prevention/National Center for Health Statistics, Department of Health and Human Services, Publication No. 99-1232, 1999 as cited in He, et al. U.S. Census Bureau, Current Population Reports, P23-209, 65+ in the United States: 2005, U.S. Government Printing Office, Washington, DC, 2005.
- 5 The Lewin Group analysis of the 1999 National Long-Term Care Survey, 2002 Medicare Current Beneficiary Survey, and 2005 CMS Minimum Data Set as cited in *Why You Need to Plan for Potential Future Long-Term Support Needs* by Lisa Alecxih, prepared as background for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 6 Peter D. Hart Research Associates, *Long-Term Care: The Public's View*, National Academy of Social Insurance, Health and Income Security Brief No. 8, November 2005.
- 7 Ibid.
- 8 Ibid.
- 9 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.
- 10 Activities of daily living are activities related to personal care and include bathing or showering, dressing, getting in or out of bed or a chair, using the toilet, and eating. <http://www.cdc.gov/NCHS/datawh/nchsdefs/adl.htm>.
- 11 Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone. <http://www.cdc.gov/NCHS/datawh/nchsdefs/iadl.htm>.
- 12 Alecxih, L., *Why You Need to Plan for Potential Future Long-Term Support Needs*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 13 The Genworth Financial 2007 Cost of Care Survey, [http://longtermcare.genworth.com/overview/cost\\_of\\_care.jsp](http://longtermcare.genworth.com/overview/cost_of_care.jsp), as cited in *Why You*

*Need to Plan for Potential Future Long-Term Support Needs* by Lisa Alecxih, prepared as background for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.

- 14 Kemper, P., H. Komisar, and L. Alecxih, *Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?*, Inquiry, Vol. 42, 2005.
- 15 Alecxih, L., *Why You Need to Plan for Potential Future Long-Term Support Needs*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 16 Kane, R. L., *A Consumer's View of Long-Term Care*, slide presentation at *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 17 Burwell, B., *Long-Term Care Planning Research: A Brief Overview*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 18 The Own Your Future Campaign is a collaboration of the Centers for Medicare & Medicaid Services (CMS), the Office of the Assistant Secretary for Planning & Evaluation (ASPE), and the Administration on Aging (AoA), and has support from the National Governors Association (NGA).
- 19 U.S. Department of Health and Human Services, National Clearinghouse for Long-Term Care Information, Own Your Future Campaigns, [http://www.longtermcare.gov/LTC/Main\\_Site/Planning\\_LTC/Campaign/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/Planning_LTC/Campaign/index.aspx).
- 20 Burwell, B., *Long-Term Care Planning Research: A Brief Overview*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 21 Spillman, B., *Consumer Preparedness for Long-Term care: Personal Financing Options for Long-Term Care*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 22 National Association of Insurance Commissioners, Shopper's Guide to Long-Term Care, [http://www.naic.org/index\\_Itc\\_section.htm](http://www.naic.org/index_Itc_section.htm).
- 23 Kane, R.L. and West, J., *It Shouldn't Be This Way*, Nashville, TN, 2005.
- 24 Kane, R. L., *A Consumer's View of Long-Term Care*, slide presentation at *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 25 Kane, R. L., *A Consumer's View of Long-Term Care*, slide presentation at *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 26 Spillman, B., *Consumer Preparedness for Long-Term care: Personal Financing Options for Long-Term Care*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.
- 27 Spillman, B., *Consumer Preparedness for Long-Term care: Personal Financing Options for Long-Term Care*, background and slide presentation for *Building Bridges: Making a Difference in Long-Term Care*: 2007 Colloquium, Orlando, FL, June 2, 2007.