THE FUTURE OF LONG TERM CARE IN AMERICA

VIEWS & RECOMMENDATIONS BY PROMINENT EXPERTS

Genworth Financial
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Views and Recommendations by Prominent Experts

Genworth Financial
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Note: Each chapter is introduced by a vignette relevant to its topic. Chapter vignettes were made possible by the National Family Caregiver Association and others.
Foreword

Buck Stinson
President, Genworth Financial Long Term Care Insurance

 Millions of Americans will face the prospect of needing or providing long term care at some point in their lives. The broad-reaching impact is compelling when you consider the full spectrum of long term care—from nursing home care for those with the most complex needs, to adult daycare and assisted living facilities, to home care often provided by family members or home health aides.

With the aging baby boomer generation nearly 80 million strong, long term care is an ever-increasing focus for our nation’s policymakers as more people look for solutions to effectively address the financial and emotional consequences of long term care.

Nationally, we spend more than $140 billion each year on long term care, and this doesn’t include the value of donated services. Government programs such as Medicaid, particularly at its current funding levels, cannot provide the volume and quality of long term care needed in the years ahead. At the state level, governors are fighting an uphill battle to contain Medicaid long term care expenditures as their states face mounting shortfalls. Meanwhile, in just a few short years, families can deplete an entire life’s savings as they pay for a loved one’s increasingly expensive care out of their own pockets.

Considering these facts, we must acknowledge that, as a nation and as individuals, we are not prepared for the social and financial crisis that long term care presents right now and into the future.

Genworth Financial is committed to elevating awareness of this important issue. To that end, we engaged leading experts
on long term care issues in America to cover multiple dimensions of this complex topic and asked that they draw on their diverse professional experiences to offer possible solutions to the impending crisis. Genworth gave these authors no instruction beyond providing us with their unique insights. We asked them to explain the long term care situation as they see it today and as they see it evolving in the future. And this is precisely what we present to you in this book.

We thank these authors for their time and thoughtful contributions. While Genworth’s positions may not always align completely with our authors’ views, it is through the frank exchange of ideas and a collaborative effort between public and private sectors that we will find solutions to our nation’s long term care problems.

We believe this dialogue needs to begin now both on the national level and around every family’s kitchen table. Being prepared for long term care in America requires that we plan for the future today.
The Baby Boomer Generation’s
Unique Health Care Needs

My name is Michelle and I am 32 years old. My 42-year-old sister, Jaci, was diagnosed with stage 4 lung cancer around Thanksgiving 2002. She was not a smoker. No one had expected (or was prepared for) this diagnosis. She was a working mother of two children and a wife who had recently relocated to Kansas City. Jaci’s and her husband’s families live in Minnesota. I live in Massachusetts. There are no “free” caregivers living near them. Luckily, I am a teacher and was able to take a month-long break over the holidays to be with her. While I was there, I cared for her daughter, cooked, took her to medical appointments, took her out in her wheelchair, and was her shoulder to cry on as she lost her independence and health. But I’ve had to return to work and my siblings and elderly parents are unable to be with Jaci due to their own care responsibilities and financial limitations.

With the loss of Jaci’s income and having one child in college, her husband must continue working. For the most part, she is alone during the daytime. Her minister and former coworkers stop by, but she has made few close friends in Kansas. The telephone is her only access to loving caregivers.

With the increased mobility of the American workforce, our situation cannot be unique. How do families deliver care when family members must spread across the US to get good jobs?

Michelle
Williamsburg, MA

This vignette is from the National Family Caregivers Association Caregiver Story Project
www.thefamilycaregiver.org/connecting_caregivers
The Boomers: Igniting a Revolution
to Reinvent Long Term Care

William D. Novelli
CEO, AARP

The 78 million men and women we identify with the handy cultural term “baby boomers” are getting on in years.¹ We may expect that their impact and influence on the delivery and distribution of health and long term care will be substantial and perhaps cause a social upheaval. This is not necessarily something we should fear.

It is difficult to characterize such a large cohort as the boomers along socio-economic or cultural lines; it would be foolhardy to attempt to write a profile of a “typical” boomer. Some are rich, others are not. Some are religious, others not at all. Many have university degrees, but many more do not. And, since they live everywhere in the United States and, in some cases abroad, they share no regional characteristics. There is also some cleavage between the older boomers (those born, say, no later than 1955) and their younger brothers and sisters because of the older group’s coming into young adulthood during the Vietnam War. Regardless of how one felt politically about the war, it was a defining event for the older boomers, much more so than for their younger counterparts.

If, however, there is a common denominator for the boom-

¹The term “baby boomers” refers to the generation born between 1946 and 1964. There is some debate about the term and the idea behind it, some writers locating the beginning of the boom in 1943 when birth rates began to rise and others arguing that it ended in 1957 when birth rates began to decline. My purpose is not to debate these findings, but only to use the term as it is widely understood with an acknowledgement that it may not always be precise.
ers it may be that they have a history of getting their way and this, in turn, engendered changes in everything they touched, some of those changes being transformational. Among other phenomena, the boomers transformed popular music, embraced politics (on both the left and right) and activism more than their parents, established youth as a lifelong pursuit, if not status, through cosmetic surgery and “dressing down,” they brought consumerism to heights never before imagined by their parents or even marketers, and altered the concepts of marriage and family through divorce, late marriage, not marrying at all and delaying childbirth.

These facts about the boomers are well known, but their influence is even more pervasive, sometimes in small ways. For example, it is possible, I believe, to make a case that the sidewalk café, once a rarity in our most sophisticated American cities, became ubiquitous after the wealthier of the older boomers saw them in Europe and wanted them at home as well. They got what they wanted.

We need to put that in the future tense as well: they will continue to get what they want. What they want (or, as they are more likely to put it, “What I need”) may be more services, especially for their health and long term care. The outlook for this is mixed at best. Over the years, it has become clear that boomers also have a strong sense of legacy. By and large, they want to leave the world a better place for their children and grandchildren. So, when it comes to figuring out how to provide and pay for the services they want and need, boomers are concerned about not leaving the bills to their children and grandchildren.

More than half the boomers are at least 50 years old; the youngest are 43 and will turn 50 in 2014. The oldest boomers will turn 62 in 2008, the so-called “earliest eligibility age” for Social Security. If history is a guide, many will claim it—either out of choice or necessity, even though they will keep working. Median net worth for people between 55 and 64 is $165,000, not nearly enough to support retirement or high out-of-pocket expenses
for health care. Many of the more affluent boomers have their wealth in non-liquid assets, mainly real estate.

What we see then, is an aging generation that is, on average, reasonably well off, but hardly by any means rich. They are closing in on a period of life where chronic conditions (e.g., arthritis, hypertension, diabetes and coronary artery disease) become more common, and where inevitably for most, the body grows increasingly frail. While medical interventions, personal adjustments of lifestyle, better health information, and public health advances have made the entire population—again, on average—healthier than it was even just half a century ago, aging still has a debilitating effect on our physical and mental health, especially as many more of us live into our eighties and beyond.

Moreover, as people live longer, we are seeing more instances of diseases and disorders that were uncommon a generation or two ago, such as Age Related Macular Degeneration, or extremely rare—Alzheimer’s being the obvious example. Indeed, the Alzheimer’s Association reports that as the population ages and people live longer, the sheer number of people projected to suffer from the disease will mushroom from just over 5 million today to up to 16 million by mid-century.

But this doesn’t give us the complete picture. AARP’s research tells us that boomers want to remain active and independent, not merely for as long as possible, but evidently forever. But our research also tells us that this may not be in the cards.

When boomers were asked which area of their lives were most important to them, only 19 percent responded by saying “physical health,” substantially below the number who put “relations with family and friends” and “spiritual or religious life” first on their list. And when they were asked how satisfied they were

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2 The figures are from 2001, but there has been little if any middle-class movement in overall wealth accumulation in the last several years.

3 These findings are from “Boomers at Midlife: The AARP Life Stages Study” (2004), accessible at http://assets.aarp.org/rgcenter/general/boomers_midlife_2004_1.pdf.
with their physical health, only 32 percent said they were “very satisfied.”

These findings suggest that in the not-too-distant future, large numbers of boomers will need increased health care including eventually long term care and, as has been their habit, they will demand what they want in no uncertain terms.

Moreover, many boomers are already coming face to face with the state of the delivery and distribution of long term care in America as they take on the responsibility of caring for elderly parents. Many have close and personal experiences with long term care’s successes and its failures. And by and large they do not like what they see.

To illustrate, they see that the average cost of a private room in a nursing home in 2006 was $75,000 a year and, for a semi-private room, $67,000. Home care (e.g., assistance with daily activities) is bought at the rate of about $19 an hour; thus, the cost of a year’s worth of such care for only four hours a day is more than $27,000 a year. All the prices I have listed here are, by and large, too costly for many older adults today who need services.

Boomers have also observed the turnover rate in many nursing and other care facilities go over 100 percent a year, the many gaps in the continuity of care, and the challenges of finding and arranging for high quality care.

Among family caregivers (including boomers) with the most intense level of caregiving responsibility, 92 percent report major changes in their work patterns, 41 percent took a leave of absence, and 37 percent went from full to part-time work in order to care for relatives. Women bear a heavier burden than men, since most informal caregivers are women, so this has a severe and negative effect on their finances and on their own health: caregivers are more likely to have chronic health conditions than those who are not giving care.

It is not surprising that the boomers do not like what they see. Given their history, it is not surprising that they will want—in fact demand—better. That is why I believe they will ignite a revolution
to reinvent long term care. This undoubtedly will cause a social upheaval in the delivery and financing of long term care.

As I noted earlier, such an upheaval is not necessarily something we should fear or try to head off. It may be the only way to bring about a change for the better. Such a revolution in long term care need not be chaotic or destructive. It can be orderly if it is thoughtfully considered, planned, and executed. AARP has been thinking about long term care, especially in light of what we know about the wants and needs of the boomers as they age.

Ideally and practically any amelioration in the delivery of long term care needs to be part of an overhaul of health care delivery and financing in America. Nevertheless, given what we know about the boomers’ expectations for themselves, their experiences with long term care through their parents, their self-described health status, and their history of getting what they want, several steps can be taken to make long term care more rational, affordable and equitable.

First, we need a new point of view—one that stresses enabling people to live full and productive lives (a goal for most boomers), not just offering long term care when needed. To this end, we should look at a person’s home or community as the ideal setting for care. This may seem a very plain proposal, but it is in fact revolutionary given how long term care is often delivered today.

Medicaid, which pays the costs of long term care for those without their own means to pay (which is a significant number), has what we may call an “institutional bias.” That is, it will pay for nursing home care, but it will not usually pay the costs of home and community-based services (HCBS). About 63 percent of Medicaid long term care spending is for institutional care.

versus 37 percent for HCBS. This goes against good sense and good economics.

It makes sense that people are better off physically and emotionally when the care they need is available to them in familiar places, where they want to be. As they age, most people want to be at home. Generally, nursing homes are more expensive than HCBS. In many cases, HCBS can be delivered at lower cost.

The bias against HCBS also has ill effects in the matter of independence, control and choice for consumers of care. Even Medicaid beneficiaries who do have home care do not always have a say in who provides the services to them, when they are provided, and how the care is actually delivered. This top-down model of care seems indifferent, if not authoritarian and, still worse, appears to invite the wrong kind of care. We cannot possibly hope for the best outcomes in a system like this. If our goal is to enable people with disabilities and chronic conditions to function at their highest possible level, then any assistance provided to them should be tailored to their specific wants and needs.

Home care and consumer choice are inseparable in a new and better model of long term care. They are also the foundation of the new point of view we need to adopt in order to understand and revolutionize long term care: that people with disabilities should not be warehoused, that they are not too old or feeble to have a say in what is best for them, and that the point of any kind of care, from the simplest to the most intense, is not merely to prolong life, but to enrich it.

Let me offer an analogy. There is a constant debate in museums between the curators—who are in charge of displaying works of art—and conservators—who restore and repair them. The curators want to hang the pictures on the wall for all to see, while the conservators' ideal is to lock them all away in a dark room with perfect climate control and no foot traffic. Fortunately for us, the curators win most of the time in museums. Unfortunately for us, the conservators have been winning in matters of care. Individuals have not had the choice and control they deserve over
the services they need and how, when, and where they receive these services to help them live life to the fullest. We have to become curators, we have to upend the bias, and it will seem to some like an upheaval. And so it will be.

Perhaps the most daunting problem in mending long term care is the question—or rather the many questions—of how to finance it. This problem, of course, is part of the much larger one of paying for all kinds of health care and thus will probably not find a complete solution on its own. Until we develop a universal system of health care, any response we attempt will be fragmented. But that is no reason not to get the conversation going and the overhaul underway.

Medicaid is the primary funder of long term care, in part because there is a lack of affordable financing options to pay for it. Providing Americans with an expanded array of public and private sector financing options is critical. This would also help reduce the common occurrence of individuals spending down their resources to impoverish themselves and become eligible for Medicaid.

We need reform in the private market for long term care insurance as well. Premiums are generally very high and attractive to a comparatively small market. Consumer protections are a critical part of long term care insurance policies. Standards and protections for long term care insurance policies could make them better products that consumers are more likely to buy. Adequate inflation protection is important to prevent the value of the insurance benefit from eroding over time. Premium stability helps protect consumers whose premiums increase. Sufficient agent training and consumer education are also vital.

It could also help if we lowered the high costs of reverse mortgages. The costs are so high that many people who could choose to use the funds for their own care are hesitant to do so. Lowering the costs, possibly through a subsidy or other tools, could enable more people to stay in their homes and directly pay for and receive HCBS.
Family caregiving is the backbone of long term care in this country. AARP estimates that the economic value of such care in 2006 amounted to about $350 billion. There is also an estimated loss of productivity to American businesses (mainly through lost time) of another $33 billion. While the funds are not available to compensate all these caregivers even at a modest hourly rate, it is possible to offer federal tax credits to these caregivers and have some public programs allow family caregivers to be paid for providing care. A credit would be available to people with specific levels of disability who could either take the credit themselves or give it to their caregivers. The credit would enable the individual with a disability to spend more on his or her own behalf or would compensate the family caregiver for some of the costs of providing care. It is also critical to provide family caregivers with other supports such as respite care, workplace flexibility, assessments of their own needs, information, counseling and training.

It is also critical to improve the long term care workforce to ensure that there are sufficient numbers of adequately trained staff to provide services to individuals who need long term care. For example, turnover in the long term care workforce is very high, due to factors such as low pay and a lack of benefits. Reform is necessary to provide direct care staff with more input into and respect for the work they do, higher wages and improved benefits, training and educational opportunities as well as safer work conditions. An improved long term care workforce would also improve the quality of care and quality of life for individuals receiving services, as would the effective oversight and enforcement of quality standards.

If, as I said, we need a new point of view about long term care, we also need a new context for it. Improving consumers’ choices, financing, support of caregivers, and the other reforms I have described cannot succeed if they are individual components without a common context to connect them. AARP believes that we can create such a context as we build more livable communities.
This is clearly a long term project, but that should not deter us or make us short-sighted.

In livable communities, new houses and apartments are built according to the principles of “universal design,” which require one entrance at least without a step, doors wide enough to accommodate a wheelchair, and one full bathroom on the first floor; a room that can be converted to a bedroom on the first floor adds additional value. There are other elements that are a little more costly, e.g., kitchen cabinets designed to be removed so a person can work in the kitchen sitting down. These basic elements add little if anything to the cost of new construction.

But their impact is substantial. A single step, even a threshold, can be an insurmountable impediment to a person in a wheelchair or someone who walks with difficulty. The wide doors and the first floor bathroom speak for themselves. And what they say is this: small adjustments in design can make living at home and with greater rather than lesser independence available to more people as they age. And this, of course, connects the context with the point of view that care is aimed at independence and choice, with a goal of enriching life, not warehousing it.

Livable communities are more than design principles. The more we can create common spaces that are readily accessible to all, the more we engage all people (irrespective of their age and the quality of their health), in social activities, the more we improve both mental and physical health. Livable communities, in other words, remove barriers that create social isolation, one of the worst problems faced by older adults and people with disabilities.

To summarize my thoughts on long term care beyond the general ideas of point of view and context and the more particular nuts and bolts I have discussed, what is at issue here is assuring a consistent and high level of quality. Doing away with institutional bias, focusing on home and community-based care, broadening the choice and control of consumers of long term
care, supporting family caregivers, expanding financing options, improving the conditions and compensation of the long term care workforce, and reforming the private insurance market are simply parallel roads—maybe a multilane Interstate—leading to the goal of high-quality care for all. No one lane, or element, is dispensable. We need them all.

And we need to get to work on this road because what we have now is an intersection of many roads without stoplights or a traffic circle, leading to gridlock and crashes. As the boomers age and need more care, things will come to a halt without improvements. The good news, as I see it, is that the boomers’ insistence on getting their way will move these changes along more quickly than we might imagine. We may also find that the boomers, who know the value of a dollar, will be willing to pay for a system that works, but will balk at a non-system that does not.

The revolution in long term care is coming and the boomers will ignite it, lead it and accelerate its arrival. To keep the revolution orderly, not chaotic, it is important to focus on the changes that can be made to our long term care system to create a better system that gives people choices, has affordable financing options and helps those who help others. As more and more boomers deal with long term care issues, either for themselves or their loved ones, the demand for change will increase. And given their history of changing society at every stage they have encountered, it is impossible to imagine they will not demand the best care for their parents, themselves and their children.
Caring for Our Loved Ones

My caregiving story began in 1974 when my husband Steven was diagnosed with Multiple Sclerosis. MS, if you are not familiar with it, is a degenerative neurological disease that has no cure. Steven was 31 years old at the time. I was 28 and our daughter was five.

When Steven was diagnosed we lived hundreds of miles away from either of our families, and they lived hundreds of miles away from where they reared us.

At the time, MS was an extremely difficult disease to diagnose. We were lucky; Steven’s symptoms of pins and needles up and down his legs were given a name in just a week. Back then, many people went for years without knowing what was wrong. Today doctors can take an MRI and look inside someone’s brain.

Steven is 64 now. People with MS tend to have a normal life span. I could easily be a family caregiver for another fifteen years. I find the idea daunting, to say the least. Before the discovery of antibiotics he would most likely have died years ago from a bladder infection or some other consequence of his disability.

The world we live in today with families spread across the country, women being a key part of the workforce, and people over 85 being the fastest growing segment of the population is radically different than at any other time in history. These changes in society and science are what have changed “giving care” into “caregiving.”

The details of my story are mine alone, but my story is in many ways the story of all family caregivers. Those of us who live outside the norm in which most families are healthy and vigorous share a common emotional bond. We are sad and frustrated and angry. Our lives are much harder than necessary because our societal systems are not designed to support families dealing with chronic conditions. We feel very isolated even when we know—as I do—that there are millions of other family caregivers in the country. We find an inner
strength we never knew we had, but it comes at a very high physical and emotional price. I would give it back in an instant if I could wake up one morning and Steven was well.

Suzanne Mintz
Author of *A Family Caregiver Speaks Up—It Doesn’t Have to Be This Hard*
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Caregiving: Being There for Our Elders

Gail Hunt
President and CEO, National Alliance for Caregiving

Introduction
How will we face the challenge of caring for our elderly relatives and friends? Who will be there to care for us when we grow older and frail? As the population lives longer, but with chronic illness, we will need more loving hands to ably help us with the tasks of everyday living—first, helping with the groceries and housekeeping and getting to medical appointments, and ultimately helping with bathing, dressing and feeding. While caregiving has always been a balancing act for caregivers, changes in the American family as well as the entry of many women into the workforce have placed pressures on the traditional family caregiving structure. For those of us without family and friends available, or with conditions that require professional help, we will have to rely on the paid caregiver workforce.

There are 44.4 million family caregivers in the U.S. today¹ (21 percent of the adult population); many are juggling work and caregiving, and facing substantial financial and physical burdens. Eighty percent of long term support and services is provided by family members and other unpaid caregivers, such as volunteers, friends, and neighbors.² There are also 2.4 million workers providing paid direct care services, many of whom are family caregivers as well. As Boomers age, the demand for both family caregivers and direct care workers will continue to grow in the coming years. Common issues for caregivers and direct care

workers, to help enable them to continue providing care to our elderly and disabled, include recognition, training and education, as well as financial support.

**The Challenge of Family Caregiving**

The typical family caregiver is a 46-year-old boomer woman who works and spends on average 20 hours per week caring for her elderly mother who lives nearby. A large minority (41 percent) of family caregivers have children under 18 living at home. Many of these women are part of the “Sandwich Generation” who delayed childbearing and are now caught between the demands of childrearing, eldercare and work. Quite a few choose not to identify themselves as caregivers, and feel that they should be able to fulfill the needs of those in their care on their own, even if—as is often the case—they do need help.

Caregiving can place strains on a family caregiver, who both loves what she is doing, but worries about her various responsibilities. In addition to impacting employment (62 percent of working caregivers say they have had to make some workplace accommodation), providing care can place a significant financial burden on families who pay for specialized medical equipment and home care services. Long distance caregivers face special challenges, trying to arrange and monitor services for their relatives from many miles away. Some caregivers neglect their own health in their effort to focus all their attention on the care recipient. Many report a need for more time to themselves.

There are more than 2.4 million grandparents who are caring for more than 4.5 million grandchildren under the age of 18, because the children’s parents are unable to care for them often due to mental illness, substance abuse, or incarceration. These elder caregivers find an important sense of purpose in caring for their kin. However, they take on this role at great personal sacrifice and

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3 “Caregiving in the US” NAC/AARP.
4 “Caregiving in the US” NAC/AARP.
face a range of challenges, including securing medical coverage for their grandchildren, enrolling children in school and special education, and securing appropriate housing. These grandparents may incur substantial financial, emotional, and even physical tolls, feeling isolated and perhaps neglecting their own health. Because care of children by grandparents and other relatives prevents children from going into the formal foster care system, conservative estimates show these arrangements save taxpayers more than 6.5 billion dollars each year. More importantly, they provide a much more caring home environment than even the best foster care system could offer.

When asked, family caregivers say that they want information about services, including respite (some time for themselves), training to ensure that they are correctly fulfilling their caregiving responsibilities, keeping their loved one safe at home, and finding ways to balance work and family. There are some existing programs that have begun to help with support to family caregivers:

- The National Family Caregiver Support Program (Title III-E of the Older Americans Act) offers, through the aging network, some respite care, information, counseling, support groups, assistance in accessing services and supplemental services. It is currently funded at $162 million for FY 2006. However, much of the federal and state legislation, including the National Family Caregiver Support Program (NFCSP) is limited to adult children caring for elderly parents.
- Home and community-based services (HCBS) waivers under Medicaid finance some respite care for family caregivers of low-income elderly and disabled people.
- In some states Medicaid pays cash allowances to low-income elderly and disabled clients who can then pay family members for the caregiving services they need. (Arkansas, New Jersey and Florida were the three original demonstration states.)
• About half of the Fortune 500 U.S. corporations have some type of corporate eldercare program to support family caregivers, typically information and referral to resources or geriatric care management, or seminars and support groups for employees.
• Faith-based groups, including Faith in Action, and many local churches and synagogues have volunteer caregiver respite and friendly visiting programs.
• Many states and counties underwrite family caregiver programs, typically respite and support groups. Hospitals often offer caregiver support groups.
• Some states give tax credits for family caregivers to reimburse them for some of the long term care expenses they incur.
• There are at least two Medicare-approved insurance programs where respite and training are offered to family caregivers.
• The Internet has blossomed with websites that support family caregivers with information about resources and services and chat-rooms where they can share experiences.

Conditions are changing for family caregivers. The media is paying more attention to the issues confronting caregivers, especially those who are juggling work and family. Businesses, especially large corporations, are beginning to adopt some corporate eldercare initiatives. These initiatives can be as simple as directing employed caregivers to good websites, or as sophisticated as offering geriatric care management (which shows promise in increasing presenteeism, more time at work and on-task, for employees).

Technology offers a number of important opportunities that will soon help to greatly improve the lives of caregivers. Some promising products can help families communicate more effectively around the older person’s care via an Internet family diary; older adults compensate for cognitive decline with telephones that
show photos of the caller with key information; passive in-home monitoring systems record the older person's activities (making breakfast, leaving the house) and email the data to the caregiver at a distance to increase peace of mind. Assistive technologies can help caregivers with lifting and transferring as well as everyday activities such as bathing and dressing. Technology may also help compensate for the increasing scarcity of caregivers by making better use of the caregiver’s time.

Many examples of these important technological breakthroughs were presented by the Center for Aging Services Technologies (CAST), in partnership with the American Association of Homes and Services for the Aging (AAHSA), at the 2005 White House Conference on Aging exhibit hall. Featured products included a medicine cabinet that can remind a care recipient what pill needs to be taken, an interactive walker, a personal caregiving robot that helps provide services around the home like carrying groceries, washing dishes, and doing the laundry, and a wristwatch that transmits important vital signs to the caregiver and the doctor. Though technology can never replace the need for human interaction and support, many of these kinds of products will go a long way towards improving the lives of both caregivers and care recipients.

The family caregiver is the hub of family-centered health care. As an active member of the care recipient’s medical team, along with the physician and the patient, caregivers already know a great deal about their loved ones’ medical history, symptoms, and the home environment. Information technology, such as interactive electronic health records, decision support systems, and medication management tools, will support the caregiver in this role, as well as allow for electronic reminders to maintain his or her own health.

New companies are stepping in to offer some information solutions, especially web-based ones, but caregivers still need to be able to talk to a knowledgeable, trained and experienced person who can assess the situation and offer solutions at the local level where the older person lives.
Solutions
Some solutions to meeting the challenge of addressing family caregiver issues include:

- Expand the legislative definition of “family caregiver” to include non-traditional caregivers. To better reflect the diverse caregiving situations in contemporary family life, “caregivers” should include non-traditional families and non-kin informal caregivers, such as friends and neighbors, as well as diversity in terms of geography (urban/rural), income level, and ethnicity.

- Expand the size and scope of Aging & Disability Resource Centers (ADRCs), which currently are funded as one-stop sources for long term care information in 43 states, to offer a single point of information for caregivers, as well as elderly and disabled people across the country. Congress should permanently authorize ADRCs to reach out to family caregivers at various locations including libraries, hospitals, doctors’ offices, malls, and the Internet.

- Promote economic security for caregivers if they must leave the workforce to provide care.

- Focus policy efforts on caregivers in the workplace. Encourage employers by creating incentives for them to provide information and referral, geriatric care employment, caregiving leave, flextime and other programs to employees.

- Significantly increase the current appropriations level for the National Family Caregiver Support Program (NFCSP) and include aging caregivers of adults with lifelong disabilities, such as mental retardation and developmental disabilities, within those served by the NFCSP. Currently, the 70-year-old parent of a 35-year-old child with Down syndrome cannot get services under the NFCSP.

- Expand training and education opportunities for both family and paid caregivers under the NFCSP. This training and education needs to be culturally and lin-
guistically appropriate, and simultaneously there needs to be extensive outreach to boomer and younger caregivers to ensure that they know about the training and other services and how to access them.

- Increase respite programs to caregivers for people of all ages and disabilities. Special attention should be paid to developing models of respite for hard-to-serve populations, such as those caring for people with Alzheimer’s.

- Amend federal Medicaid regulations to allow family caregiving as a paid service, and develop a system allowing consumer choice in paying family members where “money follows the person.”

- Support evidenced-based and emerging best practices, in order to target funding for programs with the best outcomes.

- Use the Uniformed Services Employment and Re-employment Rights Act (USTERRA) as a model for family caregiver leave. This law requires all public and private employers to provide benefits and return-rights to employees on military leave.

- Extend services and resources to long-distance caregivers, especially in rural areas, who have to travel long distances to take care of their loved ones.

- Set up a waiver pool for civic organizations to provide transportation and other activities for care recipients. Create a system of in-home respite care services using volunteers, in order to help caregivers maintain older adults in their homes as long as possible.

- Actively pursue and implement public, private, and faith-based partnerships, including tax credits and incentives for corporate participants and family caregivers.

- Lower current age restrictions to allow for increased support to younger grandparents who are taking care of others. Amend laws to provide a legal role and responsibility
for grandparents, as well as address financial burdens on caregivers by creating tax incentives, strictly enforcing child support laws, and promoting consumer direction in the use of public funds.

- Establish a bipartisan commission on family caregiving appointed by the Surgeon General to bring visibility to caregiving and to foster research by employers and community organizations on the best ways to conduct caregiver outreach and support programs.
- Develop, fund, and implement a national program to assess family caregivers’ needs and link them to case coordination services.

The Challenge of Supporting Paid Caregivers

Even though family caregivers are the largest providers of care to those needing long term care, in the coming years, society must turn its focus to the paid caregiver because of the increase in the aging population and the fact that fewer children were born to boomers. High-growth and rural areas are especially in need of qualified paid caregivers; pay rates for these workers have increased somewhat but are still very low.

With the high rate of turnover, more than 200,000 Americans will need to enter the paid caregiving workforce each year in order for supply to keep up with demand. Like family caregivers, direct care workers receive very little training or support or recognition for the important work that they do. Most are independent contractors, and rarely is their work evaluated or monitored by outside groups or agencies. Paid caregivers also have liability concerns; one mistake or accident could cost them their financial well-being. Few have benefits such as health insurance.

Solutions

Some solutions to meeting the challenge of addressing family caregiver issues include:
• Create improved training programs for direct care workers, along with stronger standards, and certifications. Key recommendations include the creation of new courses at the high school and college level as well as online training programs that emphasize key competencies, including remedial support for individuals who need additional assistance with translation services, and tuition and job training tax incentives. The California child daycare worker education ladder, where individuals are expected to earn a certain number of course units prior to certification, is a possible model for the creation of an education ladder for paid caregivers. Nonprofit organizations could take the lead in developing the training materials, as well as teach ways to address the growing diversity of the care recipient population.

• Establish standards in paid caregiving, both to assess the direct care workers’ capabilities and to ensure a quality level of care for the older person receiving it. Mastery of these standards should be required to earn certification. Long term care insurance companies and others who are payers in the home health and long term care system, might limit reimbursement only to those with certification.

• Direct states to provide further incentives, such as continuing education and career ladders, to help keep paid caregivers on the job.

• Create a liability waiver program, at the state and federal level, for all people willing to work in direct care professions.

• Establish geriatrics as an underserved profession and support expanded training opportunities, loan forgiveness, benefits, and appropriate reimbursement.

• Create a new national association of paid direct care workers (such as the Paraprofessional Healthcare Institute) to establish and oversee accreditation programs for education and training, establish and oversee the
certification program, negotiate group rates on medical insurance for both independent and group workers, and provide bonding/indemnity for direct care workers. This group would be able to speak for and support the paid caregiving workforce.

- Organize a stronger recruitment effort to attract a diverse and qualified caregiving workforce. The heightened recruitment should focus especially in rural areas and in locations with diverse populations, and with people who are looking to change careers and want to make a real difference in their communities. The legions of family caregivers who no longer need to care for family members are also an untapped labor market.

- Encourage the growth of corporate caregiving by creating a new type of in-home care staffing agency to provide families with caregivers that may be better trained or compensated. The Department of Labor should monitor and then issue an annual report on the direct care workforce.

- Develop and implement training for direct service providers who work with adults with disabilities, so that these caregivers are better prepared to monitor the nutrition, wellness, medication management, and other health-related needs of these adults.

Conclusion
Caregivers are the bedrock of America’s long term care system; we would not—and could not—continue without them. Most family caregivers lovingly embrace the everyday tasks of caring for a relative or friend, and are both proud and satisfied with the work that they do. However, they often struggle with isolation, depression, financial burdens, and the challenges of balancing work and family. Likewise, most paid caregivers are dedicated to the patients for whom they care. But the caregiving environment, including the lack of recognition, information and adequate
training, can make it difficult to continue caregiving. Direct care workers face low wages, few benefits, and no career ladder in a physically demanding job.

Successful caregiving benefits both those involved in care as well as American society in general. Studies consistently show how strongly our elders want to age in place, and that elders with in-home care remain in better health than those placed in institutions. Aging in place also saves those paying for care, whether the recipient, their family, or the government, thousands of dollars every month as compared to the cost of care in an institutional setting. But families need to begin planning for long term care far in advance of needing it. Today’s boomers need to explore options such as long term care insurance to help pay for tomorrow’s caregiving needs.

Our Nation’s entire long term care policy depends on the willingness of family caregivers to continue their important work, and for paid caregivers to cover the gaps where family caregivers are not available or able to provide care. In the face of increased demand and reduced availability of family and paid caregivers to meet our nation’s needs, it is imperative that America find better ways to support its caregivers. Without willing and able caregivers, both paid and unpaid, families with loved ones needing care, and the American taxpayer will be forced to pay the high cost of a nursing home as the only way left to provide care. Supporting the caregiving population in their tasks is essential to maintaining an economically viable long term care system.
Being a Caregiver

Being a caregiver is a very rewarding job, but it's also a hard job. It's not so much about the work that has to be done but the fact that people don't usually get better, they get worse. Every time I start to work for someone new, I tell myself that this time I won't get too attached to them. But the truth is you have to get close in order to be a good caregiver. You have to understand what makes them happy and learn to do the special things that other people don't have the time to do. Sometimes I know them better than their own family.

I have twelve brothers and sister who are all younger than I am. My mother has diabetes and is in a wheelchair, my father died a few years ago from cancer. It seems like I've been a caregiver my whole life. I went to school and got the C.N.A. certificate so that I could earn a living doing something I already knew how to do. But sometimes it's hard to make ends meet because you lose a client and then you have to find someone else. And some folks don't want to pay as much as you were making before, but you have to take the job anyway. I'm trying to go back to school so I can be an LPN. Then I can work for a hospital or facility with steady hours and health benefits. And I'll be a nurse. Nurses get more respect in the community and I want my little girl to be proud of me. I hope she grows up to be a doctor.

Nancy
Richmond, VA
Home Is Where the Care Is!

Larry Minnix
President and CEO, American Association for Homes and Services for the Aging

Three epiphanies about the future.

In the late eighties, I worked at Wesley Woods, a not-for-profit organization based in Atlanta serving a predominantly low-income population. Driving home one night from a speaking engagement at a church fellowship supper, I had an epiphany. We needed a strong fund-raising program to underwrite un-reimbursed and charitable care.

Wesley Woods had a good reputation with waiting lists, but we had an interpretation problem when it came to fund-raising: the public perception was that the government paid for everything when the elderly needed service. Unfortunately, it was not true then, not true now.

That evening during the lively Q&A segment of my speech, there was not a single question about how to get in a Wesley Woods facility. Instead, all the questions centered around our corporate plans to help people stay at home. At the time, we had no plans to offer such a service, and our response was: maybe we can build more facilities near you!

Second epiphany. As the Wesley Woods program evolved throughout the eighties, we developed—in association with Emory Healthcare—a specialty hospital with outpatient clinics. We began to see nursing home bed vacancies. During a rather tense meeting with our admissions and social work staff on strategies to keep beds filled, not without trepidation, an outstanding member of our staff bluntly stated: “We don’t sell people on the idea of a bed if they don’t really need to come to a nursing home! Is it ok if we just help people get what they
need?” The epiphany that day was that we needed to transform our “bed-selling office” into a “helping-older-people-and-their-families-get-what-they-need office.”

Third epiphany. By the early nineties, the Wesley Woods program was turning into a comprehensive geriatric center with numerous inpatient and outpatient specialty medical programs, housing options, and budding case management services. A member of our board of directors sent us a referral: one of his colleagues with global responsibilities was traveling from Australia to Europe, where he was to join his wife for a corporate event. The wife’s mother, who lived in another state, was facing a health crisis. Could the Wesley Woods staff put together a services plan while the corporate couple was in another part of the world? We found the mother a geriatrician in her state, where a comprehensive evaluation was performed. The mother was treated and returned to her home, with needed service and support. They were a busy and complex family that needed peace of mind when caring from a long distance is the only alternative. A universal emerging family problem!

Why are 25-year-old epiphanies from a provider perspective important to the public, the business world, and policy makers? Because the needs of an aging society are outgrowing the service delivery, payment, and policy systems we have to manage them. We are in a transformational era of aging services where we predict that:

- Quality of service will become an automatic public expectation
- Consumers and their families will be in charge of services to meet their own needs
- Home will become the dominant venue of choice for people facing chronic conditions
- In most communities, the creation of community-based networks of care will become the dominant business paradigm
- New and innovative housing with services models will emerge as new types of elder-friendly neighborhoods
- New services enterprises will sprout all over America for older consumers to stay in their homes
- Technology will be the accelerator to make consumer-directed, home-centered care the new model
- Financing to meet needs will evolve to a broad-based public insurance model where money follows the client, and insurance plans will be tailored to enhance both quality of life and choice of services

The consumer has been sending these signals for generations: he/she wants to stay at home if at all possible! Many families go to great lengths to make that possible, and they will drive changes to get what they want!

Evidence of this phenomenon is reflected in the fact that the vast majority of long term care already takes place at home, that support groups and self-help mechanisms flood our bookstores, that the Internet is creating global communities that share support and knowledge, home support businesses are springing up everywhere and policy is favoring home services programs.

In fact a year ago, Dr. Mike Magee of Pfizer told an audience of our association that over the next decade, the convergence of consumer power, technology applications, and changes in the finance and insurance industries will render current service models and providers obsolete. “Current provider silos will vaporize,” he said.

Eric Dishman of Intel recently told an international audience that the technology giant’s research on the needs of an aging world reveals consistent findings about consumer needs and wants:

- People want to feel safe and secure
- They want support for cognitive impairments
- They want help in orchestrating needed services
• They want health care at home
• They want social interaction, even through technology
• They want a meaningful and useful life
• They want to live in an environment of choice

So, what new business models will emerge over the next decade to deliver the services people need, when they need them, in a place they call home? There are several options:

New Neighborhoods. New types of planned communities are emerging throughout America that are tailored to older people and their families. The most mature is the continuing care retirement community (CCRC). These communities feature apartment suites, townhouses, condominiums, and duplexes—all on one campus that offers increasing levels of care as people become more dependent. The public will see the joint venture options of these new neighborhoods that combine and leverage the expertise of developers with that of service providers in order to create new models and standards of homes with services package integration.

CCRCs are considered an insurance product in most states and are becoming the home option of choice as the needs change. They offer quality of life amenities, immediate response to health crises, and maintenance-free accommodations. They also offer friendships, security, useful life activity, and higher level of care services as needs change. They validate the Intel research on what consumers want.

Today, continuing care retirement communities reach a middle to upper income market, but newer models are becoming more affordable to older people of more modest means. Some, like Erickson, are experimenting with Medicare Part A service integration as well.

There are variations to this theme: active adult communities, naturally occurring retirement communities, and cooperative models. These combine the best features of neighborhoods, gated communities and architecturally tailored to the needs of an aging population.
In-Home Concierge. Organizations experienced in aging services through various types of facilities are beginning to package their services brand to deliver them to seniors in surrounding communities. Judson Retirement Community in Cleveland (with over one hundred years of history) and Kendall (multi-state based in Philadelphia), now offer Kendall or Judson “at-home.” Service packages can include meals, fitness plans, travel, artistic activities, coordinated planning, and transportation.

Some organizations like Sears Methodist based in Austin, Volunteers of America, The Evangelical Lutheran Good Samaritan Society and Front Porch are developing a technology that features specialized response and monitoring devices.

More clinically complex packages are available for people with conditions such as diabetes and congestive heart failure; personal vital statistics can be monitored through telehealth devices with video cam support from professionals in order to keep the human contact at the heart of the experience. These services are more likely to be offered by hospital and medical center complexes because they require physician and nurse management of disease and care coordination. The Eddy in Troy, New York and Visiting Nurses Associations of America in Boston are using such systems. These services reduce unnecessary emergency room and doctor office visits, increase patient compliance with treatment plans, and are often very helpful to family caregivers who would otherwise be responsible for providing emergency response and transportation.

Currently, telehealth services are reimbursement-driven and paid by Medicare on a limited basis. But the future will see more entrepreneurial packages where client families will be willing to pay out-of-pocket for the quality of care, and insurance and managed care companies will negotiate cost-effective packages on behalf of their client base. An ethical issue arises when lower income elderly need services beyond third party coverage but cannot afford to pay out-of-pocket. This needs remedy through a broader means of financing long term care, which will be addressed below.
Technology Packages. Comprehensive security and entertainment packages are already available in many homes in America. More technology companies will offer comprehensive health monitoring packages and health services delivery support. The Internet highway will add “new lanes” for health. These are likely to be independent of local and conventional services delivery systems initially because the companies that offer current packages through television or computer already have direct access to international markets through existing personal computer and television. Many will skirt the legal boundaries of current, traditional health care practice through mail-order medicine approaches, but eventually, the great preponderance of care can be accessed through the air waves because the technology is emerging to do so, and the public will get what it wants based on value, convenience, and choice.

A La Carte. The Yellow Pages are increasingly filled with specialists in services that make it easier for older and chronically impaired people to stay at home. Food delivery companies, mail order medicine, private transportation, home maintenance (both paid and volunteer), homemaker–health aid are but a few. Most are privately paid, but some are now covered by Medicaid programs in certain states for lower income seniors in need. But, again, the need far outstrips traditional coverage.

There are emerging private legal and case management services that manage the process of service orchestration for families who care for their elders but must do so from a distance. This professional role will most likely be the fastest growing professional role in health care, with experienced nurses and social workers hanging out their shingles to help people manage chronic care complexity on a daily basis.

Financing of Long Term Care at Home. The financing of home-centered, person-directed care will undergo a revolution in the next decade. The cash to help with these expenses is already coming from new programs like reverse mortgages. Long term care insurance products will undergo change to offer more
flexible options with delivery of in-home services, with covered populations not just covered individuals.

But major reform will likely be needed because the existing Medicare and Medicaid programs are in a financial crisis and current long term care insurance has marketplace limits. So, a new approach through a public-private insurance for all should emerge where the dollars follow the person—not the provider—and long term care insurance products will have more choices for a wider range of consumers.

The public generally wants to stay in the place they call home, and they will eventually demand the products and financing options that will allow them to get what they want. Existing models of services are as antiquated as the rest homes, widow’s homes, and alms houses of a century ago. We are entering a transformational era characterized by entrepreneurial possibilities shaped by an increasingly demanding and diverse American public that wants choice, comfort, access, quality and personal service . . . because home is where the care is!
Nursing Homes and Assisted Living Facilities

I have been conducting research in nursing homes for over twenty-five years with the majority of my work involving direct care with residents. This length and depth of research has provided me with an excellent frame of reference for how difficult it is to improve resident functioning and how labor intensive it is to do so. From my experience I have concluded that many nursing homes remain challenged by funding, staffing, and other issues that impede their ability to provide the highly consistent care that is necessary to improve or sustain functioning and quality of life. In order to make what I would consider “real” progress in regard to key staffing and management issues in the future we need to start by answering the following questions:

- How many and what type of staff members are necessary to provide care consistent with regulatory and best practice guidelines presuming that staff works efficiently?
- What are the best methods of managing staff to achieve optimal levels of efficiency and how do factors such as environment (e.g., small units) and staffing models (e.g., universal workers) affect staff’s ability to provide care?
- Given evidence that all residents do not want or would not benefit from some best care practices, what is the best method to individualize care and how does such individualization affect staffing requirements and efficiency?
- What are the clinical and quality outcomes if care is provided on a consistent basis? And to what degree do these outcomes offset the cost of providing better care?
- How can effective staffing models and management techniques be transferred to nursing homes in order to improve practice?
I believe a more proactive approach, one that would create demonstration sites, is needed since we have made little progress in answering the above questions using the research strategies that have characterized our efforts during the last twenty years. These sites would implement care under controlled conditions to produce scientifically defensible data relevant to the quality and dissemination of the questions posed above. Management and analytical technologies that are seldom used in long term care (time/motion, electronic documentation of care provision, cost accounting) would be applied to this effort.

The continued failure to address the questions listed above can only lead to pessimistic predictions for long term care given the future funding and work force pressures discussed in this chapter by Bruce Yarwood of the American Health Care Association. However, this research model is not without political risks—which may in part explain why it has not been implemented. For example, providers, advocates, and regulatory agencies would have to be open to admitting the possibility that the highly ambitious care recommended in practice and regulatory guidelines is not being implemented given current staffing restraints, and that good care is more expensive to provide than what is possible under the current reimbursement systems. One result of this effort is that we may have to rethink our expectations for what long term care can accomplish and how it is funded.

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The Future of Facility-Based Long Term Care in America: Nursing Homes and Assisted Living Facilities

Bruce Yarwood
President and CEO, American Health Care Association and the National Center for Assisted Living

It is a little daunting to tackle a subject like the future of facility-based long term care in America. But, talking about who will provide it, how to deliver it, and who will pay for it starts with understanding where we are today and how we got here.

Where We Are and How We Got Here
Nearly sixty years ago, the American Health Care Association (AHCA) began working to improve the standards of the long term care profession and to promote a better understanding of what comprises a supportive, quality-focused care environment. Not much has changed since then in terms of AHCA’s mission—we are still focused on how to improve quality of care and quality of life for America’s seniors and people with disabilities for whom our membership cares each day.

What has changed, however, is the financing, legislative, and regulatory environment in which we work. Just as significantly, the choices now available for consumers to determine where and how long term care services will be delivered did not exist sixty years ago.

More than forty years ago, the federal government established the Medicare and Medicaid programs, which provide an important safety net to assure that frail, elderly, and disabled Americans have access to health care. Twenty years ago, landmark legislation—The Nursing Home Reform Act—contained in the Omnibus
Budget Reconciliation Act of 1987 (OBRA ’87) changed government oversight of federally-funded nursing home care. Then, in 1999, the U.S. Supreme Court handed down the Olmstead decision (Olmstead v L.C. [527 U.S. 581 (1999)]), which has in effect expanded the options available for long term care and services. Just over a year ago, implementation began for a new prescription drug benefit—Medicare Part D—to help seniors deal with the rising costs of prescription medications. Each of these milestones has altered, and continues to impact the long term care choices for frail, elderly, and disabled Americans.

One of the promises of OBRA ’87 was a culture change in the delivery of long term care, and a shift toward more patient-centered care that focuses on quality of life and promotes autonomy, dignity, and consumer choice. Assisted living, independent living, and innovations like the Green House Project, Eden Alternative, and the Pioneer Network have helped to inculcate that culture change as part of a broader array of alternatives to traditional institutional nursing facility care, which also is changing to offer more home-like settings and a greater choice of services.

Indeed, Americans now have more choices when it comes to long term care and services. The continuum of long term care ranges from home- and community-based services (HCBS) to assisted living and skilled nursing, rehabilitation, and post-acute care.

Nursing homes have grown in order to meet the more clinically complex needs of today’s long term care patients. In fact, we are seeing with enforcement of Medicare’s 75% Rule that there is capacity to care for a greater number of patients who are entering facilities for rehabilitation before returning to their homes and communities. Today, the average nursing home stay is only 27 days. As we look toward the future, we anticipate that this trend will continue with a growing emphasis in nursing home facilities on short-term rehabilitative care. Concurrently, some

less acute, longer stay patients will increasingly seek and receive care and services in the home or community.

Despite this trend, currently the average nursing home resident is an 85-year old grandmother with cognitive or functional impairments and multiple co-morbidities that typically require nine medications per day. More than half of the nursing home population has some form of cognitive impairment or dementia. Since 80 percent of long term care patients rely on Medicaid or Medicare—and almost all people with severe and profound mental retardation rely on Medicaid—to pay for their care in a skilled nursing facility, long term care is one of the most highly regulated industries in the country.

**Consumer Choice Expands Continuum**

The baby boom generation has had a tremendous impact on the American marketplace, and long term care is no different. Consumer demand has already expanded the assisted living and other long term care choices across the continuum, with many skilled nursing facilities and assisted living residences diversifying services to include home care or hospice as a way of broadening their reach into the marketplace. This trend will continue as baby boomers and other consumers with means seek amenities and conveniences that long term care providers must consider when evaluating existing physical plants and future renovations.

As the federal government seeks savings, Medicaid waivers are encouraging more home- and community-based care. Already Medicaid waivers pay for in-house visits, and there could be future efforts to encourage more in-home care, such as tax incentives for home owners who make modifications that allow older adults to stay in their own homes.

Health information technology also is driving change. For example, telehealth may allow a greater number of older adults to remain in their homes. Meanwhile, nursing homes that are adapting to advances in technology and medicine are beginning to more closely resemble a post-acute health care setting, where
there are more Medicare short-stay patients than there are longer term patients covered by Medicaid or private pay. Still, with more than half of today’s long term care patients having some form of cognitive impairment, nursing homes and assisted living facilities will need to continue to provide Alzheimer’s or memory care.

Continuing Care Retirement Communities (CCRCs) are attracting private pay residents, which may allow for more financing and building of such communities. Even so, the CCRC marketplace may grow at a slow pace as research indicates that while older persons are likely have greater assets, data also shows only meager retirement savings.

In 2001, the average defined contribution among all households ages 55–59 was only about $10,000, partially because 36 percent of households had no individual retirement accounts (IRAs) or defined contribution plan account. Excluding those households, the median balance for this age group was just $50,000. Putting figures into context, these resources are likely to be consumed fairly rapidly by long term care costs as, on average, a one-year nursing home stay costs $70,000.

If mortality rates continue to drop without a considerable uptake in advanced planning for long term care needs, seniors could possibly be forced to spend down at some point in order to qualify for support from Medicaid. Since there seems to be limited capacity for state and federal government education about private long term care options, nor sufficient incentives such as direct subsidies or tax incentives for the purchase of private long term care insurance, the possibility that many seniors will opt to spend down their assets to receive Medicaid benefits is more likely. Four states—California, Connecticut, Indiana, and New York—created Long Term Care Partnership Programs that allow individuals who exhaust qualifying long term care insurance policies to then access Medicaid to pay for their long term care needs. The Deficit Reduction Act of

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2005 included provisions that expanded this partnership program option to all states and called for a National Clearinghouse for Long Term Care Information to better educate consumers about long term care insurance and public/private long term care options. More needs to be done to clarify the public misconception as to how care is funded and explain that citizens are only eligible for Medicaid after they have impoverished themselves.

Quality also will continue to be a force for change in nursing homes and assisted living facilities in the future. The Centers for Medicare & Medicaid Services (CMS) data shows several key quality indicators—including pain management and depression—are indeed improving.

Still, the survey system we have today is designed to look at compliance around the Conditions of Participation in the Medicare and Medicaid programs and patient safety. It is not designed to assess all the complex clinical issues common to long term care patients and residents. Even though most states do a good job of regulating assisted living, there is increasing pressure for federal regulation. Should calls for federal regulation take hold, it would be important that assisted living providers be included in the process to help shape any future federal oversight system of assisted living. By including assisted living providers in crafting any such oversight, assisted living could avoid some of the pitfalls that nursing homes have experienced in the wake of OBRA ’87.

One thing is certain—quality of care is dependent on adequate, stable funding. So, the investments we make now will affect the quality of long term care in the future.

Who Will Provide Care?
Human contact is essential to treating long term care patients and you will never be able to replace the role that people play in providing long term care. So, while technology may be available to assist caregivers with certain monitoring functions in the future, technology can only serve an adjunct function—it is not a replacement for trained health care workers.
Estimates developed by the U.S. Bureau of Labor Statistics for 2003 show that the long term care delivery system employed more than 3.85 million workers, with 72 percent of the total long term care workforce engaged in facility-based care and services.

The current long term caregiver shortage will likely worsen over the next decade with the number of Americans requiring long term care services increasing and a significant numbers of caregivers retiring. The U.S. Department of Labor’s Bureau of Labor Statistics predicts that there will be a 45 percent increase in demand for new long term care workers between 2000 and 2010, which is the equivalent of approximately 800,000 new jobs.

According to AHCA’s 2003 report on nursing staff vacancy and turnover, the annual turnover rate for nurses in long term care was about 49 percent, while certified nurse assistants (CNAs) turnover rates reached 71 percent annually. These vacancies and turnover are estimated to cost the long term care profession more than $4 billion each year.

While the long term-care profession and other health care settings struggle to recruit and retain nurses and nurse assistants, more Americans are receiving care in home- and community-based settings which oftentimes calls for nursing staff and further strains the pool of qualified caregivers who would otherwise work in a skilled nursing facility or assisted living residence. High costs for trained caregivers also mean that more family members are acting as caregivers.

How Will Care Be Delivered?
Long term care is not a “one-size-fits-all” proposition. Every consumer—with the aid of their families, doctors, and trained caregivers—should choose, and have access to, the most appropriate care facility for their health care needs as well as their environmental preferences. Care, then, must focus on the patient, his/her satisfaction, care outcomes, and the degree to which the facility meets those clinical and quality of life needs.
Who Will Pay for Long Term Care?
Presently, the majority of long term care and services, about 80 percent, is paid for by governmental programs with private pay and long term care insurance making up the difference. In June 2007, according to the Centers for Medicare & Medicaid Services (CMS), which oversees nursing facility care, 65 percent of all nursing home residents relied on Medicaid and an additional 14 percent depend on Medicare for their care and services. In 2004, Medicare payments to skilled nursing facilities totaled approximately $17 billion—less than 7 percent of the nation’s entire Medicare spending. There is no indication at present that there will be a dramatic change in terms of payers, even though there may be changes to the payment system.

The skilled nursing facility prospective payment system requires that patients be assessed and classified into a payment category known as a Resource Utilization Group (RUG). Each RUG category is paid a per diem rate that is adjusted for case mix, wages, and setting, and covers everything provided to the patient. In 2006, the RUGS-III system was overhauled to include an additional nine RUG categories. Future payment systems could replace RUGs with a bundled post-acute Medicare payment that would more closely resemble the hospital Diagnosis Related Group (DRG) payment system.

Addressing Today’s Obstacles
As we look ahead to an elderly population that will double over the next thirty years and to the challenges of having a dwindling workforce to contribute to the resources needed to meet the upcoming demands on our Medicare, Medicaid, and Social Security system, we recognize the critical time we are in.

Today, the three biggest obstacles the nursing home profession faces are financing, oversight, and workforce issues.

First, quality care is inextricably linked to stable funding. As the majority of long term care patients and residents—nearly 80
percent—rely on Medicare and Medicaid to pay for the care and services they need, it is critically important to understand the cross-subsidization of these two programs. So-called overpayments from Medicare continue to prop up significant Medicaid under funding of long term care and services, which totaled $4.5 billion annually in 2006. An infusion of private funds, including long term care insurance, is also integral to stabilizing the currently shaky system.

Second, our oversight system is broken. One of the changes OBRA ’87 instituted was a greater regulation of skilled nursing care by the CMS Survey and Certification Program. Surveyors simply do not have a clear understanding of the challenges nursing facility staffs face each day in caring for frail, elderly, and disabled patients. Moreover, there is tremendous inconsistency in the survey process and inconsistency in surveyor training. Add these inconsistencies to CMS’ lack of transparency regarding the criteria for identifying poor performers such as those in CMS’ Special Focus Facilities program to other concerns with survey and certification, and the job of a long term care provider is made even tougher. Encouraging greater transparency, as well as concurrent training for surveyors and providers alike, in addition to some hands-on experience with day-to-day operations of a nursing home as part of new surveyor training would go a long way to assure an oversight system that is fair, consistent, and vigilant about patient safety and quality issues. It also must be noted that while CMS has made strides in overseeing and focusing on quality of care in HCBS, it must go further to ensure that the care meets the needs of our vulnerable populations.

Third, health care—and the long term care profession in particular—suffer from a workforce shortage. In 2007, there are some 100,000 vacancies for registered nurses (RNs), licensed practical nurses (LPNs), and certified nurse assistants (CNAs) in long term care. Comprehensive immigration reform that includes a guest worker program and eliminates caps on nurse visas could help to ameliorate this shortage by allowing foreign-born workers to fill the more than 50,000 CNA jobs that Americans are
not taking. Similarly, reauthorizing and fully funding the Nurse Reinvestment Act, which would include educational financial assistance to caregivers across health care settings and enhance the numbers of nurse educators, would help to address these serious workforce recruitment and retention issues.

Future: A Culture of Cooperation
Twenty years ago, the passage of the Omnibus Budget Reconciliation Act of 1987 ushered in an era of change in our approach to patient care. Congress’ mandate was clear—all certified facilities must “attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident.” OBRA ’87 also broke ground by requiring that each patient receive a comprehensive assessment using a uniform Minimum Data Set (MDS), and that each facility create and use an ongoing quality assessment and assurance committee to evaluate daily processes and procedures that could generate positive patient outcomes.

We are still far from the ideal of a resident-centered, outcome-oriented, consistent system of oversight as OBRA ’87 intended. Today, we know far more about quality and we have better tools to measure it than we did twenty years ago. So, we need to intelligently change the regulatory process to allow and encourage us to use what we have learned—to place quality over process, care over procedure, and most importantly, to put patients and their care at the center of what we measure and why.

As we look for ways to take long term care quality to the next level, we recognize that providing quality care for seniors and people with disabilities depends on having a collaborative relationship among providers, government, consumers, and the other stakeholders. That kind of “culture of cooperation” is exactly what long term care providers, led by AHCA, are cultivating.

A leading example of this change is a coordinated effort to improve care quality through the two-year, voluntary Advancing Excellence in America’s Nursing Homes campaign. The campaign was launched in September 2006 by a coalition of health care
providers, caregivers, medical and quality improvement experts, government leaders, consumers and other stakeholders. Nine months later, more than one-third of nursing homes are voluntarily participating in the campaign to improve the quality of life and quality of care for both residents and staff.

While we cannot predict the future, we can work together toward a future that fulfills the promise of OBRA ’87 of patient-centered care. Some of the components of that future long term care system include having standardized, comprehensive, and clear quality measures that can be applied across care settings as patients often move among care settings (note: we mean care settings as in from hospitals to nursing facilities, etc. depending on patient’s care needs) and across the full spectrum of care; using individual and family satisfaction data to better understand what health care consumers want in addition to what long term care and services are needed; reflecting person-centered care and the quality dimensions that go along with that care in an oversight system that fairly, objectively, and consistently reviews compliance with standards; and recognizing best practices and perhaps even offering incentives for providers who demonstrate dedication to continuous quality improvement.

Conclusion
Understanding the care needs of the individual, and getting the appropriate care in the appropriate setting is critical, especially for the millions of Americans being cared for in long term care facilities now and for those who will need care in the future.

AHCA/NCAL is working toward a financing system that enhances quality care; an oversight system that is fair, consistent, and that rewards quality; and a workforce that meets the growing needs of our nation. With those components in place, we will have a system that encourages transparency and accountability, and provides economic stability that will allow for continued improvement in quality care. Ultimately, however, it is the consumer who will decide what long term care and services will be part of the future.
A Resident’s Letter to Her Long Term Care Facility

I have been a resident here since August of 2003. I have never experienced a day when I have questioned the decision I made. I have been perfectly content with the lifestyle I have chosen at this residence. That is primarily due to the philosophical model that you and your staff have created and I would like to express my appreciation.

I never dreamed that when I sold my home, leaving an existence that I was very comfortable in, that I would find the opportunities that I have discovered here. In the time I have been here I have explored opportunities in the TV studio, learning how to work the scroll and develop voiceovers. I have dabbled with learning how to edit DVDs and still pictures, and I developed a commercial for last year’s New Year’s Party.

I have had the time to learn new skills on the computer, which afford me the pleasure of doing the Entertainment Committee publicity. I have had the privilege of chairing the Decorating Committee for the Gala for two years in a row, which opened up doors and taught me better organization and communication skills. I have the opportunity to participate in several of the ongoing clubs, contributing to my social existence.

With Trips & Travel I have the chance to expand my existence beyond the gates of our community, and I have frequently taken advantage of this opportunity. I am free to come and go. I could go on and on about my opportunities, but the point I wish to make is that “The Golden Years” should not be years of idleness.

You have given me the opportunity to take advantage of talents I never had the time or chance to explore before or that I never even knew existed. It helps me feel that I am returning a service to the community in my small and limited way. I want you to know that you have a special gift for improving senior living.

Edith
Warminster, PA
The Future of Independent Living Communities

David Schless
President, American Seniors Housing Association

Introduction
For the vast majority of the nation’s seniors, the years of retirement are relatively active and productive. Indeed, most seniors lead very independent lives and intend to “stay put” in their homes and familiar surroundings as long as possible. The reality, however, is that due to longer life expectancy and increased likelihood of functional impairment associated with age, at some point in their lives many seniors ultimately face the question as to whether their current home environment is best suited to meet their physical and/or social needs. Increasingly, seniors are seriously considering and in many cases choosing independent living over the option of living at home.

Independent living has emerged as a preferred lifestyle alternative for many seniors because it is uniquely positioned to balance the needs of those who desire a highly residential living environment with one that offers essential physical and social support. In many respects, it combines the best of all worlds—it allows seniors to maintain a relatively independent lifestyle in the privacy of their own apartment, and at the same time benefit from a range of physical, dining, and social supportive services. The living environment is specially designed to accommodate those with diminished functional capacities as well as those seeking a highly active and stimulating social environment.

The decision to move to independent living is typically “need” driven. In other words, physical or health limitations such as chronic arthritis, limited mobility, falling, and mild cognitive
decline often precipitate a move. For some, managing basic household activities, such as grocery shopping, meal preparation, and home maintenance becomes challenging. While health issues often precipitate a move to independent living, the decision to move is also driven by a strong desire for the social connectedness associated with living with others. This is particularly true for many seniors living at home who have become isolated from others due to the loss of a spouse or close friends or the inability to drive. Significantly, people who live in independent living communities are more satisfied with their daily lives and more likely to be happy than their contemporaries who remain in their own homes.¹

The substantial growth in seniors housing, and in particular independent living, would not have been possible without large capital infusions from institutional investors. Debt and equity investors have been attracted to independent living for several reasons. First, it is a consumer-driven, highly residential housing concept that is very attractive to the burgeoning seniors market. Second, independent living is predominantly private-pay and therefore not dependent on government subsidies. Third, it is a housing model that enjoys high customer satisfaction and high occupancy. Finally, it enjoys a steady base of customer referrals from highly satisfied seniors and their adult children as well as health care professionals.

Independent Living Communities Defined
The availability and range of services provided in independent living communities has grown substantially over the past several decades. They are now commonplace throughout much of the country, including more rural areas, and public awareness of the range of services available in independent living is growing among health care professionals, policymakers, as well as seniors and their adult children.

Independent living is uniquely positioned between the more protective environments of skilled nursing and assisted living and living environments with minimal, if any, onsite supportive services such as active adult retirement communities, 55+ apartments, and private homes. Independent living is generally defined as:

An age-restricted community designed for seniors who pay for a core set of services (e.g. weekly housekeeping, utilities, transportation, 24-hour security, central dining, linen service, and social and recreational activities, etc.) as part of a base monthly fee or rental rate, and who require little, if any, assistance with activities of daily living. Typically, independent living units are not licensed for health care. Residents of independent living units may receive home health care services provided to them by either an outside agency or an affiliate of the property management. Independent living communities may be of two types: a rental model (no upfront entrance fee at time of occupancy) or an entry fee model (typically a continuing care retirement community where the resident pays an upfront entrance fee at time of occupancy and nursing care is offered under a contract).

Independent living communities are typically multifamily properties with 75 to 250 units in garden-style to high-rise buildings. They provide seniors with the opportunity to enjoy a high quality of life in a professionally managed setting that provides a full range of hospitality services. Amenities typically include a library, fitness center, convenience store, beautician/barber, 24-hour security, scheduled transportation, etc.

Rents vary greatly depending on the region of the country, size of the living unit, services included as part of the base monthly fee, and the range of service amenities available within the community. Many communities offer a variety of unit types to choose from, including studios, one-bedroom and two-bedroom designs. The range of fees runs the gamut, but generally
range from $1,500–$2,500 (studio type) up to $3,500–$4,500 (two-bedroom unit) per month.

Demographic and Social Characteristics of Independent Living Resident and Non-Residents
Below are key findings of a recent independent living study from residents of 66 independent living communities in 10 markets throughout the country. The study compared the lives of people who reside in independent living communities (“Residents”) with people who have similar demographic characteristics and live in the neighborhoods of the independent living residents’ previous residences, but do not live in an age-qualified community (“Non-Residents”).

- **Demographic Characteristics**: Widowed, white females in their mid-80s make up the largest percentage of residents in independent living. Most of them have annual household incomes ranging from $25,000 to $75,000 and a total net worth ranging from $100,000 to $500,000.
- **Long Term Care Insurance**: Most Residents do not have long term care insurance policies, however, a statistically significant greater proportion of residents (37 percent) have purchased long term care insurance than Non-Residents (29 percent).
- **Residents Are Primary Decision-Makers**: For the vast majority of independent living residents, the decision to move to independent living is one of their own choosing. According to a recent study of adult children 45+ years of age who have at least one parent living in an age-qualified community:
  - 46 percent of adult children with a parent living in independent living reported that their parents made

2 ibid.
the decision to move to independent living entirely on their own, and 28 percent participated as an advisor and offered their opinion to their parents, but did not make the final decision.  

- **Residents Desire the Company of Others**: While health considerations top the list of reasons why people move to independent living, the most striking factor as to why people choose to do so is that Residents prefer the company of others.
  - 84 percent of the Non-Residents compared to only 14 percent of Residents would prefer to live in their own house, even if that means that they would be alone much of the time.
  - 49 percent of Residents would rather eat a meal with strangers than eat alone compared to 18 percent of the Non-Residents.

- **Residents Are More Satisfied with Their Daily Lives**: Residents are more satisfied with their daily lives and are more likely to be happy than Non-Residents who remain in their own homes (see Table 1). A statistically significant greater proportion of Residents (90 percent) compared to Non-Residents (77 percent) are satisfied with their daily lives.

- **Residents Are Very Satisfied with Independent Living Community**: The vast majority of Residents (91 percent) are satisfied with their overall experience of living in the community (see Table 2).
  - 97 percent believe they have their privacy when they want it.
  - 97 percent feel safe and secure in their retirement community.
  - 89 percent believe they have control over what they do.

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• **Health:** A statistically greater proportion of Residents (10.3 percent) than Non-Residents (4.1 percent) rated their health better today than it was two years ago (see Table 3). Residents and Non-Residents are similar to each other relative to all of the various chronic limitations that are typically present in advanced age, with the exception of stroke and hearing impairment. A statistically significant greater proportion of Residents (35 percent) than Non-Residents (23 percent) uses an assistive device (i.e. cane, walker, scooter).

• **Leisure Time:** Residents spend a statistically significant greater amount of time in a group activity or event each week (2.9 hours) compared to Non-Residents (1.4 hours). Non-Residents spend more time watching television, an average of 18 hours per week vs. Residents, who average 13.9 hours per week.

**Trends in Independent Living**

Market rate, for-profit independent living communities comprise the vast majority of the independent living sector. The sector has emerged as a highly dynamic and consumer-driven housing model. Today’s seniors have access to a wide range of independent living communities, from moderate priced rental communities with basic services to more upscale rental and entrance fee communities with high-end services and amenities. The physical designs have been adapted to accommodate seniors’ demands for more spaciously designed apartments, greater choice of floor plans, and enhanced common areas that promote a more intimate dining and social experience.

Not surprisingly, seniors want access to a wide range of service amenities. Here too, newer independent living communities have responded by expanding their menu choices and hours of dining service and offering such service amenities as a wet bar, massage therapy, indoor swimming, a business center, banking services, concierge services, a fitness center, and movie theater, etc.
Most importantly, independent living communities have responded to seniors’ desire to have access to a continuum of services in familiar homelike surroundings. For residents in need of minimal to moderate assistance, they have the option to pay privately for home health care services within the privacy of their apartment. For those requiring more extensive assistance, the vast majority of independent living communities built in the last several years offer residents onsite access to licensed assisted living. Some rental communities also offer special care for residents with memory impairment, and the vast majority of entrance fee communities offer skilled nursing.

Future Challenges
The concept of independent living has flourished precisely because it is not a “one size, fits all” model, but rather a highly consumer-driven model. Independent living communities vary greatly in terms of physical design, scope of services, and cost. With a wide range of fee structures and service packages available, hundreds of thousands of seniors across the country are not only able to afford independent living, but have made a deliberate choice to move to independent living.

Demand for independent living is at a record high with occupancy levels running at over 90 percent throughout most of the country. Current estimates of independent living capacity in the top 100 metro markets in the U.S. are approximately 365,000 units. Over the next two decades, it is expected that independent living capacity will need to increase by at least 50 percent in order to meet future demand.

Despite the enormous growth and success of independent living over the past two decades, there remain formidable challenges. The challenges are threefold: 1) to remain a highly residential housing model; 2) to support the service needs of seniors without

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compromising the independent character of the community; and 3) to remain a private-pay, consumer-driven housing model.

Remaining a highly residential seniors housing alternative poses a real challenge. One of the distinguishing features of independent living is the residential character of the building design. As new development and renovation costs continue to escalate, economies of scale tend to favor larger buildings, which can potentially jeopardize the residential appeal of these communities. In addition, larger buildings often involve greater walking distances for seniors, which can impact opportunities for socialization, particularly for persons with mobility issues. Maintaining a highly residential character is critical to preserving the integrity of independent living.

Providing an “acceptable” threshold of admission and discharge practices poses its own set of challenges for independent living. Under the Fair Housing Act, independent living communities cannot discriminate on the basis of disability. Seniors who are “physically well,” want the benefits of socialization and companionship that independent living has to offer, but are not always comfortable with dining and socializing with others who have physical or mental limitations. This poses an obvious dilemma since residents of independent living communities not only desire, but are encouraged to receive the supportive services they need to maintain their independent lifestyle. Indeed, they are free to make reasonable design modifications to their apartment and arrange to purchase home care services, should either be necessary to support their stay in independent living.

Notwithstanding the regulations under the Fair Housing Act’s disability discrimination provisions, the changing health care needs of seniors can impact the very identity of the community and could risk tilting it toward a more institutional model of services. Striking the right balance between meeting the social needs and preferences of seniors who are relatively independent with those who require formal or informal support, while main-
taining the community’s character and independence will likely remain a formidable challenge in the years ahead.

Finally, independent living is a concept that has been successfully built on a private-pay model. Its success is largely attributable to the fact that independent living providers must compete on service and price for private paying customers. Consequently, the building design, service package and monthly fees reflect the unique demographics of the surrounding communities in which they are built. This individualized, free-market approach has made it possible for seniors with more moderate financial means to afford independent living. It is not just a concept available to seniors at the upper income level. The challenge for the seniors housing industry is to insure that future independent living supply continues to be financially accessible across a wide range of income levels, and while not the focus of this chapter, there remains a critical need for adequate federal funding to support subsidized seniors housing.

In sum, the future is bright for today’s seniors and baby boomers who may ultimately choose independent living. With so many different housing models available, the opportunity to live in a community that meets one’s physical, social, and financial needs is more attainable than ever. The challenge going forward for the seniors housing industry is to continue to focus on the voice of the customer. Indeed, independent living is a highly preferred housing option for seniors throughout this country because it has continually adapted to the changing needs and preferences of seniors. Far more than demographics, the future growth potential of independent living will largely be determined by insuring the residential character of the community, by offering access to a full range of quality services, and by keeping resident costs within an affordable and acceptable range across varying income levels.
Table 1

The Percentage of Residents by Their Satisfaction with Their Daily Lives

<table>
<thead>
<tr>
<th></th>
<th>Resident</th>
<th>Non-Resident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Satisfied</td>
<td>41%</td>
<td>27%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>49%</td>
<td>50%</td>
</tr>
<tr>
<td>Neither Satisfied or Dissatisfied</td>
<td>10%</td>
<td>19%</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>1%</td>
<td>4%</td>
</tr>
<tr>
<td>Very Dissatisfied</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 2

The Percentage of Residents by Their Satisfaction with the Independent Living Community

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Satisfied</td>
<td>46%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>45%</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>1%</td>
</tr>
<tr>
<td>Neither Satisfied nor Dissatisfied</td>
<td>7%</td>
</tr>
</tbody>
</table>

Table 3

The Residents’ and Non-Residents’ Ratings of Their Health Today Compared to What It Was Two Years Ago

<table>
<thead>
<tr>
<th></th>
<th>Resident</th>
<th>Non-Resident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better</td>
<td>10.3%</td>
<td>4.1%</td>
</tr>
<tr>
<td>About the Same</td>
<td>63.8%</td>
<td>67.8%</td>
</tr>
<tr>
<td>Worse</td>
<td>25.3%</td>
<td>27.5%</td>
</tr>
<tr>
<td>Don't Know</td>
<td>0.7%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

Night and Day You Are The One

At night I slip between the bed covers, careful not to disturb the stranger lying there. His eyes are closed, but I take no chances. He is aware of me but does not know me. Soon he will wake screaming and flailing his arms as if fighting off demons. The terror of his world is my world: I am captive and victim to a once brilliant, but now demented mind. Any challenge is self-defeating and useless; I play to his realities in order to survive.

Each morning, I re-introduce myself to my husband of 25 years. His eyes are blank and mine are filled with tears. In effect, I have been “slow dancing with a stranger” ever since my physician-husband was diagnosed with early onset Alzheimer's twelve years ago at age 58. Today he is in late-stage dementia, 24/7 care and still at home. Every caregiver's story is unique, yet somewhat the same. But when the onset is early, it is like witnessing a future that will ravage the baby boom generation and I am terrified for all of us. Together, my husband and I are trapped in a “long goodbye” that could last for years because he is young and relatively healthy. He'll outlast our finances. His insurance policies didn't cover this kind of care. Medicare pays for acute, not long term chronic disease. No financial planning ever projected the cost or the pain. How short-sighted of us, and now it is too late.

Now There Are Two—Will I Survive?

Once again the terror of Alzheimer's revisits me with another face. I let myself into the apartment with a fearful anticipation of every adult child that has respected an elderly parent’s wishes too long. I have aided and abetted the illusions of independence of my proud 85-year-old teacher mother who wants to live alone. A meticulous and
organized woman, I search for telltale signs of disarray as a mirror to the creep of confusion overriding reality. As her only remaining child, I am now a target for the rage of forgetting. Misplaced items are perceived stolen even when retrieved. The refrigerator is a potential Pandora’s box of poison—checked daily, edited and refreshed for the lady who once loved to cook and now forgets to eat. The actress in her puts on a show for the doctors even though she is out of sync with the time and the place. My mother has warned that she has hidden away pills to make certain she leaves us with her mind intact.

How can I tell my mother she is losing it too? Denial will rescue her as it did my husband because the disease first overrides the area of the brain that wipes out cognition of reality. But it will be a painful and protracted nightmare I share with millions of baby boomers as we watch our parents succumb to a disease that is our fate if a cure for Alzheimer’s is not found.

Alzheimer’s Disease: The Biggest Long Term Care Risk for Baby Boomers

Harry Johns
President and CEO, Alzheimer’s Association

Alzheimer’s disease and related dementias are the greatest long term care risk most older Americans will face. Alzheimer’s disease itself is the most untreatable medical condition affecting the elderly, and the one that carries with it the heaviest need for care. On its present course, it threatens the financial security and physical and emotional well-being of as many as 16 million baby boomers who will come down with the disease by mid-century, as well as that of their spouses, children and grandchildren who will take responsibility for their full-time care.

The good news is that we still have a chance to change the course of this insidious disease. Scientists are gaining new knowledge of the disease itself, uncovering new targets for drug discovery, and closing in on early, even pre-symptomatic identification of disease. This is opening the doors for new effective treatments that can prevent or delay the onset and progression of the disease. New evidence is pointing to healthy behaviors and lifestyle changes that may reduce a person’s risk of disease, and innovative providers are developing more effective ways to deliver health and long term care that can help maintain function, prevent health care crises and excess disability, as well as

1 The term dementia encompasses all of disorders that cause irreversible cognitive decline as a result of various biological mechanisms that damage brain cells. Alzheimer’s disease is the most common of these disorders, accounting for up to 70 percent of dementia cases.
improve the quality of life for people with the disease and their family caregivers.

This chapter documents the current impact of Alzheimer’s and related dementias—for individuals, families, and society, and the epidemic that awaits us as the baby boomers enter the age of risk. It then describes the enormous progress now taking place in the search for treatment. Finally, it charts a path to change the course of Alzheimer’s disease in time to prevent the havoc that otherwise awaits us.

Alzheimer’s Disease Today: Impact on Individuals, Families, and Society

Prevalence. An estimated 5.1 million people in the United States are living with Alzheimer’s disease—most of them over age 65 but at least 200,000 younger women and men with early onset disease. One in eight people older than 65, and nearly half over 85 have Alzheimer’s disease. In 2000, an estimated 411,000 new cases of Alzheimer’s emerged. That means that every 72 seconds, someone in America is developing the disease.²

And this is only the tip of the iceberg. Because Alzheimer’s is so closely associated with age, the numbers will explode as the baby boomers begin to retire. In less than twenty-five years, an estimated 7.7 million people over 65 will have the disease—a 50 percent increase over current numbers. By mid-century, the number could be as high as 16 million—with almost a million new cases every year.

Impact on the Individual. There is nothing benign about Alzheimer’s disease. It destroys memory, judgment, reason, and inhibition. It causes challenging behaviors like aggression and wandering that put at risk the person with the disease and the person caring for him or her. It leaves the person unable to perform the most basic tasks of daily life—like eating, bathing, dressing,

² Unless otherwise noted, the information in this chapter is taken from the statistical abstract, Alzheimer’s Disease Facts and Figures 2007, published by the Alzheimer’s Association and accessible at www.alz.org.
and using the toilet. And it causes medical complications that precipitate acute care crises and premature death.

Unlike other diseases common in the elderly, where death rates are declining significantly (as the result of better treatment, early detection, and prevention), deaths from Alzheimer’s disease increased by 38 percent from 2000 to 2004. That makes it the fifth leading cause of death in older Americans and the seventh leading cause of death for people of all ages.

But it is living with Alzheimer’s disease that creates the biggest challenge. People with Alzheimer’s need much more help than other frail elderly persons. Ninety percent rely on family, friends or paid workers for assistance. Nearly one-third use paid services, usually to supplement unpaid care, and they use almost twice as many hours of paid assistance—200 hours a month—as do other frail older persons.

They also need more medical care. Almost all of them (95 percent) have other chronic conditions common in the elderly, but their dementia limits their ability to keep those other conditions under control. As a result, people with Alzheimer’s are in the hospital three times more often, and in the doctor’s office more frequently than other people their age.

Impact on Family Caregivers. Nearly 10 million Americans—mostly spouses and adult children—are providing unpaid care for a person with Alzheimer’s disease. They account for nearly one third of all of the caregivers of people age 60 and older. The work they do is particularly challenging, not just because of the physical tasks involved but also because of the personality and behavior changes that accompany the disease. Caregiving goes on for a very long time. Seven in ten Alzheimer caregivers have been providing care for more than a year and 32 percent have been at it for five years or more.

Many of these caregivers are older themselves and face their own health and frailty issues. Yet two thirds perform the most demanding kinds of personal care—bathing, feeding, lifting, toileting—and they do it for a loved one who is disoriented and
confused, who is unable to help and may actively resist. Even when they are not directly providing care, they are organizing, managing and supervising the care provided by others.

These challenges affect the health and income of caregivers. They are more likely than others their age to suffer from clinical depression, injury, and health problems that are the direct result of their caregiving. For spouses, caregiving is associated with an increase risk of death—not for their loved one, but for themselves. Two-thirds of those who are trying to juggle a job outside the home miss work to deal with caregiving; 18 percent take a leave of absence; and 8 percent leave work altogether.3

Costs of Alzheimer's Disease. Families provide the bulk of care for people with Alzheimer’s disease, at an estimated value of $83 billion a year. Even with all of that unpaid care, our health and long term care system is full of people with Alzheimer’s disease. About 25 percent of elderly hospital patients have dementia. Nearly 70 percent of nursing home residents have cognitive impairment and nearly half have a diagnosis of Alzheimer’s disease. Half or more of all elderly residents of assisted living facilities and participants in adult day services have dementia.

Most families pay for care out of pocket, for as long as they can. It is very expensive—on average, $19 an hour for home health aides, $56 a day for adult day care, $35,616 for a one-bedroom unit in an assisted living facility (with additional fees ranging from $750 to $2,200 a month for specialized dementia care), or $75,190 a year for a private room in a nursing home. It is not surprising that a significant number of families run out of money and turn to Medicaid. In 2000, half of nursing home residents with dementia and 18 percent of people with dementia living in the community were getting help from Medicaid to pay for their care.

This means that all of us are bearing the cost of Alzheimer’s,

whether or not it has affected us directly yet. In 2005, the costs to state and local governments and to businesses exceeded $148 billion. Medicare spent $91 billion on beneficiaries with Alzheimer’s and Medicaid spent $21 billion just on their nursing home care. Businesses with employees caring for people with dementia lost $36.5 billion in reduced productivity, missed work, and replacement of workers who left to meet the demands of caregiving.

These societal costs will mushroom over the next decades. In less than ten years, Medicare and Medicaid expenditures for people with Alzheimer’s will double. Twenty-five years from now, Medicare alone will be spending the equivalent of today’s entire Medicare budget—nearly $394 billion—just on beneficiaries who have Alzheimer’s disease.

Alzheimer’s Disease Tomorrow: Progress Toward Treatment and Prevention

Alzheimer’s disease is on a course that cannot be sustained. Left unchecked, it will destroy the retirement years of millions of American families, disrupt businesses, and bankrupt state and federal treasuries. There is no clearer, predictable public health crisis facing the United States today. The good news is: it does not have to happen.

If, in the next several years, we can find ways to treat Alzheimer’s at least as well as we can now treat congestive heart failure and Parkinson’s, the number of people who get Alzheimer’s could be cut by 40 percent. Equally important, most of those who still get the disease might not progress to the moderate and severe stages. That means they could continue to lead meaningful lives in the community. Within five years of the start of such treatments, projected annual Medicare and Medicaid spending would decline by more than $60 billion, with potentially even larger savings every year thereafter.4

Those outcomes are now within reach. Thousands of Alzheimer scientists are aggressively pursuing a three-pronged strategy aimed at effective treatments, earlier diagnosis, and primary prevention.

**More Effective Treatments.** Current treatment options for people with Alzheimer's disease are extremely limited. While there are five approved drugs on the market now, and they appear to alleviate symptoms in a number of people at least for some time, none of these drugs attack the underlying disease. The effort to change this is well underway. By mid-2007, several drugs that may actually slow or stop progression of Alzheimer’s disease were already in Phase III clinical trials, the last step before seeking Food and Drug Administration approval for marketing. Those most advanced in the process target beta-amyloid, the prime suspect in Alzheimer’s disease. These are the chemically sticky fragments that cause the build up of plaques in the brain and trigger a cascade of other abnormalities that contribute to the worst effects of Alzheimer’s disease.

Several years ago, there was great excitement about a potential vaccine that would mobilize the immune system to fight off the production of beta-amyloid. Clinical trials were halted when some participants developed encephalitis. Participants in those trials who had a positive effect from the treatment are still being followed and show some positive trends in function, memory, and ability to stay at home. Scientists are working now on a new approach to “passive immunization” that will soon move to Phase III trials.

Other drugs, including some that have already been approved for treatment of other diseases like high cholesterol and diabetes, are being studied for their effects on memory, brain blood vessels, and inflammation in people with Alzheimer’s disease.

Like cancer and heart disease, Alzheimer’s is a complex puzzle made up of multiple genetic and environmental factors. An army of Alzheimer scientists mobilized in academic centers around our country and around the world is identifying additional pieces
of the puzzle that will likely yield even better targets for drug discovery. Private sector companies and their scientists continue to seek such improved targets to advance more effective treatments.

**Earlier Diagnosis.** Scientists now understand that the processes in the brain that causes Alzheimer’s disease begin well before symptoms of the disease appear—perhaps as much as twenty years earlier. That understanding, combined with early data from clinical trials, suggests that drugs that attack fundamental Alzheimer pathology could work best if they are taken as early as possible. It will not be enough to have the treatments. Clinicians will need to identify the people who need them.

While methods to diagnose Alzheimer’s have improved significantly, they are still not sensitive enough to detect the first signs of cognitive change, much less presymptomatic alterations in the brain. Better approaches are clearly needed. The two most promising avenues are brain imaging and biomarkers in spinal fluid or blood.

The Alzheimer’s Disease Neuroimaging Study, a unique collaboration between the National Institute on Aging, the Alzheimer’s Association, and the private sector has engaged scientists across the country to investigate the use of MRIs and PET scans to detect and monitor early changes in the brain. The initiative is also collecting blood and spinal fluid samples to search for accurate biological indicators (so-called “biomarkers”) of Alzheimer’s disease in individuals who are not yet symptomatic.

Discovery of such early indicators would have immediate benefit in clinical trials, allowing investigators to monitor the effect of experimental therapies without waiting for clinical symptoms to appear. Once new therapies are available, such indicators would allow clinicians to identify patients who need the drugs and begin treatment soon enough to make a difference.

**Emerging Prevention Strategies.** Americans do not have to wait for the results of all of this work to do something now about Alzheimer’s disease. Studies already point to a number of
potential risk factors for cognitive decline that we know how to affect now, through primary prevention strategies. These include cardiovascular risk factors (high blood pressure and cholesterol, diabetes, smoking, and excess weight), physical inactivity, and psychosocial issues. The Alzheimer’s Association is collaborating with the Centers for Disease Control and Prevention in The Healthy Brain Initiative, a first-ever road map to make cognitive well-being part of our overall national public health goals and to develop a pilot community-level intervention to encourage healthy brain behavior.

Realizing a Better Future
We must mobilize additional resources necessary to move the best science forward as quickly as possible. Unfortunately, just as science has reached the point of maximum potential, public funding for Alzheimer research is beginning to fall off. From 1990 to 2004, Congress consistently added funds to nurture the growing field of Alzheimer research and to take advantage of emerging scientific opportunities. By 2003, annual federal support had increased to $658 million, more than double the level of funding in the mid nineties. Since then, funding has slipped. More and more highly rated research proposals are being left on the table, and costs for care and services for a disease that cannot be treated continue to escalate.

At the same time, we need to invest in developing new service delivery models and financing mechanisms to meet the changing needs of people with dementia and their caregivers, including particularly the needs of people diagnosed in the early stages of Alzheimer’s and younger people who have early onset disease. Families and payers alike are looking for holistic approaches to quality care that coordinate health and long term care services in a way that will improve outcomes and control costs. They need community-based services that support the individual with the disease and the family as care partners with their physicians and paid care providers. And they need mechanisms for financing
long term care that spread the risk of Alzheimer’s and other chronic illnesses broadly and prevent the loss of life savings when it strikes.

There is real potential for a better future, one where Alzheimer’s disease is no longer a death sentence but a manageable, treatable disease that affects far fewer people—people who will continue to lead productive and meaningful lives. We have reached this point because of the passion and commitment of outspoken family members and, increasingly, people with the disease who constitute the base and the soul of the Alzheimer’s Association. Together with the National Institutes of Health, elected officials, state and local governments, innovative care providers, and industry leaders, we have raised visibility and awareness of the disease, mobilized public and private resources for research, stimulated innovative practice in Alzheimer care, and developed specialized services and support. These efforts are among the primary reasons for the Alzheimer community’s optimism today.

We have come too far to stop now. It will take the same combined forces to realize the potential before us.
Caring for Phil

I am 58 years old. Phil is 61. Phil suffers from diabetes and all that it entails: heart disease, restrictive respiratory disease, stage four kidney disease and diabetic neuropathy. He is on oxygen 24/7 and is confined to a wheelchair. I have been honored and blessed to be his caregiver for three years. My employer put me in a position where I had to choose between my family and my job. I know I made the right choice in spite of the financial hardship it has caused us. His disability check pays the rent (thanks be to God!), while Medicare, Medicaid and Medicare Rx Plan pay for medical expenses and food stamps help some. All other expenses (like utilities) are up for grabs. However, our church has helped as much as it can.

Phil was a very active man. He lived life to the fullest until he had a heart attack. Now, he has nothing left in his eyes. Life came to grinding halt. Only our pastor comes to visit now and then. No one else comes to see him. He is very lonely and tired of all he has to deal with every day. I love him and try to make his days as pleasant and comfortable as possible and make him as comfortable as possible. Being a caregiver has taught me many life lessons, some good and some not. But I wouldn't have my life any other way than it is now.

Nancy
Roanoke, VA

This vignette is from the National Family Caregivers Association Caregiver Story Project
www.thefamilycaregiver.org/connecting_caregivers
Managing the Impact of Advanced Chronic Illness in the Elderly by the Year 2030

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Recent decades have seen remarkable advances in medical technology and early signs of compressed morbidity\(^1\). This means reducing the average burden of chronic illness and disability at life’s end. Since 1997, deficits in instrumental activities of daily living, such as driving or managing medications, have declined from about 14 percent to about 12 percent while life expectancy after age 65 has increased only 1.5 years in two decades. This suggests that older people may be living better, more than longer; adding more life to years than years to life. Nonetheless, chronic diseases remain prevalent and morbid, and function-limiting health impacts are common. Loss of basic activities of daily living such as bathing or dressing is more serious, requires more support, and remains largely unchanged at about 6 percent\(^2\). According to the 2006 National Health Interview Survey, 17 percent of those aged 85 and above require help from others with personal care\(^3\).

These modest recent changes in overall health and function are expensive. We spend about $160,000 per year of additional life expectancy after age 65\(^4\). We outspend every other industrialized

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nation on health care by more than 25 percent per capita, yet U.S. life expectancy ranks 45th, lower than Japan, the United Kingdom, Australia, France, Germany, Spain, Canada, Italy, Sweden and many other industrialized nations\(^5\).

Looming chief among the critical financial issues is the Medicare budget. In 2005, Medicare spent $330 billion serving 42.5 million beneficiaries, and used 3 percent of the Gross Domestic Product (GDP). Inflation-adjusted spending will double by 2030 and may reach 11 percent of the GDP by 2080. We will start depleting the Part A trust fund principal by 2010 and it will be gone by 2018, prompting the Medicare trustees to issue a second warning to Congress in 2007\(^6\).

The approaching challenge is the baby boom cohort. In 2011, ten thousand people will turn 65 each day, doubling the elderly population by 2030 and increasing the group who are 85 and older by at least four-fold. As we contemplate the needs of aging boomers, predicting the chronic disease burden is critical. Anticipated impacts cross all sectors, including health care, Social Security, housing and transportation and caregiving duties for younger generations.

It is increasingly evident that existing governmental programs are not structured to handle the health care and support service needs of our aging society. Thus, an important consideration will be private sector financing of long term care.

This paper will consider epidemiologic trends of importance in framing this discussion, and outline strategy related to medical care for those with advanced chronic illness.

How many elderly people will be living in 2030?

The answer to this multi-trillion dollar question depends on some trends for which the outcome is uncertain. One is obe-

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sity. The recurring national Behavior Risk Factor Surveillance System survey, published by the Centers for Disease Control and Prevention, shows obesity doubling since 1985 and rising. During the past decade, the national average has increased from 18 percent to 25 percent prevalence. In some states, more than 30 percent of people are obese and only one state (18 percent) is below 20 percent. Obesity conveys increases in diabetes, cardiovascular disease and arthritic problems, which escalate health care costs and functional losses. Another consequence is early mortality. Forty years after enrolling in the Framingham Study, 80 percent of those with normal weight were alive contrasted with 50 percent of those that were obese.

Unchecked, the obesity trend will have two effects: 1) more people will require active medical care and long term care in their 60s and 70s due to cardiovascular events; and 2) fewer people will live to develop dementia in advanced old age (85+).

Other factors may also enter the picture such as a “cure” for Alzheimer’s disease, diabetes, or cancer. As discussed below, it is unlikely that these will be found in time to address the challenges that we face in the coming quarter century.

Osteoarthritis
The most disabling condition in our society does not kill but impairs function and causes pain. In 2007, the Centers for Disease Control and Prevention announced that 46 million Americans reported doctor-diagnosed arthritis with direct costs of $81 billion in 2003. The number affected is expected to be 67 million in 2030. Arthritis causes slightly more disability than cardiovascular disorders in each elderly age group, impairing function for more than a quarter of those aged 85 and over. Like cancer, decades of

8 National Center for Health Statistics, National health Interview Survey. Figure 18; Chartbook on Trends in the Health of Americans, Figure 18. Hyattsville, MD 2006.
research have taught us much about this disease but we have no
cures. What we have produced is a cornucopia of joint replace-
ment and joint resurfacing techniques. These afford symptom
relief and improved function to those who are healthy enough
for surgery and hampered mainly by limb joint problems. Still,
we lack consistently effective treatments for small joint or spinal
arthritis and cannot correct arthritic problems in those who are too
sick for joint resurfacing surgery, leaving us with a circumscribed,
expensive treatment portfolio.

Dementia
Alzheimer’s disease becomes exponentially more common as age
rises from 65 to 85\textsuperscript{9} and it produces a prolonged state of depen-
dency. In 1980, experts used population-based epidemiologic
studies to estimate 3 million cases among those aged 65+ (11 percent)\textsuperscript{10}. Above age 84, the prevalence approached 50 percent.
These authors estimate between 5 and 8 million affected in 2030
(doubled), rising to 10 million (mid-range estimate) by 2050.
Others calculate 13 million or more.

We have untangled some mechanisms of dementia, but there
is again no promising cure in view. An increase of four-fold or
more in the old-old (those aged 85+) will likely produce a corre-
sponding four-fold increased need for dementia care settings and
caregivers. Calculated direct and indirect cost for 1988, based on
3.7 million cases, was $88 billion. Medicare costs for dementia are
projected to increase 50 percent by 2010, while Medicaid expenses
for residential care will increase 80 percent. Even if survival after
diagnosis is only five years\textsuperscript{11}, shorter than the often quoted ten years,
the burden will be substantial. Of note, two thirds of residents in

\textsuperscript{9} Ritchie K, Kildea D. Is senile dementia “age-related” or “ageing-related”?—evi-
dence from meta-analysis of dementia prevalence in the oldest old. Lancet.
\textsuperscript{10} Evans DA. Estimated prevalence of Alzheimer’s disease in the United States.
\textsuperscript{11} Larson EB, Shadlen MF, Wang L et al. Survival after initial diagnosis of
Maryland assisted living settings have dementia\textsuperscript{12} although many cases are not formally diagnosed in the records.

\textbf{Cancer}

Cancer has received much attention. Screening yields early detection and thus more cures for common problems like breast, colon, and cervical cancer. We have traced disease mechanisms to the genetic and molecular level, seen stunning successes like curative medication for the rare disorder that attacked Lance Armstrong, and improved treatment for many others. Cancer is becoming an extended chronic illness: for many people, therapy—which is often morbid and usually expensive—may add years of life. Yet, few are cured. For such patients, cancer is like advanced liver, lung, or heart disease: a disabling and eventually fatal condition that becomes a major focus in one’s final years. Overall the cancer death rate (about 200 deaths per 100,000 people) remains sadly unchanged for three decades despite the billions invested\textsuperscript{13}. We have not won the race for the cure and chronic cancer care will impact the year 2030 scenario. As with other serious chronic diseases, it is difficult to resist treating even when treatment offers temporary, limited benefit.

\textbf{Osteoporosis and Vitamin D Deficiency}

This insidious problem affects 8 million women and 2 million men. Its toll comes in late life by way of hip and spine fractures. In 2020, over 13 million will be affected\textsuperscript{14}. Using simple screening methods, we diagnose osteoporosis and start treatment earlier.

Economic analysis shows grounds for caution\textsuperscript{15}. Calcium, vitamin D and estrogen have small impacts on fracture rates, but are inexpensive. More expensive bisphophonates are cost-effective only if given selectively. They are most cost-effective late in life and in patients with severe bone loss. Ironically, highest risk patients often go untreated because of co-morbidities or care discontinuity. When started early and in healthier patients the cumulative costs from decades of therapy reduce societal value.

There is also new recognition that vitamin D deficiency is rampant and particularly common in those at greatest risk for falls and fractures. Fifty or 60 percent of the homebound or institutionalized elderly are vitamin D deficient. This is a simple, low cost opportunity that we can readily address through education. Adequate replacement (at least 800 units daily) reduces falls and fractures\textsuperscript{16} but few people consume this amount.

Cardiovascular Disease
Hypertension affected 50 million people in 2001, killing 45,000 and costing $55 billion. Hypertension prevalence is about 65 percent between ages 65 and 74, and 75 percent for those aged 75+. Prevalence of more serious conditions like stroke, myocardial infarction, and heart failure lies in the 10 to 20 percent range. Annual stroke incidence is about 700,000 and about 4.8 million have suffered stroke, the third most lethal condition after cancer and heart attacks; yet, only half die within eight years and in 1999 more than 1 million people had residual functional limitations. Estimated direct and indirect cost in 2004 was about 50 billion, and mean lifetime cost per stroke was about $140,000. Total combined cost of cardiovascular diseases in 2004 was estimated at $370 billion, and direct costs at about $225 billion.

Death rates from heart disease have declined, as shown in a recent comprehensive analysis. For U.S. males, annual coronary deaths dropped from 543 to 266 per 100,000 people between 1980 and 2000; the corresponding reduction for women was from 263 to 134 per 100,000. Approximately half of the improvement came from treating established conditions (coronary bypass, angioplasty and medical therapies), and half came from reducing risk factors (high blood pressure, cholesterol or smoking). A dozen categories of intervention combined, each making a small contribution and none predominant.

Beta blockers, aspirin, and angiotensin-converting enzyme inhibitors helped. HMG-co-A-reductase (statin) drug therapy is a major advance, using research into biological mechanisms to design drugs specific to those mechanisms. Statins are used widely to lower cholesterol, produce other benefits that aren’t as well understood. In large primary prevention studies, statins lower cardiac events by about a third, with a smaller statistically non-significant effect on cardiac deaths and no effect on overall mortality. On the procedural side, percutaneous catheter procedures for narrowed arteries make corrective action less daunting than when major surgery was the only alternative. Reported U.S. death rates from cardiovascular disease now compare with those in the European Union and Eastern countries, though still much higher than Japan.

And yet, while heart disease deaths are down, opened arteries narrow again, or other vessels constrict, we find ourselves fighting a persistent foe on a chronic basis. Most patients with significant cardiovascular disease require regular recurring interventions, and many spend their final years with doctors and hospitals to obtain the survival rates reported in the comprehensive review.

Diabetes
Based on the National Health Interview Survey (1984–2000), lifetime risk of diabetes for those born in 2000 is 33 percent for males and 38 percent for females. We are delineating the molecular biology, primarily mediated by atherosclerosis, which connects obesity, diabetes, and adverse metabolic profiles with increased morbidity and shorter lives. O’Keefe suggests that atherosclerosis may reflect incompatibility of our “Paleolithic genome,” evolved in a time when complex carbohydrates were not in the food supply, and our 21st century lifestyle. In any event, diabetes is on the rise.

Rates of diabetes (cases per 100,000) are relatively stable up to age 45, but since 1990 rates for the middle-aged and elderly have been increasing sharply. Rates in the elderly approach twice the rate for the 45–64 age group. Diabetes contributes to assorted health problems, including advanced atherosclerosis, kidney disease, neuropathy, and vision problems. Meticulous diabetes care can lower complications in Type II diabetes by about 20 percent under study conditions, but many complications are being deferred and likely will ultimately occur. At a societal level, the most beneficial intervention would be reducing obesity.

Aggregate Burden
In sum, despite remarkable advances in biotechnology, an increas-

ingly large number of older people in our society will eventually be burdened with costly and disabling chronic illness. The obesity trend may drive the equilibrium toward cardiovascular disease and away from dementia and cancer, but there is no reason for optimism that we will escape the majority of the boomers’ chronic disease impact through applied technology.

Costs of Chronic Disease Care
Costs rise exponentially with the number of chronic illnesses one has. Patients with one or two illnesses have costs that are five-fold less than people with five or more active diagnoses. A remarkably small number of ailing individuals use most of the health care services. In 2001, 5 percent of Medicare enrollees used 43 percent of the budget, and 10 percent used 62 percent. Within the high-cost group some individuals were gradually becoming more costly in the five years before 2001. In the following five years, some died but many remained in a high cost category, averaging twenty-two high cost months in the sixty month interval. Across a five-year span, 5 percent of the surviving population used 27 percent of resources, and 10 percent used 42 percent. Thus 4 million people with chronic illness determined 42 percent of the Medicare expense profile during those five years. Add two-fold to four-fold variation in costs between regions and providers, often with no linkage between higher costs and improved outcomes, and you have a large opportunity. Targeting services and coordinating care are essential.

Choosing Cost-Effective Strategies

We have employed new and improved biotechnologies with abandon, going well beyond what scientific evidence supports. Drug therapy offers numerous examples. Large clinical trials show small but significant improvements, where treating hundreds of people prevents an adverse outcome for one. The “number needed to treat” (NNT) for a particular benefit is a useful benchmark. If a drug costs $100 per month and you must treat 200 people for a year to prevent one adverse event, the cost per event prevented is high ($240,000), yet such drugs are routinely prescribed indiscriminately. Certain subgroups are far more likely to benefit, with an NNT of 10 or 20. If the NNT is 10 the cost per event prevented falls to $12,000. Indiscriminate use of technology for small or no benefit also extends to sophisticated imaging procedures such as MRI and PET scans, and various surgeries.

Disease management has received much publicity and funding in the past fifteen years, though with limited evidence of substantial overall benefit even with individual diseases like diabetes and congestive heart failure where this strategy is most touted. The strategy calls for systematic care directed at individual conditions, seeking to blunt the impact of disease by risk factor reduction plus pro-active evidence-based treatment once disease appears. The evidence favoring this approach lies mainly with improved intermediate measures such as patient satisfaction or metabolic control of diabetes in relatively healthy patients. While

this approach may ultimately have value, evidence of long term improvement in population health or cost containment in the real world of clinical practice is still lacking.

Disease management has little role in advanced chronic illness. Most high-cost patients suffer from multiple chronic diseases which cannot be managed in isolation from each other. In one year, Medicare patients with high co-morbidity see thirteen physicians and fill fifty prescriptions\(^{30}\) on average. These patients require individualized, coordinated care plans that are frequently adjusted to changing patient needs, directed by chronic illness specialists rather than the protocol-driven methods of disease managers.

In contrast, there is substantial and growing evidence that once advanced illness has occurred, targeted intensive case management can reduce health care costs, often by 50 percent, and improve patient satisfaction in a variety of populations.

Team-based mobile care for immobile, medically complex patients is a strategy that has been shown effective but is under-utilized. In nursing homes, mobile teams centered on nurse practitioner care providers have reduced hospitalization by 50 percent\(^{31}\). Another model, also featuring advance practice nurse teams, tested home care for high-risk patients after hospitalization for eight different diagnoses. In a rigorous randomized trial a 4-week intervention with house calls and telephone support bridged the transition from hospital to home. The program reduced hospitalization 65 percent and costs 50 percent, while improving satisfaction\(^{32}\). Our physician-nurse practitioner teams in Richmond, Virginia have found similar results. Keys are patient selection, plus timely availability, expertise, and mobility of care teams. The use of electronic medical records and point-of-care

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testing will enhance these models but is not yet well tested. Similar intensive case management is likely to work for complex patients who can reach physician offices but whose poorly coordinated care lacks a holistic perspective.

Our small national investment in testing such care models pales by comparison to the hundreds of billions spent on biomedical research that has produced extensive knowledge of specific disorders and terrific new technologies, despite only modestly improved outcomes and exponentially rising costs. It is time to expand that investment and to create operating parameters and incentives that encourage physicians and others to engage proactively in creating robust, responsible care models that follow complex patients with advanced chronic illness across settings, and delivers high quality care where the patients live through the use of mobile technology. Benchmarks for quality should be truly patient-centered, should include managing costs and locus of care, and should not rely on intermediate disease-specific measures such as metabolic control parameters currently used in pay-for-performance models. Evolution of a strong workforce for advanced chronic care will follow incentives as surely as specialties like cardiology and oncology have blossomed with advances in technology and compensation.

In considering this tapestry we must pay constant attention to unpaid family caregivers. Caregiver burden, particularly with persistent chronic diseases, is associated with increased caregiver mortality\textsuperscript{33},\textsuperscript{34} which indicates the seriousness of this issue.

**Summary**

Despite improvements in some functional measures as well as in short and intermediate-term survival from conditions like cancer and cardiovascular disease, the available evidence suggests that


in coming decades, advanced chronic illness will be a persistent, weighty factor in the lives of many older Americans. As the population “ages” with the baby boom, we will need different, better strategies for health care and support of older adults with advanced chronic illness. Along with better and more varied care settings, this should include growth of specialized chronic medical care teams and alternative financing mechanisms for both health care and long term care.
Financing Long Term Care

Today, we are spending $140 billion dollars a year on long term care for the elderly in this country. This is from all sources—public and private. Sixty percent of these dollars are currently spent on institutional care.

States are key policy-makers when it comes to long term care. And it is the states that are facing the most immediate challenges in financing long term care as a result of the fiscal pressures that are being placed on their Medicaid long term care budgets.

Josefina G. Carbonell
Assistant Secretary for Aging
U.S. Department of Health and Human Services
Remarks made at ASA/NCOA Joint Conference Critical Issues Session March 9, 2007
Introduction
As has become widely appreciated, the aging of the baby boom generation will lead to a rise in the elderly population of the United States, both in absolute terms—it will double by 2040—and as a share of the population. The arrival of the baby boom generation will trigger tremendous pressures for change in the provision and financing of long term care in the United States. As people age, the chances of facing physical impairments rise and the need for long term care services grows accordingly.

Complicating the challenge of meeting the increased demand for long term care is the fact that the baby boomers’ retirement will place tremendous strains on federal government finances. Indeed, the broad issue of the increase in health care spending is the United States’ leading economic and social policy challenge. In 1970, national health expenditures were $1,300 per person and consumed 7 cents out of every national dollar—the equivalent of 7 percent of Gross Domestic Product (GDP). Over the past three decades, spending per capita grew on average 2.5 percentage points faster every year than did income per capita. The upshot of this phenomenon—which is referred to as “excess cost growth”—is that in 2004 spending per capita rose to $6,300 and health spending constituted 16 percent of GDP.

1 See Financing Long-Term Care for the Elderly, The Congressional Budget Office, April 2004.
These trends cannot continue. To see this, consider for current federal budget practice. At present, the federal government raises about 18 percent of GDP in receipts—essentially the postwar average. (Business as usual in the United States is that the federal government spends 20 cents out of every national dollar, raises 18 cents in revenue, and borrows the remainder. This is nearly identical to how the federal government closed the books for 2006.)

On the spending side, if Social Security is not reformed and benefits are paid as currently scheduled, outlays for Social Security will rise along with the retirement of the baby boom generation from about 4.5 percent of GDP at present to 6.5 percent of GDP in 2030, and then continue to drift north to about 7 percent of GDP. Now consider health care. If excess cost growth continues at historic rates, Medicare and (the federal share of) Medicaid will increase from 4 percent of GDP at present to 22 percent of GDP in 2050, which is larger than the entire current federal budget. Conventional assumptions (such as those of the Medicare trustees) are that excess cost growth will eventually moderate to 1 percentage point. Based on this assumption, Medicare and Medicaid will still triple in size to 12 percent of GDP by 2050 and the potential for deficits will grow explosively.

Meanwhile, the same increase in costs will most likely pressure states to scale back Medicaid coverage. At the federal level, the rising cost of Medicare will consume greater and greater amounts of general revenues as, by design, premiums cover only one quarter of outpatient physician drug costs. Under provision in the recent prescription drug legislation, the Medicare Modernization Act (MMA), the President and Congress will be under sustained pressure to reign in costs. The upshot will be the potential for political crisis at both the state and federal level.

Under these circumstances, the chances of a broad expansion of the government’s role in the existing long term care system are unlikely. Accordingly, it is important to contemplate the scope
and character of more dramatic changes in these programs in the United States.

In exploring this topic, first we will briefly review the existing provision and financing of long term care services in the United States, before moving on to discuss the pressures on the current system that will arise as time evolves, as well as alternative approaches to reform. In the final section we will look at some of the conclusions.

To anticipate the outcome, the combination of demographic and financial pressures will demand that a greater fraction of long term care services be provided through formal, market transactions. This will occur best if policies provide a flexible labor market, results-oriented regulations, and reimbursement policies that give market participants adequate incentives.

The most efficient financing of these market transactions will take the form of pre-funded long term care “insurance”—either in the form of private long term care policies, or self-insurance through additional savings prior to retirement.

The Current Provision and Financing for Long Term Care

The current demand for long term care is substantial. Nearly 20 percent of seniors are subject to chronic impairment, a rate that rises to 55 percent among the oldest of the old (those 85 years of age and older).¹ The financial reflection of these physical needs was the spending of $135 billion in 2004, or roughly $15,000 per senior in need of long term care.

However, a striking feature of long term care in the United States is that even among the severely impaired, a majority receive care only from “donated services”; i.e., care from friends or family members such as a spouse or child. Valuing these contributions is a challenging analytic issue, but if we add a rough number of $75 billion from this source, it brings the overall spending up to

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¹ This section draws heavily on Financing Long-Term Care for the Elderly, The Congressional Budget Office, 2004.
over $200 billion (roughly 2 percent of GDP) or about $25,000 per impaired senior.

Who picks up this bill? The largest source is donated services—the private, non-market bundle of service provision and financing in informal arrangements. Next in line are out-of-pocket payments, which one can think of as private, self-insurance totaling roughly $5,000 per senior. In contrast, private long term care insurance policies contribute on average only $750 per senior. The low rate of utilization of long term care insurance is one of the most striking features of the current configuration of long term care financing.

In contrast, in 2004 the contribution of government insurance programs—pay-as-you-go social insurance—was quite substantial with Medicaid providing $5,500 and Medicare $4,000 per senior.

In sum, the current system has two striking features: a heavy reliance on informal, donated services and a large financing role for government programs. Both features are likely to change dramatically in the decades to come.

Rolling the Clock Forward: Options for the Future of Long Term Care

It is likely that the current configuration of production, distribution, and financing of long term care services is unsustainable in the long term. First, the demand for long term care services will rise along with the demographic shift in the United States. By 2050, the share of the population that is 85 years of age or older—those most heavily in need of long term care services—is expected to more than triple from 1.5 percent to 5 percent. Accordingly, spending on long term care services is projected to rise by 15 percent and reach 2.3 percent of GDP. However, this projection assumes that the rate of impairment continues to decline in the future. If, instead, the rate of chronic impairment stays at current levels, then long term care spending will reach 3.3 percent of GDP. In short, the first pressure is a rising demand for long term care services.
Demography plays heavily in the second key pressure—the likely diminishing supply of informal caregivers. If current labor market trends persist, the share of the market supplied by donated services usually contributed by women—spouses and daughters—will be participating in paid work and will therefore be unable to provide these long term care services.

The result will be pressure for greater market provision of long term care services. However, a robust and well-functioning market will depend on prudent public policies. Such markets should be flexible in their use of alternatives sources and mixes of labor, equipment and new technologies. Federal and state regulations can foster such flexibility by focusing on outcomes—appropriate care, improvements in impairment, etc.—and avoiding rigid prescription of the details of care routines. Such markets would have robust innovation and allow new entrants to compete aggressively. Given the large role of Medicaid and Medicare in the current financial structure, the evolution of payment rules should reward cost-effective care, permit flexibility in new institutional arrangements, and reward innovation and cost-saving efforts.

The third central pressure will be the squeeze on government financing as other entitlement commitments grow. These pressures are a great challenge in their own right, and addressing them will be central to retaining the vibrancy and international competitiveness of the United States. However, even forward-looking and anticipatory reforms that support robust growth will not be a panacea for financing long term care services.

Instead, it seems most reasonable to anticipate that a greater fraction of the overall bill will be picked up by the private sector—an outlook that raises issues of considerable importance.

One possibility is that pay-as-you-go financing will continue. For example, an unattractive possibility is that impaired seniors will themselves pick up the check for the cost of their market-provided long term care services out of their current incomes. Given the costs ($25,000 on average at present), this form of financing raises serious questions about the resulting quality
of life. Moreover, such an outcome would be at odds with the notion that insuring against the likelihood of the need for long term care services raises economic well-being.

Alternatively, it may be the case that the cost of market services is paid for by spouses or children. If writing checks replaces the direct care of elders, the result will be an informal form of social insurance. The costs of long term care services will be spread through family and friend networks. However, from the perspective of preserving superior overall economic performance, it would be desirable to finance the costs of long term care services by “pre-funding”—accumulating in advance the funds needed to pay these bills.

Why is pre-funding important? From the perspective of insurance, pre-funding allows for greater sharing of risks. Costs are distributed not only over a group of people—perhaps only the senior himself or herself, but perhaps also the family, friends and informal network—but over a large number of years. By spreading risks more broadly, the costs of long term care place a smaller demand on the overall annual lifestyles of those paying the bills.

From the perspective of the overall economy, pre-funding serves to increase national saving. Each additional dollar of national saving provides another dollar that can be devoted to investing in equipment, structures, education and labor skills, or innovation and other technologies. These types of investments are the foundation of economic growth, and that growth is ultimately the source of better standards of living for seniors and workers alike.

Finally, the costs of greater long term care spending could be financed by private long term care insurance policies. Because private insurers accumulate and hold financial reserves against the costs of long term care services claims, this approach provides pre-funding of long term care costs. At the same time,

3 Note that insurers typically invest their reserves in financial instruments such as corporate bonds or U.S. Treasury securities. In this way, the funds are injected into financial markets and made available for investment.
widespread use of long term care insurance would spread risks broadly across the population—in exchange for premium payments, elders would spread the costs to shareholders, debt holders, and financial market participants across society.

The coincidence of the fact that broad use of private insurance has desirable characteristics and the fact that it is unlikely that the pay-as-you-go government programs Medicare and Medicaid will be able to burden additional costs raises a key question: why is long term care insurance currently used so infrequently? Researchers have focused on a variety of potential explanations. Administrative costs are relatively high, lowering the overall benefit-cost characteristics of insurance. In addition, writing such policies has been made more complicated by the fact that overall health care costs have risen faster than the economy. The result has been instability in premiums and circumstances in which the policy (which promises dollars) cannot cover the costs of a given level of service. Finally, there is concern that long term care insurance is plagued by the phenomenon of “adverse selection”—those in good health and with knowledge of their family history choose not to insure. Instead, the demand for insurance is focused on those that have the greatest long term care service costs. The result is that it becomes progressively more difficult to sustain a profitable, private sector insurance market.

However, a growing body of research suggests that these problems do not constitute an insurmountable obstacle to a healthy market for long term care insurance. Instead, recent research focuses on the fact that Medicaid offers an alternative, subsidized competitor to private long term care insurance. Put bluntly, Medicaid crowds out private insurance. This observation suggests that an important element of future public programs toward long term care services must be to preserve incentives for private insurance. Moreover, given the stark financial outlook for Medicaid, a sensible strategy would be to begin reforms soon—in

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anticipation of the rise in demand for long term care in the baby boom generation—that scales back the pay-as-you go Medicaid program for those most able to shoulder their costs. The result will automatically improve the conditions for private long term care insurance—an important first step.

Summary and Conclusions
The provision and financing of long term care services is a pillar of the standards of living for America’s seniors. In the years to come, the current configuration of long term care services will face strains from the simultaneous increased demands of an aging population, reduced flexibility for informal means of supplying services, and budgetary pressures on government financing. In these circumstances, public policy should promote flexible and efficient market mechanisms to provide care services. Also, policy should recognize that increased reliance on pre-funded mechanisms to insure against additional costs will provide the best combination of risk spreading and faster economic growth. Of particular importance are simultaneous reforms that slow the growth of Medicaid and provide a foundation for robust primary markets for long term care insurance.
My Own Quiet Care

From an on-the-job injury, I have from the neck below, (with 24/7 hourly relapses), permanent and progressive neuromuscular disabilities. I am now in my mid-50s, both progressively ill and progressively disabled, and largely homebound.

I no longer drive or own a vehicle.

Despite my many disabilities, I remain as independent as I can be, living in my own home. For mobility, I use an electric wheelchair, walker, cane, and other assistive devices to get around my house.

Earlier this year, my "Pathways" Hospice of Lake-Sumter, Leesburg, FL nurse approached me about installing a new wireless wall sensor monitoring technology in my home since I live alone.

She was concerned about my safety because I fall a lot, and about sudden medical changes that without 24/7 care may go unnoticed and could jeopardize my life.

Historically, most people in my condition would have been involuntarily or voluntarily institutionalized for life due to a standing Florida state requirement mandating institutionalized care for my current diagnoses.

But QuietCare has revolutionized health care in allowing people with serious chronic illnesses and/or debilitating physical conditions to remain at home for the first time ever, without violating this mandatory Florida state law.

This is especially significant for single people like me.

I am the very first person in the country, (not elderly and with my diagnoses), to have QuietCare in order to help me live life to the fullest potential while living in my own home. This 24/7 home monitoring system saved my life in the first four months of installation! Twice, I had sudden, life-threatening medical conditions that I was unaware of.

Each time, QuietCare alerted my nursing staff and neighbors of my
unexpected medical changes and I was immediately taken to medical services and successfully treated.

I love living in my own home and I shudder at the thought of living in an institution! Every single day I thank God for directing me to QuietCare so that I can continue to live on my own.

Unlike in an institution, living at home gives me the freedom to get up when I want to get up. I eat what and when I want to eat. I watch my own television. I have total freedom. I continue to live a quality life living in my own home, yet I have on-call QuietCare emergency help whenever I need it, whether I am aware I need help or not.

Mr. Dana Karl Hall, M.Ed.
Retired Federal Law Enforcement Officer
September 3rd, 2007
Meet Ernesto. He’s 87 years old and lives with heart disease, high blood pressure and also experiences mild congestive and cognitive decline. He has a team of doctors managing his care. He’s close with his family, but they live an hour away. Ernesto, however, lives independently at home, manages multiple medications, and still enjoys weekly poker games with friends.

How does he do it? With the help of everyday technologies like cell phones and computers. These products helped Ernesto, his family and his health care providers to create a network that monitors Ernesto’s health conditions, promotes communication among those who care about him, improve his quality of life and, most important, allows him to live at home.

For example, Ernesto’s cell phone is programmed to remind him when and how to take his diabetes medications and also prompts him to check his blood sugar. Then, Ernesto uses his computer to send the results to his new doctor, who can monitor any changes and send him suggestions and support with a mouse click.

But it’s not just about tests and treatments. These technologies also allow Ernesto to celebrate his birthday with his daughter across the country using videoconferencing and play online card games through his television to improve his memory and chart cognitive changes.

Sounds good, doesn’t it? Right now, Ernesto’s story is more vision than reality. But if we are to meet the needs of our aging population and meet them in a way that is palatable to the baby
boomer generation, we must harness technology’s potential to create what millions of seniors deserve: a caregiver network.

The Caregiver Network
What does a caregiver network offer? The answer is easy: communication. This network would allow individuals to connect in a new way and with information at their fingertips, deliver care in more meaningful ways. Instead of today’s typical eight-minute exam, networks will use technology to promote proactive and preventive care focused on education, empowerment, behavior modification and planning across generations.

A network like this would also support family caregivers, especially those who are providing care from a distance. Right now, nearly 34 million Americans provide care to older family members, and 15 percent of these caregivers live an hour or more away from their relative. As our population ages, the trend of providing long-distance care is not likely to change. That’s why it is imperative that individuals and family caregivers have the ability to become engaged and involved in care planning, regardless of their location.

Most importantly, the caregiver network encourages individuals to connect and build stronger relationships. Technology can collapse the thousands of miles that separate families while improving the senior’s social network. In addition, relationships among professional care teams can be strengthened to form a partnership approach to health care decision-making.

The Center of the Caregiver Network: The Personal Health Record
The technological foundation of the caregiver network is the personal health record (PHR). PHRs consolidate an individual’s health information and history so information follows the patient to different physicians and settings.

More importantly, PHRs offer consumer empowerment. When seniors and their family caregivers have control and responsi-
bility for their health information, they are more motivated to track and monitor their health. Their involvement can also help to ensure the correctness and accuracy of information, giving a clear picture of seniors’ medical histories and helping to avoid potentially dangerous and costly medical errors.

Foundations like the Robert Wood Johnson Foundation (RWJF) and the Markle Foundation recently began investing into enhancing the PHR’s role across the health care field. RWJF is sponsoring the “Project Health Design: Rethinking the Power and Potential of Personal Health Records,” a $4.4 million initiative to design and test new tools that advance the field of PHR systems over eighteen months. This new program will extend the range of uses that existing PHRs offer by supporting multidisciplinary teams to design and test a broad spectrum of innovations in how consumers can use information technology to better manage their health and more easily navigate the health care system.

The Markle Foundation is leading the “Connecting for Health” initiative, a public-private collaborative of more than 100 organizations committed to enabling health care professionals and patients to maximize the role of information technology in offering the best care possible. In December 2006, the collaborative released a white paper that describes a networked environment where consumers could establish secure electronic connections with multiple entities that hold their personal health information—not unlike the ways in which millions of Americans bank online today.

In the near future, large companies such as Google also plan to become more involved in consumer empowerment within the realm of health care. At a recent press conference, Adam Bosworth, vice-president of Google, discussed the company’s strategies for improving people’s ability to find the health information they need, including labeling sites and pages across the Web so health-related searches are easily refined and ordered by relevance.

According to Bosworth, innovative solutions to accessing and providing holistic, comprehensive health information to
consumers are badly needed in order to enable transformational change in the way care is provided. He said everyone needs a “Health URL” to store and share personal health information, minimize the fear and worry of the health care professionals managing diseases and help the people who care for them.

Provider Networks
What do all of these changes mean for organizations that provide care and services for older adults? It means that these organizations must not be providers of care, but facilitators of it. Technology is already revolutionizing our lives and older adults are insisting on highly specialized services, on their own terms, in their own homes. Providers must develop and maintain their own networks that knit together essential services and knowledge for older adults and their loved ones. Through technology and linkages with retail stores, banks, technology companies, hospitals and professionals, aging-services organizations will provide a seamless continuum of health, social, and consumer services for the people they serve.

Already, leading-edge providers are starting this process. Eskaton is a senior housing and service provider in northern California that is working with Intel to pilot test PHRs for its residents and their family members. This system is designed to help seniors easily store, manage, and search for their personal health and medical information in a secure, Internet-based platform.

Since the pilot began in mid-2006, a small group of residents has offered feedback to Intel about the PHR system’s usability and value in their lives. One of these residents is Al Hida. When he first heard about Eskaton’s partnership, he was intrigued. How could a computer company solve his health care problems? Now, Al uploads everything from prescriptions to X-rays into his secure “Internet Filing Cabinet” for his family members and health care providers to view. But that’s only part of it. He’s also working with the project leaders to create a more integrated way for his doctors to communicate with him using a similar program.
Intel is also conducting several surveys and focus groups with Eskaton residents, and using their insights to redesign the PHR application for increased simplification to input, download, and search for specific health and medical records. Recently, all residents of Eskaton were invited to participate in the use of the online PHR system.

The moral of this story is that providers who, like Eskaton, embrace opportunities to pilot technologies and, more important, who include implementation of technology solutions as part of their strategic planning, will be the ones to thrive in the future.

The American Association of Homes and Services for the Aging (AAHSA) recently completed its second scenario planning process to help not-for-profit aging-services providers identify trends and uncertainties for the future. Increasing consumer demands and the lack of a talent force to meet those demands were identified as the two greatest uncertainties facing these providers. Consumer demand for specialized, tailored, at-home services will increase with the aging of the baby boom generation, and our need for a larger workforce will grow. Technologies like PHRs will be an essential element in helping us face both of these uncertainties.

**Impediments to Creating the Caregiver Network**

In spite of a continuous spiraling of health care costs and reimbursements, it is difficult to address some core policy issues that inhibit technology’s potential to transform aging services. There are seven key impediments that must be overcome to actualize Ernesto’s visions for millions of American seniors:

1) **Reimbursement for on-site wellness and health care systems**

Telehealth technology, sensoring and monitoring devices and personal emergency response systems will help seniors live where they want, remain healthy through monitored care and exercise and stay safe. These in-home devices make it possible to monitor changes in behavior and medical conditions without the expense of providing onsite health care providers. Living at home is the...
preferred choice of seniors, and it is considerably less expensive than institutional settings.

These technologies also offer important benefits to the general population with the potential for substantial savings to our national health care bill. Currently, Medicare, Medicaid and private insurance carriers only provide limited support for reimbursement of these types of equipment. Studies by the Veterans Administration have shown substantial savings by implementing these technologies in the home. Many companies also indicated that they do not invest in health care and wellness type technologies out of fear of reimbursement.

Whether it is the private sector or the government, these studies show that everyone is missing an opportunity. The boomer generation is the first generation that seems willing to make their own investment in technologies that help them feel younger and healthier. Not only does the opportunity exist, but it has become very necessary to have consumers take greater responsibility in managing the costs of their own care. However, it is important to provide incentives to drive them in that direction. Government and private pay insurance companies need to offer consumers incentives to buy and use these technologies.

We also need to revamp the way in which physicians and other care specialists are reimbursed. Many of these technologies can help our society save dollars on health care costs through monitoring and reduced physician visits. A program to pay physicians and other health care specialists for monitoring and responding to medical conditions needs to be established.

2) A lack of federal funding for technologies that promote proactive care

There is a need to increase the funding of specific research on senior care directed to the integration and development of technology in order to reduce the costs and increase the level of quality of care. Unfortunately, proactive care solutions do not fit into the existing funding structures. National Institutes of
Health (NIH) funding is ordered by specific disease conditions, technology that focuses on wellness or improved health delivery all-too-often will not receive knowledgeable consideration by NIH reviewers. On the other hand, funding from the National Science Foundation (NSF) is mandated to support basic technology and will not cover the clinical testing needed to show beneficial health outcomes.

The fact of the matter is, it is not unusual for technology-based health care proposals to fall into the gap between NIH and NSF funding methodologies. Both NIH and NSF should create opportunities for cross agency technology-based solutions to address the needs of aging services and care. NIH should create multi-disciplinary review panels that include experienced technologists to review applications that utilize technology aimed at the proactive improvement of senior health and wellness. Both NIH and NSF should dedicate funds that would be jointly administered—and reviewed by multi-disciplinary review committees—to support technology-based solutions for aging services.

Much larger trials are taking place and outcome data is being developed in Europe and the Far East than in the United States. Most of this is happening because the governments of those countries are supporting the pilots. We also need to be able to support technology trials that involve multiple types of technology applications coming together as a coordinated service.

3) Senior housing regulations that do not recognize the need for ‘smart’ housing solutions that seniors to stay in non-institutional environments

Currently, the U.S. Department of Housing and Urban Development’s (HUD) regulations do not take into consideration the benefits of using technology to make senior housing both safer and more affordable. HUD should provide funding for all new and renovated senior housing so that high-speed wireless access is installed in the communities in order for medical monitoring and communication technologies to be used.
Special purpose sensors embedded in the housing would also enhance resident safety and compensate for the deteriorating vision, hearing, mobility and cognitive processes of senior residents. For example, sensors can passively monitor whether a stove has been left on, or whether a resident has just suffered a fall.

Finally, HUD should allow the pre-approval of plans and specifications that will better utilize technological solutions. HUD should consider requiring that a fixed percentage of total funding for senior housing be set aside for technology solutions.

4) Cross-state licensure for nurses and physicians that do not encourage opportunities in telehealth, wellness monitoring and remote care management

If we are to realize the opportunity for seniors to live safely and extensively in the environment of their choosing, professional caregivers must be encouraged to use new technologies. Currently, health care services are controlled by—and limited to—health care professional societies in each state. As officials of the Mayo Clinic have told us, they may undertake professional consultation and remedial activities between Minnesota and Dubai, but not between North and South Carolina.

That’s why, if we are to control health costs and meet the desires of our seniors, there is a compelling need to move more technology into the home. Medicare and Medicaid should encourage the development of state compacts that allow health professions to serve seniors through telehealth opportunities in all states.

5) Real and/or perceived liability barriers that inhibit research and development of technology solutions

Many technology companies avoid getting involved in aging-services technologies because they lack information on the liabilities of their participation. Congress needs to create a bright line on liability by creating a safe harbor defense for companies undertaking aging-in-place health and wellness research and development.
6) Challenges in a global marketplace
The global market in the field of aging services offers a great opportunity for technology leadership. There have been estimates that place the size of this market as high as $140 billion. Unfortunately U.S. companies are falling behind their counterparts in Europe, Japan and South Korea. More and more, we are seeing how U.S. companies are encouraged—through benefits and friendly environments for trials and pilots—to set up their research and development outside the U.S. The danger is both the loss of trade opportunities and intellectual capital. While the U.S. has always been an export leader in the area of medical and health equipment, the margin of leadership is dramatically shrinking. Congress should hold hearings to identify what can be done to motivate companies to invest in this growing market as well as to maintain research and development in the U.S.

The Solution: Pilot Programs and Epicenters
The bottom line is that technologies must be researched and refined to ensure that they are of the highest quality. That’s why AAHSA’s Center for Aging Services Technologies established a Pilots Committee. This committee is focused on facilitating projects and partnerships among provider members, technology companies and universities that offer organizations the information and support they need to bring technologies into their facilities.

This type of work, however, is not without its challenges. Partnerships among these stakeholders can be fragmented and uncoordinated. The quest to receive funding from traditional sources like grants and federal appropriations takes partners significant time and effort. There is also no universal methodology or implementation framework for partners to use in developing and evaluating their work.

All of these challenges signal the need for a more proactive approach to partnerships. That’s why CAST is establishing the Living-Laboratories and Technology Pilots Epicenters.
Because most current pilots are typically small in sample size and short in duration, these epicenter projects would help create a larger case for driving policy changes, expediting the removal of impediments and accelerating the development, adoption and proliferation cycle of proven technological products that will enhance the care, health, and quality of life of older adults, while potentially reducing care burdens as well as the health care bill.

Hence, when a CAST member starts a pilot project, they can maximize CAST’s resources and support through the project process. Members can use this support to find funding, receive expert consultation, avoid pitfalls and potential project failures, evaluate their work effectively, receive communications support and maximize the success of their work for their organization and other aging-services providers. Most important, it means that our country will move one step closer to making Ernesto’s story a reality for millions of future seniors.

Using technology to transform aging will require a transformation in how we finance, regulate, develop, evaluate and market technologies. In a world where we can use cell phones to monitor our children, PDAs to compare prices while shopping and digital video recorders to help us keep up with our favorite television programs, we have a responsibility and a mandate to harness the power of these consumer technologies to help older people remain independent while maintaining their own personal dignity. We all deserve to live like Ernesto, and we must all become facilitators of care in order to make his experience a reality.
Long Term Care in America

“Seventy-five percent of Americans have made no long term care plans, although most have expressed concern about being able to pay for it . . . it’s unbelievable and scary . . .”

—The Newark Star Ledger, April 4, 2007

“I think people are shocked, and they also think the government, Medicare, will pay for those expenses, and they don’t.”

—Richmond Times Dispatch, April 4, 2007

“Most people don’t want to think about [long term care], and they don’t think about it until a crisis . . . When they do, they get sticker shock and realize they haven’t prepared adequately.”

—The San Diego Union Tribune, April 4, 2007
Long Term Care and
the American Electorate

Glen Bolger, Co-Founder and Partner,
Public Opinion Strategies
Mark Mellman, President and CEO, The Mellman Group

With candidates, the press, and even voters already engaged in
election 2008, a fairly clear picture is emerging of the issues likely
to be at the core of the debate. The war in Iraq, the economy,
health care and education have already taken center stage and
will continue to be discussed in great detail over the next year.
Yet, our research reveals that there is one issue which concerns
many Americans and is getting relatively little attention at this
point: the state of our nation’s long term care system.

In August 2007, a bi-partisan polling team—Public Opinion
Strategies and The Mellman Group—conducted a nationwide
poll of 800 likely voters from all walks of life to get their impres-
sions on America’s long term care system, its actual and potential
impact on them and the place the issue will occupy in their minds
as they make voting decisions in 2008.

Americans Are Concerned About Long Term Care
How many Americans have been impacted by long term care? Do
people understand its costs? Are they prepared to pay for these
costs? What we have learned is not altogether surprising, but it
should concern the public and policy-makers alike.

A majority (55 percent) of voters have a family member (parent,
spouse, child, or close relative) who has needed long term care
either at home or in a nursing facility. One in five voters (21
percent) expect to need long term care for a family member with
in the next five years. Seniors are far from being the only group directly affected by long term care—61 percent of 18–34-year-old voters have a family member who has needed long term care.

Despite the fact that most voters have family experience with long term care, and that 40 percent expect a family member to need long term care in the next ten years, nearly seven out of ten have made no preparations to address that need. Only 18 percent have made any preparations to deal with the cost they are to about to incur. In fact, more than two-thirds (69 percent) of those expecting to need long term care for a family member within five years have made no preparations and just 19 percent have begun to prepare for the costs of the care they will need to provide.

This failure to prepare for an eventuality voters see coming, cuts across demographic lines. For example, 71 percent of voters earning between $40,000 and $80,000 a year have done no planning, despite the fact that their incomes render them ineligible for Medicaid and other assistance programs, thus creating a huge at risk pool consisting of millions of Americans.

Voters Generally Underestimate the Cost of Long Term Care

Americans’ failure to prepare for long term care may stem in part from the fact that they seriously underestimate the financial burden it imposes. Nearly two-thirds (64 percent), believe it would cost less than $60,000 per year. Indeed, 44 percent think the cost would be $40,000 or less. In reality, long term care costs almost twice as much (roughly $75,000 per year). Without some form of prior planning, many Americans are in for an unpleasant surprise, and serious problems, when they need to pay for long term care services.

Presidential Politics

As the Republican and Democratic presidential candidates begin defining their positions on the various issues, long term care has yet to break through and become a major agenda item in the campaign.
Polling done by our respective firms has consistently shown health care to be one of the top three or four issues on which voters are focusing as the 2008 election looms. In fact, it is clearly one of the top two domestic priorities for voters. However, while issues of cost, increased access, rural care, and universal coverage receive robust attention from campaigns on both sides of the partisan aisle, long term care issues have been given relatively short shrift.

Despite the paucity of attention from the campaigns, nearly eight in ten Americans (78 percent) believe long term care should be included in the health care reform proposals presidential candidates offer. Somewhat surprisingly, the youngest cohort is most likely to support the incorporation of long term care coverage in health care reform. Among those aged 18–34, 89 percent want long term care issues included in the candidates’ plans. Young women aged 18–34 were nearly unanimous with a stunning 96 percent asking for long term care plans to be included as part of broader health care reform proposals.

As more and more young people witness long term care needs in their own families, they are clearly becoming more sensitive to the burdens the current system imposes on families and therefore want their elected leaders to offer solutions.

Women, who often deal directly with such issues as care providers, are particularly interested in having long term care addressed by the candidates—with little difference between working women (84 percent) and homemakers (80 percent).

Long term care is also of particular importance to minorities as an overwhelming 92 percent of all African Americans feel this issue needs to be discussed by the presidential candidates.

While all segments of the electorate want to see long term care addressed by the presidential candidates, that sentiment is also more widespread in the Great Lakes region where 83 percent of the respondents there said it should be included. This area includes traditionally important battleground states such as Ohio, Michigan and Wisconsin.
Voter interest in long term care extends beyond the desire to hear a discussion. Were it to become a significant topic of debate, it could emerge as a voting issue. Forty-four percent thought the issue of long term care was either very important or one of the most important issues in the campaign. A clear majority of Democrats (55 percent) expressed this view as did 35 percent of Republicans surveyed.

**Voters Are Willing to Pay Part of the Cost, But See a Role for Government**

A further indication of the importance voters attach to long term care comes in their expressed willingness to make a sacrifice for coverage. Voters are willing to shoulder some of the burden to make long term care more accessible.

A solid majority, 59 percent, would be willing to support additional taxes or a higher payroll deduction in order to improve the current long term care system. Retirees over the age of 60 were most willing to pay extra to improve long term care with 82 percent offering that response. In addition, 85 percent of all African Americans would support additional new taxes or payroll deductions to improve the current long term care system. Even two-thirds of Republicans (66 percent) express willingness to pay higher taxes for improved long term care, along with 87 percent of their Democratic counterparts and 66 percent of independents.

Of those respondents who said they would be willing to pay higher taxes, 78 percent reported they would pay between $25 to $100 per month (that is $300–$1,200 per year) in order to improve or create a new long term care system. Younger voters are the most willing to ante up, with an extraordinary 87 percent of 18–34 year-olds willing to pay between $25 and $100 per month in additional taxes to offset the cost of improving long term care—higher than any other age group. This is particularly interesting because younger workers today have many more years to contribute to a benefit they might need further down the line.
Regionally, 90 percent of those living in the Farm Belt (Nebraska, Kansas, Iowa, etc.), would be willing to pay $25 to $100 per month in higher taxes to improve the long term care system, along with 86 percent in the Pacific states (California, Oregon, Washington) and 77 percent in the battleground Great Lake states in order to improve the long term care system.

Government Insurance vs. Incentives for those Who Choose to Plan Early

When given a choice between providing tax incentives and a payroll deduction to pay for long term care, voters prefer tax incentives for the purchase of long term care insurance. We asked our respondents which of the following candidates they would be willing to support: “Candidate A who has a plan which would increase long term care coverage by providing tax incentives to lower and middle income people who purchase long term care insurance; or Candidate B who would call for a new payroll deduction similar to the one for Medicare that would pay for long term care services for lower and middle income people.”

By 45 percent to 39 percent voters support the candidate who offers the tax incentives. Beneath the surface, however, there are some partisan divisions. Republicans prefer the tax incentives by 49 percent to 34 percent, while Democrats select the payroll deduction by 46 percent to 42 percent. Independents who hold the balance, looked more like Republicans, preferring the tax incentive approach by 43 percent to 36 percent.

While voters are clearly willing to contribute their personal financial resources toward improving long term care coverage, they also see some role for government in dealing with this issue. After informing our respondents that the average cost of one year in a private nursing home room is $75,000, we asked who they think should bear primary responsibility for paying for long term care. Over three-quarters of the participants (77 percent) said primary responsibility rests with individuals and
their families along with some assistance from either the federal or state governments. Just 16 percent think the individual and family should bear the cost alone.

The perceived need for government assistance to families in dealing with long term care cuts across party lines. A majority of Republicans (65 percent) wanted the government to assist families, as did 89 percent of Democrats.

Voters clearly believe that the 2008 presidential candidates aren’t talking enough about long term care and they overwhelmingly want these candidates to include the issue of long term care in their health care proposals. There is also very strong support for universal access to long term care even if it requires new taxes or payroll deductions.

Long term care is one of those issues that is of real concern to voters but has yet to capture the imagination of politicians. Americans want long term care to be part of the health care debate, are willing to judge candidates in part on their proposals in this arena and are willing to bear part of the cost of the long term care solution. Yet politicians have largely ignored the issue, preferring the well-trodden ground in the health care debate. A candidate who engages on this issue is likely to find electoral rewards, but perhaps more importantly, this reveals a looming public policy crisis. Experts estimate that the demand for long term care will rapidly increase, yet only a small percentage of the population has made any kind of preparations, and most people seriously underestimate the costs they could incur. Coming to grips with long term care represents a political opportunity and a public policy necessity.
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William Novelli is CEO of AARP, a membership organization of over 38 million people aged 50 and older, half of whom remain actively employed. AARP’s mission is to enhance the quality of life for all as we age. Prior to joining AARP, Mr. Novelli was President of the Campaign for Tobacco-Free Kids, whose mandate is to change public policies and the social environment, limit tobacco companies’ marketing and sales practices to children and serve as a counterforce to the tobacco industry and its special interests. He now serves as chairman of the board.
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The Future of Long Term Care in America
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