

Independence for Older Americans

An Investment for Our Nation's Future



A Report by the Alliance for Aging Research

Independence for Older Americans: An Investment for Our Nation's Future

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Executive Summary

As the United States experiences the greatest longevity revolution in history, the ability of the majority of older Americans to remain living independently is a major challenge – and one which will continue to grow into the next century. Over the next 50 years, the number of Americans over age 65 is projected to at least double, while those over age 85 will more than quadruple to almost 18 million.

Due to the multitude of debilitating chronic and long-term illnesses that tend to strike later in life, this huge population of older people will be at increased risk for mental, mobility, and visual impairment, often leading to loss of independence. Alzheimer's disease, osteoporosis, vision impairment (particularly age-related macular degeneration) and incontinence are among the most disabling of aging conditions which can trigger nursing home admission or dependent care in the home. And yet, there are few truly effective treatments, little prevention, and no cures for these conditions which afflict millions of Americans.

The Alliance for Aging Research, a not-for-profit advocacy organization, with assistance from a panel of experts, developed this report to reveal the enormous economic and social costs which result from lost independence among our older population. The panel, which includes leaders in the fields of geriatrics, demography and economics and health policy, conducted a thorough analysis of Medicare data on disability, nursing home admissions, and costs of health care of older people. They found that the United States currently spends more than **\$26 billion** annually in additional health care costs for people over 65 who lose their ability to live independently over the course of a single year. This number does not at all reflect the total cost of care for persons already disabled or living in nursing homes. The \$26 billion estimate solely reflects the additional costs incurred in the year when older people actually lose their independence. This huge expense will only escalate if our nation does not act now to find better cures, preventions and treatments for the diseases that erode the independence of older Americans.

The Alliance for Aging Research also outlines a series of recommendations in this report, which, if acted upon, could do much to change the way we take care of older people in this country, and enhance their ability to live at home independently. The recommendations are as follows:

1. Research funding at the National Institutes of Health should be increased with a special emphasis on diseases that cause disability in older people.
2. Evaluations of Medicare reform proposals should not solely be based on costs incurred, but also on improvements in the functional health status of beneficiaries.



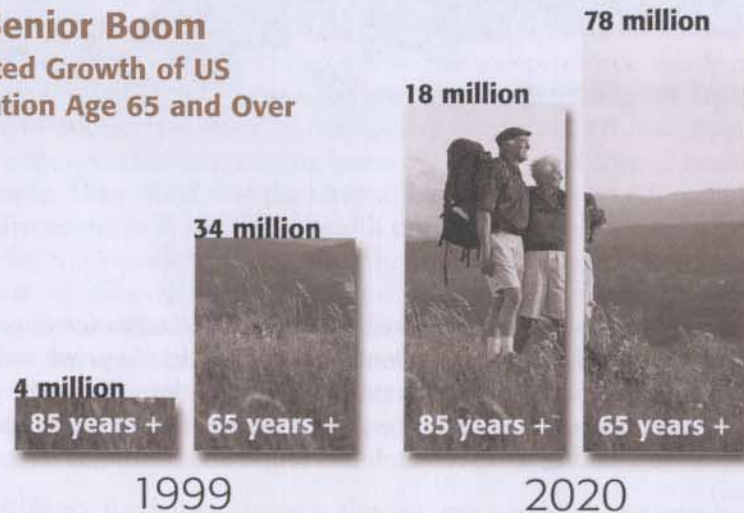
3. Research funding should be mobilized to improve outcomes for the chronically ill and elderly, and to identify strategies that improve access and reduce unnecessary health expenditures. In addition, the health community should begin to close the gap between what we know and what we do (i.e. taking what research has found and putting it into practice.)
4. Research should have an increased focus on the impact of preventive measures postponing the impact of conditions or illnesses that affect loss of independence in the elderly.
5. Better and more reliable population and cost data on the conditions which affect the health and independence of older Americans must be collected, analyzed and made a part of regular health care.
6. Medical providers should be better trained to assess risk of older patients for disability and nursing home admission, and be better trained to slow that transition.

The Aging Challenge

The United States is in the midst of a demographic revolution. Each day, more than 6,000 Americans celebrate their 65th birthday. Currently, Americans age 65 and over make up more than 13 percent of the population. The oldest old, Americans age 85 and older, represent the fastest growing segment of the population. And there are now more than 50,000 Americans who have reached 100 years of age or more.

But this is just the tip of the iceberg. In 2011, the first Baby Boomers will begin turning 65, signaling the start of the “Senior Boom”. By the year 2020, the over 65 population in the U.S. is projected to double from 34 million today to 78 million, and the number of Americans over the age of 85 is expected to more than quadruple from 4 million to almost 18 million in the same time period. Just ten years later, in 2030, there will be more older people in the U.S. than younger people, with people under 18 years of age representing 18 percent of the population and people over 65 representing 20 percent.

The Senior Boom Projected Growth of US Population Age 65 and Over



This new longevity is due in great part to medical and public health advances, which have reduced dramatically the incidence of acute illness in early life. Antibiotics, vaccines and other advances in research have helped to eliminate many killer diseases of past centuries, including infectious illnesses that once claimed millions of young lives. Consequently, both the total number and proportion of older Americans is the largest it has ever been. However, while scientific and medical research advances have helped limit mortality from acute illness, it is now chronic disease that poses a threat to our nation's health and economic well being.

Vulnerability to chronic age-related diseases increases exponentially after middle age. At 50, the risk for many age-related conditions begins to double every five to seven years.

Degenerative conditions like Alzheimer's disease, heart disease, adult-onset diabetes and Parkinson's disease often require long periods of care without hope of full recovery. Many older people are afflicted with numerous chronic illnesses and conditions for which we currently lack the ability to effectively treat, prevent or cure. Conditions such as arthritis, osteoporosis, age-related macular degeneration and urinary incontinence, while seldom a cause of death, are the cause of much dependent care and a greatly diminished quality of life for millions of older Americans. Alzheimer's severely affects mental ability; osteoporosis often results in falls and fractures and mobility impairment; age-related macular degeneration impairs the ability to drive, read, or even prepare food; and incontinence diminishes quality life leading to social isolation and depression. These separately and combined can lead to the decision to put a loved one into a nursing home or to require care-giving assistance in the home.

Chronic disease poses a threat to our nation's health and economic well being.

The decision to enter a nursing home is a complicated one that involves many social and psychological as well as physiological factors. But the primary cause of most nursing home admissions is the inability to perform one or more activities of daily living (ADLs), including bathing, dressing, eating, toileting, and getting in and out of bed. There are currently more than one and a half million people living in nursing homes in the United States, and more than 90 percent of those residents age 65 and older need assistance with one or more activity of daily living. More than 65% are reported to have memory impairment or disorientation.

Aside from the emotional distress that often accompanies such a determination, health care costs also increase substantially with nursing home admission. According to the panel of experts who prepared this report, the annual average costs of care for a person who must enter a nursing home is more than seven times that of someone who can remain living in their home independently. And yet, as the population ages and falls prey to chronic diseases which cause disability and loss of daily function, the need for long term and dependent care will grow in magnitude.

The Cost of Lost Independence

For the older Americans who lose independence each year, the increase in medical and long-term care costs are \$26 billion greater than if they had maintained their level of independence over that year.

Of the \$26 billion in additional costs, \$22 billion is for people who begin the year independent and then lose independence, resulting in need for help with self-care at home or admission to a nursing home. An additional \$4 billion is incurred for those who begin the year disabled in the community and make the transition directly to nursing home care during the year.

This calculation was developed from analyses of comprehensive data from 1995 on disability, nursing home admission, and cost of care collected as part of the Medicare Current Beneficiary Survey, a representative sample study of older persons by the federal Health Care Financing Administration, the governmental agency that administers Medicare and Medicaid programs. The \$26 billion estimate does not reflect the total costs of caring for disabled persons in the community or living in nursing homes, but only the additional costs incurred in the year when older persons actually lose their independence.

For the older Americans who lose independence each year, the increase in medical and long-term care costs are \$26 billion greater than if they had maintained independence.

Of the \$26 billion, \$22 billion is spent on people who begin the year independent, then lose independence, resulting in the need for help with self-care at home or admission to a nursing home. The additional \$4 billion is costs for those who begin the year disabled in the community, but transition to nursing home care during the year. These findings suggest that prevention or postponement of disability in older people would have a very substantial impact on both the quality of their lives and the costs of medical and long-term care.

The Medicare Current Beneficiary Survey is an ideal data source for estimating the cost of change in level of independence for several reasons. It combines information obtained in personal or proxy interviews with Medicare administrative and claims data; includes people living in both the community and in nursing homes; obtains longitudinal follow-up on participants; and can be extrapolated to nearly the entire older population of the United States.

The total estimated cost of losing independence was derived by determining the number of persons making transitions across three states of functional dependence and the additional costs incurred in the year when they made these

transitions. The three states that were used to evaluate the transitions were:

- (1) independence in the community in performing activities of daily living (ADLs),
- (2) living in the community but needing another person's help to perform ADLs, and
- (3) residence in a nursing home.

Since estimates are only for those people who survived for the full year of observation, the total cost does not reflect loss of independence occurring in the year prior to death, which may be less amenable to preventive interventions than disability which occurs earlier. Because people need to be in the Medicare program at least a year before they qualify for the Current Beneficiary Survey, these estimates are for persons age 66 and older. The costs of long term care used here are only for formal, paid care. The costs associated with informal care, such as the caregiver's lost time from work, are not included.

Additional findings of interest from this study include:

- In 1995, of the \$26.1 billion additional cost for care in those losing independence in a year, \$12.8 billion was for long-term care, including nursing home care (which includes skilled nursing facilities) and paid home care. The remaining \$13.3 billion was for medical care, including inpatient and outpatient hospital care, medical provider care, prescription medications and dental care.
- Total average annual cost of care for people who remained independent over the year was \$4,800. For those who began the year living independently, but ended it living in the community needing help with ADLs, total costs were \$18,000. If an individual entered a nursing home during the year, costs were \$36,600, more than seven times that of the person who remained independent in the community.

Costly Facts About Loss Of Independence

\$4,800

The total average annual cost of care for a person who remains independent during the year.

\$18,000

The total average annual cost of care for a person who lost independence during the year and needed help with daily activities.

\$36,000

The total average annual cost of care for a person whose lost independence caused him or her to enter a nursing home.

\$26 billion

The additional costs of medical and long-term care each year due to lost independence.



Cost Of Care

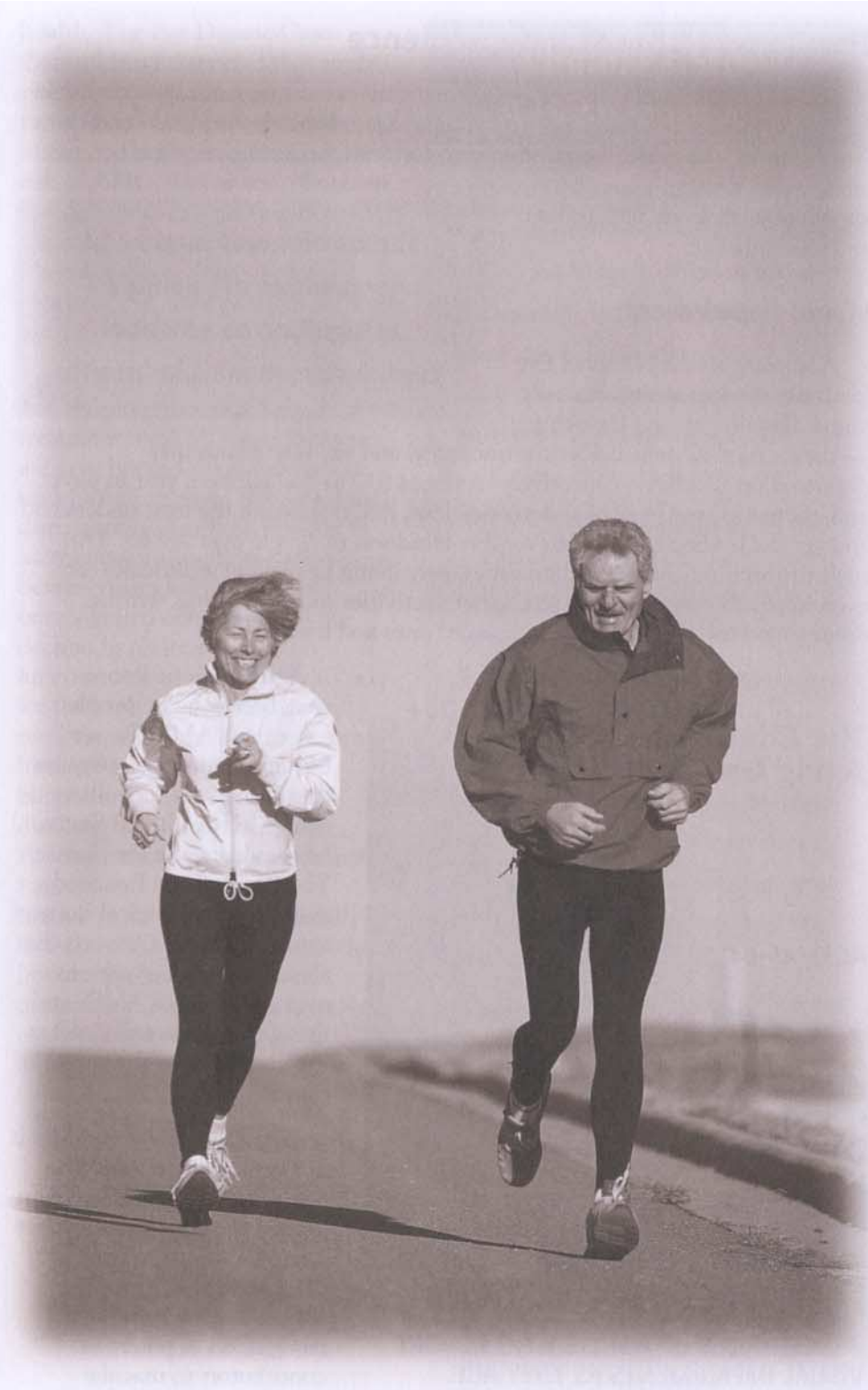
\$4,800
PERSONS WHO REMAINED INDEPENDENT ALL YEAR

\$18,000
PERSONS WHO STARTED YEAR INDEPENDENT ENDED WITH ADLS

\$36,600
PERSONS WHO ENTERED NURSING HOME AT BEGINNING OF YEAR

- Total average annual cost for persons with ADL disability in the community whose status remains unchanged was \$19,400, but if they entered a nursing home, it rose to \$40,900.
- Average annual long-term care costs were \$3,400 for those who made the transition from independence to staying in the community, but with a disability with self-care activities; \$6,800 for those beginning the year with ADL disability whose status remained stable, and over \$21,000 for all persons who began the year in the community but entered a nursing home at some time during the year.
- Of those people living independently, 3.3 percent developed ADL disability over a year. Overall, 1.1 percent of those initially independent had nursing home use during the year, compared to 8.9 percent of persons starting the year in the community with ADL disability.

There are several important caveats that need to be taken into account when interpreting this findings. They are discussed in the appendix.



The Causes of Lost Independence

Loss of independence among older Americans is most commonly attributable to disabilities that result from several specific age-related diseases and conditions. Among these, the greatest contributors to lost independence are: visual impairment, dementia, mental impairment, mobility impairment and incontinence.

Visual Impairment

According to the National Eye Institute, the four main causes of visual disability among the aging — cataracts, glaucoma, diabetic retinopathy, and age-related macular degeneration (AMD) — collectively represent \$30 to \$40 billion a year in direct and indirect costs. Of all of these conditions, AMD is one of the least understood and yet the leading cause of irreversible blindness in people over age 65. This highly frustrating condition diminishes daily living by making it difficult — or even impossible — to engage in ordinary activities such as reading, writing, driving, and social interaction with loved ones and friends.



The carotenoids lutein and zeaxanthin are gaining recognition as potential contributors to macular health.



The Effects of Aging On Vision

AGES 45-64

AGES 65-74

AGES 75+

15%

17%

26%

PERCENTAGES OF ADULTS WHO REPORT VISUAL IMPAIRMENTS AS THEY AGE.

While no one knows exactly how many people suffer from AMD, Prevent Blindness America estimates that as many as 13 million people in the United States have evidence of the disease. The Beaver Dam Eye Study, a major epidemiological study of aging in America, reports that about one-third of persons over age 75 have AMD, and many of the rest will develop the condition by the time they are 80.

The exact cause of AMD is not yet known, though the role of nutrition in protection against the condition is under scientific scrutiny. The carotenoids lutein and zeaxanthin are gaining recognition as potential contributors to macular

health. The Eye Disease Case-Control Study reported that study participants who consumed many fruits and vegetables containing lutein had a 43 percent reduction in risk of AMD. Lutein contributes to the density of macular pigment — the component of the eye that filters blue light. The denser the pigment, the more protection there is from damage caused by blue light.

But the fact remains that little is known about the causes and treatment for AMD, and therapies are very limited. And this lack of understanding about this insidious disease may contribute directly to increasing nursing home admissions. Severe vision loss may be “an unrecognized contributor to the decline in patients’ cognitive function and in their ability to care for themselves”. Nursing home residents are 13 to 15 times more likely to experience bilateral blindness than are community-dwelling persons of the same age. Among persons with severe visual impairment, 39 percent were limited in their activities of daily living and 70 percent had mobility limitations, compared with 7 percent and 29 percent respectively among people who had 20/40 vision or better.

Severe vision impairment can rob seniors of their independence and may contribute directly to nursing home admissions.

Virginia's Story: A Wish Unfulfilled

In the small Ohio town where she was born, Virginia taught school for nearly fifty years and outlived two husbands. Fiercely independent, she repeatedly said she wanted to die in the house she had built next to her childhood home, something which her pension gave her the means to do. However, age-related macular degeneration began to threaten her plans. When she first developed the condition, Virginia adapted and kept going. But soon she couldn't drive, a loss that is especially difficult in rural settings where public transportation is limited. Fortunately, neighbors and relatives drove Virginia where she needed to go and helped her with daily activities like shopping. But seeing to her needs became increasingly burdensome as Virginia developed dementia. Even with home care, safety issues arose. Eventually, Virginia fell on her front steps, unable to see and forgetting momentarily where she was. She awoke in the hospital wanting only to go back home. But that was impossible: the chronic diseases Virginia had developed, for which science has not yet found an answer, had stolen her ability to remain independent. Reluctantly, Virginia's family decided that she had to leave her home for safer surroundings. Now, she sits in a nursing home, where her dementia has worsened and friends seldom visit.

Dementia and Mental Impairment

When a loved one dies, family and friends experience the loss of a lifetime friend, parent, sibling or spouse. When a loved one progressively loses the ability to remember, think, and behave appropriately due to dementia, the loss is perhaps even more devastating. Dementia is an umbrella term used to describe the loss of cognitive or intellectual function. Many conditions can cause mental impairment, including Alzheimer's disease, Parkinson's disease, Creutzfeldt-Jakob, Huntington's disease, and vascular disease.

Alzheimer's, a progressive, degenerative illness that attacks the brain, is one of the most costly and devastating of these diseases. Resulting in impaired memory, thinking and behavior, Alzheimer's robs a person of their ability to care for themselves. Currently, Alzheimer's affects 4 million Americans, or approximately 11 percent of the population over age 64, with a total price tag of more than \$100 billion annually in health care and other costs to society. Unfortunately, the outlook for prevalence of this disease is not good. Experts predict that the number of people afflicted with Alzheimer's will more than double over the next twenty years and could nearly quadruple by the middle of the next century.

Research is needed on early detection of Alzheimer's since many believe that treatment may slow or stop, but not reverse, the progression of the disease. Research is also needed to establish biological markers that might be part of a blood or urine analysis to detect the disease in its earliest stages, well before any cognitive decline is present. Basic research also needs to continue on the causes of and risk factors for all the dementias, including Alzheimer's disease. While there have been advances in the treatment of Alzheimer's disease in recent years, continued research is critical in order to better understand the underlying causes of this disease so that methods of treatment and prevention will be possible.

Mobility Impairment

Osteoporosis and arthritis are among the major causes of loss of independence due to mobility impairment. The Centers for Disease Control projects that 59.4 million people, almost 20 percent of the population, will suffer from arthritis over the next twenty years. Osteoarthritis is the most common form of arthritis affecting persons age 45 and over. It is estimated that the United States could save \$10 billion in health costs, most of them stemming from loss of independence, if the onset of osteoarthritis could be delayed by five years.

Research has contributed substantially to improving the ability to diagnose and treat arthritis and related diseases. Exercise has also been shown to improve function and decrease pain and medication use in osteoarthritis. There is hope for further advances through new pharmaceutical and medical treatments especially with advances in molecular biology and genetic engineering.

Osteoporosis, a disease that reduces bone mass and causes structural deterioration of bone tissue, causes more than 1.5 million fractures annually, injuries that can lead to permanent disability, loss of independence, and even death. Estimated national direct expenditures for osteoporosis and related fractures is \$14 billion annually. Osteoporosis is a major public health threat for 28 million Americans, 80 percent of whom are women. Currently, 10 million people in the United States have osteoporosis, and another 18 million have low bone mass, a condition that increases their risk of getting the disease. One out of every two women and one in eight men over 50 will have an osteoporosis-related fracture over their lifetimes.

A balanced diet rich in calcium and vitamin D, weight bearing exercise, and a healthy lifestyle can maintain bone mass and significantly reduce the incidence of osteoporosis.

There have been advances in the treatment of this disease. Using diagnostic tools called bone density tests, physicians today can identify people who already have osteoporosis, or are at risk for it, before fractures occur. New medications are also available to prevent or treat this disease, and advances in research are being made each day.

Yet, despite these advances, there is no cure and additional research is urgently needed. Research about the mechanisms of bone growth and bone loss is essential for new approaches to preventing, detecting and treating this disease. Research is also critical to apply the information in clinical practice.



20% of the U.S. population will suffer from arthritis over the next 20 years

Helen: In a Nursing Home & Worried

After her husband died, Helen, with support from her only daughter, found a way through her grief to live independently for another decade. Breast cancer didn't stop her; neither did high blood pressure or hearing loss. Helen continued to keep her own apartment spotless, walk to the store, play cards with her friends. But osteoporosis and arthritis slowly made walking more difficult for her; falls became more frequent. As she lost mobility, Helen also developed incontinence. Fastidious, she no longer felt comfortable socially and stopped going out. Eventually, she submitted to moving into a nursing home. Today, the high cost of nursing home care is depleting Helen's funds, and she spends a lot of time worrying that she'll outlive her assets and become a financial burden on her daughter.

Incontinence

Urinary incontinence is one of the nation's greatest health care problems. It affects as many as 25 million Americans, the vast majority of whom are women, and often leads to disability and dependency. Indeed, urinary incontinence is a leading cause of nursing home admissions; approximately half of nursing home residents suffer from it. Urinary incontinence is also very expensive: currently, annual care costs are more than \$28 billion, but that amount is bound to increase as the population ages.

Urinary incontinence takes several forms and strikes for various reasons. For example, it is often found in people with diabetes, stroke, dementia, Parkinson's disease, or multiple sclerosis. Incontinence also affects new mothers, men, women and children suffering from an illness, birth defect or spinal cord injury. Other possible causes include weakened pelvic muscles, pelvic trauma, medications, dietary irritants, prostate surgery, and tumors.

The impact of urinary incontinence is devastating. It often produces side effects such as rashes, pressure sores, and skin and urinary tract infections. In addition, many of the joys and rewards of life can fade away. Sufferers can experience sleep disturbances, restricted social lives, reduced sexual activity, loss of self esteem and depression. Employment may become difficult or impossible.

Urinary incontinence is a leading cause of nursing home admissions; approximately half of nursing home residents suffer from it.

Fortunately, nearly 80 percent of urinary incontinence can be reduced or even cured through treatments that include exercises of the pelvic muscles, medications, surgery and diet. Nevertheless, more research must take place to make treatments more effective so that millions of older Americans who are otherwise healthy may lead more normal lives and the attendant costs of caring for them are reduced.



A Road Map for the Future - Recommendations

Action is needed now to ensure that the older Americans who will soon populate society in unprecedented large numbers will continue to lead independent, satisfying lives, and that the United States is in the strongest possible position to accommodate them. National leaders, researchers, and health care officials must take steps immediately to avert millions more cases of lost independence and the enormous attendant costs.

In addition, it is imperative that health care professionals practice and promote preventive medicine, which can head off the looming crisis from loss of independence among older Americans.

In order to guide the way, the Alliance for Aging Research has the following recommendations.

1. Research funding at the National Institutes of Health should be increased with a special emphasis on diseases that cause disability in older people.

NIH sets the tone for federal medical research, and while it has been a remarkable leader on many fronts, the subject of disability in older people has yet to receive sufficient attention. NIH can play a critical role, not only in terms of devoting more funding to this critical, underdeveloped area, but also by setting an example of priorities for the research world.

2. Evaluations of Medicare reform proposals should not solely be based on costs incurred, but also on improvements in the functional health status of beneficiaries.

As a critical resource for tens of millions of aging Americans, Medicare must be reformed in a comprehensive way. Such reforms include strategies to enhance the ability of older Americans to revert disabling conditions and loss of functional independence. It is important that measures be developed which would quantify the impact of conditions and illnesses that cause older people to lose independence.

3. Research funding should be mobilized to improve outcomes for the chronically ill and elderly, and to identify strategies that improve access and reduce unnecessary health expenditures. In addition, the health community should begin to close the gap between what we know and what we do (i.e. taking what research has found and putting it into practice.)

Breakthroughs in science must be implemented into daily clinical practice. Currently it takes between 6 and 10 years for clinical practice to adopt new knowledge for conditions that affect the majority of patients in this country. The advances research provides must reach the practitioner and patient to close the gap between what we know and what we do today in health care practice.

4. Research should have an increased focus on the impact of preventive measures on postponing the impact of conditions or illnesses that affect loss of independence in the elderly.

Preventive measures have the potential to eliminate some conditions that affect older people, or at least delay their onset. The promise of research into nutritional interventions, for example, is demonstrating that diet can improve health status over a lifetime. The importance of prevention is that it must begin long before old age – even in childhood – to have optimal effect. Research must establish specific recommendations for prevention that can reduce the cost of elder care.

5. Better and more reliable population and cost data on the conditions which affect the health and independence of older Americans must be collected, analyzed and made a part of regular health care.

Despite its real and profound impact, loss of independence is an under analyzed condition. Better and more reliable data needs to be developed so that the best care possible can be delivered individually, and health and social planners have the information they need to allocate society's resources effectively.

6. Medical providers should be better trained to assess risk of older patients for disability and nursing home admission, and be better equipped to slow that transition.

Unfortunately, most medical professionals in the United States are not adequately trained in geriatrics, the field of medicine that deals with the unique care needs of the elderly. Health care providers must recognize that older people require specialized care; become familiar with the most up-to-date information available from geriatric professionals and centers; and embrace and practice preventive medicine in order to head off the loss of independence for millions of older people.



Appendix

Methodology for Estimation of the Increased Cost of Medical and Long-term Care in Older Persons Who Become Disabled or Enter a Nursing Home Over One Year.

Overview of Medicare Current Beneficiary Survey

The data used to perform the analyses in this report come from the Medicare Current Beneficiary Survey (MCBS). The MCBS is an ongoing survey of representative samples of the Medicare population funded by the Health Care Financing Administration (HCFA) [1]. Its overall goal is to comprehensively describe health status and health care spending of Medicare beneficiaries and to use these data to model the impact of potential changes to the Medicare program. This is accomplished by combining data from HCFA administrative records with interview data obtained from the MCBS sample about their health and health care spending. The interview data includes information on non-Medicare spending, which is not available in the HCFA administrative data.

Field work for Round 1 of the MCBS began in September, 1991. MCBS began with a longitudinal sample design with follow-ups every four months and periodic supplementation of participants to maintain adequate sample size in the face of death and loss to follow-up and to add beneficiaries who subsequently became Medicare eligible. The survey includes Medicare eligible disabled persons under age 65 but the estimations presented here are only for the population age 66 and over. Persons age 85 and over were over sampled to provide more accurate estimates for this age group. At Round 10, begun in September, 1994, the design of the study was converted from a longitudinal sample with periodic supplements and indefinite periods of participation to a rotating panel design, with each panel having a limited period of participation [2].

Sampling and Study Population

The sample used for these estimations was derived from the 1995 MCBS Cost and Use sample, which represents all individuals enrolled in Medicare at some point during 1995. The sample was drawn from 107 major metropolitan areas (primary sampling units, PSUs) chosen to represent the U.S., including the District of Columbia and Puerto Rico. Within these PSUs, 1,432 geographic clusters were employed in Round 10 [2]. The Cost and Use sample is constructed from several panels of respondents. The main interview round for each respondent occurs between September and December of each year.

The estimations presented here are limited to persons for whom survey data existed just prior to 1995, and who survived through the end of 1995.¹

¹ Because each year's sampling frame is drawn well in advance (i.e., in January of the year prior to the year of the first fall interview), all beneficiaries in our sample survived at least two years beyond the date they enrolled in Medicare.

The total number of survey participants that met these criteria was 6,011. To obtain estimates for the U.S. population whom this study population represents, sampling weights were employed. About 40% of the 1995 ever-enrolled (weighted) sample were excluded, generally because they lacked the necessary 1994 data. This large number of records with missing data primarily represents respondents added to the sample as part of the conversion to a rotating panel design. To adjust for this, the weighted estimates derived from the 1995 beneficiaries who met the criteria for this investigation were multiplied by 1.66 to extrapolate to the full U.S. population with these characteristics.

Ascertaining Disability Status and Nursing Home Residence

Interviews are obtained on MCBS participants three times per year. For the study population used for these estimates, baseline status was obtained from the Round 10 interview, performed in the last 3 months of 1994, and one-year follow-up status from the Round 13 interview, performed in the last 3 months of 1995. Interviews were done in participants' homes using computer assisted personal interviews (CAPI), which allow direct entry of interview responses into an electronic data base. For those not able to complete the interview themselves due to physical or cognitive impairments a proxy respondent was used, usually a spouse or other family member. A proxy respondent was used for all institutionalized persons, using a modified, shortened assessment instrument.

Disability in activities of living (ADLs) was assessed by asking participants or proxies whether help was received from another person that was either hands-on help or stand-by assistance. If persons received help in one or more of five ADLs (eating, dressing, bathing, using the toilet, or getting in and out of a chair), they were considered disabled in ADLs for that round.

Characteristics of the site at which the interview took place were noted. A long-term care facility was defined as having three or more beds and providing long-term care services throughout the facility or in a separately definable unit [2].

Ascertaining Medicare Costs and Medical and Long-Term Care Expenses Not Covered By Medicare

The MCBS Cost and Use files document all health care spending for Medicare beneficiaries, for services both covered and not covered by Medicare. Survey data were linked to Medicare claims using the Health Insurance Claim Number (HICN), which was available for each participant at the time they were selected for the study and was verified against their Medicare identification card at the time of their first interview [3].

During each interview, the MCBS participant or proxy was asked about multiple aspects of health care utilization, including hospital, outpatient, institutional, outpatient prescribed medication, dental, emergency room, and home health care utilization. They were further queried on the charges for these services.

In constructing the MCBS files, HCFA used a complex algorithm to reconcile Medicare claims with self-reported service use, generally relying on patient self-reported expenditure information for services deemed to be not covered by Medicare.

Estimating Increased Cost

The goal of the analyses of Project Independence is to estimate the incremental increase in costs in older persons whose functional status deteriorates, or who enter a nursing home compared to what their costs would have been without those changes over a one-year-period.

Transitions were defined by status at baseline, status at one year, and use of a nursing home over that year. Three transitions were used to make the estimates:

| <u>BASELINE</u> | | <u>TRANSITION OVER ONE YEAR</u> |
|--------------------------------|---|---|
| 1. No ADLs*/community-dwelling | → | 1+ ADLs/no nursing home use |
| 2. No ADLs/community-dwelling | → | any use of a nursing home over the year |
| 3. 1+ ADLs/community-dwelling | → | any use of a nursing home over the year |

*activities of daily living

It was possible to stratify those who entered nursing homes into those who ended the year in a nursing home and those who had a nursing home admission and then returned to the community. However, the latter group was represented by a very limited number of actual observations. Spending for the two groups was generally similar, so they were combined for the purpose of the analyses in this report.

Spending estimates were made in four steps:

1. Estimate of the number of people in the United States in transition, using weighted data
2. Estimate of the average spending in a person who remains in the baseline state and does not transition, and the average spending of a person in transition
3. Multiplication of the difference in average spending (spending of those in transition—spending of those not in transition) by the number of people in transition to get the total additional cost of making the transition
4. Sum of spending for each of the three transitions.

An important caveat in interpreting these findings is that the cost of change in level of independence estimated here may not represent the net savings if we could actually postpone these transitions for a year. Firstly, there may be costs associated with providing patients with interventions to prevent disease and the functional consequences of disease that result in these transitions. Secondly, the aggregate level of health care expenditures is only partly a function of the underlying health of the population. It is also a function of the financing and organization of the delivery system, with greater spending possible even after the health status of the population improves. Thirdly, postponement of disability is likely to be accompanied by some postponement of death as well. Although better treatment of arthritis may not lengthen life, interventions to prevent or treat conditions such as heart disease and stroke can lead to postponement of disability and longer life.

Current research does not allow for an exact calculation of the proportion of the annual \$26 billion cost of disability that actually would be saved if these transitions were postponed for a year. For example, if delaying disability for a year resulted in a six-month extension of life in the disabled state, it would equal postponing disability for six months, with a net cost of about half of the \$26 billion, or \$13 billion.

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