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**Becoming Disabled After Age 65:
The Expected Lifetime Costs of Independent Living**

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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FOREWORD

The American population is aging, and for most of us a longer life span is associated with a longer period of good health and functioning. However, many of us will experience the onset of disability in later life. Most of us who experience disability want to continue living in our own homes.

So the question arises: What are the lifetime costs of obtaining appropriate services in their homes by persons who develop disabilities after age 65? The question is fairly easy to ask, but much more difficult to answer. Much of the current services experience for people who develop disabilities later in life is affected by limitations in the coverage provided by Medicare, and for some, Medicaid, and the difficulty in paying for needed services out-of-pocket. Also, over a million older persons with disabilities receive care in nursing homes, and not in the community. As a result, we currently have little to go on to answer the question.

The AARP Public Policy Institute contracted with LifePlans, Inc. for this report, “Becoming Disabled After Age 65: The Expected Lifetime Costs of Independent Living”, in order to begin developing our knowledge of the lifetime costs of obtaining services needed to continue living in their own homes by older persons who develop disabilities. The analysis uses as a starting point data for a well-insured sample of older persons receiving such services in their homes. The services obtained by persons in this sample should approximate appropriate care, as they are much less affected by the level of a person’s income or coverage limitations. Lifetime service costs were generated for each person in the sample, and these costs were then adjusted to be more representative of the U.S. population. This process included estimating the lifetime probability by age and gender that a person would become disabled after age 65. These probabilities are also presented in the report.

This report is a starting point, an exploration that takes advantage of the contractor’s unique data set – not the final word on this important question. We hope that it will stimulate examination of other data sets and other techniques to produce additional estimates to refine our knowledge of the costs that individuals and society face in providing appropriate care in their homes to older persons who develop disabilities.

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Executive Summary

Background

Over the next several decades, the United States will face the challenge of providing for and financing the long-term service needs of nearly 76 million baby-boomers who will soon begin to retire. Individuals use Social Security, pensions, savings, and possibly insurance to maintain living standards throughout retirement. Yet, studies consistently show that most individuals do not adequately appreciate the possibility that they may face high long-term care costs. The costs of these services pose a threat to living standards if individuals do develop a need for long-term care, and/or may impose serious burdens on unpaid caregivers, so it is important to have a sense for what potential liability a person faces. And given most people's stated preference to remain living in their own homes even if they develop disabilities, it is also important to determine the resource levels that are required to ensure that if long-term services are necessary, one can arrange for them at home rather than moving to a nursing home.

Purpose

The purpose of this analysis was to estimate, for persons 65 and over, the remaining lifetime probability of developing a disability and needing long-term care services, the service-related costs associated with avoiding nursing home placement and remaining at home while receiving appropriate quality care, and the costs associated with supporting currently institutionalized older persons in the community. This report does not analyze persons who have developed disabilities before the age of 65.

Methodology

We analyzed information from two national datasets. The first was the 1999-2000 National Database for Long-Term Care Insurance Claimants. A clinical panel of two experienced nurses conducted individual case reviews to generate trajectories of disability, service package requirements, and life expectancy estimates for the privately insured disabled older persons in this data set who received long-term care insurance benefits at home. We used data for persons with private long-term care insurance because they are likely to receive care in the amount and variety that is sufficient to maintain them at home, without leaving unmet needs or increasing the burden of unpaid care. The second dataset was the 1994 National Long-Term Care Survey, which we used to estimate the incidence of disability and to adjust the results from the Long-Term Care Insurance Claimants database to make them more representative of the U.S. population. We used published data from government and trade association sources to obtain information on the cost of such home care service providers as home health aides, nurses, and therapists. All costs are presented in year 2002 dollars.

Study Limitations

The estimates presented here require both using imperfect data and making some assumptions. Specifically, the database used to summarize baseline service use is derived from a sample of individuals with private long-term care insurance. Even after we made adjustments to account for several differences, the insured individuals are likely to differ in relevant respects from the general older population. A major component of the service cost estimates is based on the clinical panel's projections of disability trajectories and resultant changes in the use of services; these projections may be as much art as science.

We also do not assign dollar values to the significant level of unpaid care provided by family members and friends to the claimants in our sample at the same time that they are receiving services paid for by their insurance coverage, and we assume that this provision of unpaid care will continue.

The analysis presented here focuses on *mean* average spending on long-term services by persons who develop disabilities after age 65. The *median* is representative of the spending for a “typical” individual, because it is the level where half of all persons who develop a disability have lower service costs and half have greater costs. However, people may want to consider the entire potential range of service needs that may accompany developing a disability, and particularly if they are risk-averse, will likely want to prepare to some degree for the possibility of high costs, not just typical service costs. Because of a small percentage of very expensive cases, the mean costs of needed services is greater than the median (typical) level of costs. So in this illustrative analysis we recognize this risk-aversion to some degree by focusing on mean spending, which gives equal weight to all cost dollars, including those for the most expensive cases. Persons may even want to plan for the possibility of needing long-term services with costs in excess of the mean level.

It is difficult to predict future care patterns, even if we could accurately predict levels of disability. Specifically, the dataset did not permit us to analyze individuals who access services in assisted living facilities, either now or in the future. Finally, while we have attempted to estimate the service costs associated with keeping all individuals who develop significant disabilities after age 65 in their own homes, we recognize that there

will always be some individuals who will need nursing home care, regardless of their desire to remain at home.

Findings

Lifetime Risk of Disability

- The probability of having a disability increases greatly with age: For example, the probability of having a disability at any given point in time for a person aged 85 (35 percent) is more than seven times greater than the probability that a person aged 70 to 74 will have a disability (4.6 percent).
- The lifetime probability facing a 65 year old of *developing* a disability in at least two primary activities of daily living for at least three months or becoming cognitively impaired is 44 percent for males turning age 65 and 72 percent for females. Therefore, women face a 64 percent higher risk than do men.
- The lifetime probability of developing a disability declines slightly with age. For example a female aged 65 faces a 72 percent chance of developing a disability over her remaining lifetime, whereas the figure for a female aged 85 is 61 percent.

Lifetime Costs of Home-Based Services

- The average costs for paid care associated with maintaining disabled older persons at home throughout their entire course of disability are estimated at about \$174,000 (in year 2002 dollars). Median costs are estimated at \$135,000. The average monthly cost of care is \$2,924. This average includes a small proportion of individuals with disabilities who incur very high costs, combined with the majority who incur much lower costs.
- The average expected lifetime costs of care for maintaining a nursing home resident in the community rather than in a nursing home are estimated to be only slightly higher—\$179,000—than the costs for a disabled individual already living at home. Nursing home residents are typically more disabled and have higher average monthly costs (roughly \$4,000), but they also have shorter life expectancies than do individuals with disabilities living at home.
- Combining these two groups, the average lifetime service costs associated with ensuring that all individuals who develop a disability can remain in their homes, and can have their needs met, total \$175,000.

Summary

The costs associated with assuring that an individual can avoid institutional care and receive a level of service that meets his or her needs at home throughout a lifetime are significant. To cover these costs, an individual would need to have saved regularly over a period of years or have adequate income to pay for costs as they occur. Also, many individuals have the option of purchasing long-term care insurance. But for many other people of modest means, publicly funded programs, mainly Medicaid, may be the only option.

The figures presented here are for an individual. A couple concerned about the possibility of both partners becoming disabled would need to double these amounts, resulting in an estimate of potential service costs that is greater than most households can be expected to achieve. And if one wanted to plan to cover costs higher than the mean, or to cover the possibility of earlier onset of disability, then the costs to be considered would be much higher. For some persons, the inability to pay for necessary services might result in their increased receipt of unpaid care from family and friends. However, such care presents its own non-monetary costs.

These cost estimates probably best serve to highlight the fact that the substantial costs associated with developing a disability are beyond the individual financial capacities of most people. Public policy therefore needs to focus on various forms of risk-sharing arrangements—that is, private sector products or public sector programs that involve pooling risks with regard to payment for long-term care services at home. Some programs are available in the private sector, such as long-term care insurance, but there is little in the way of government programs that provide pooling for the financial burden of

services received at home. While Medicaid provides a safety net for services to assist those with disabilities, these services are provided primarily in nursing homes, not in a person's own home, and are available only to those whose incomes are low and whose assets are minimal. Given most individuals' stated desire to remain living independently in their own homes throughout their lifetime, it is important to recognize that a lack of private saving for long-term care needs and/or the absence of alternative publicly supported programs significantly increases the possibility that an individual may need to rely on institutional care.

Table of Contents

I. Background..... 1

II. Purpose..... 3

III. Method and Analytic Models..... 4

 Estimating the Lifetime Risk of Developing a Disability..... 5

 Determining the Level of Services Required to Meet the Needs of Community-Dwelling
 Individuals with Disabilities and Allow Them to Remain in Their Homes..... 8

 Determining the Level of Services Necessary to Maintain Currently Institutionalized
 Individuals in the Community..... 13

IV. Findings and Discussion..... 14

 Lifetime Risk of Disability..... 14

 Lifetime Probability of Using Services..... 18

 Use of Services by Privately Insured, Community-Dwelling Older Persons..... 21

 Expected Lifetime Costs of Care to Maintain an Individual in the Community..... 25

 Expected Costs of Caring for Currently Institutionalized Older Persons in the Community..... 29

 Total Costs of Receiving Care in the Community 31

 Study Limitations 32

V. Conclusions..... 36

Appendix 1: Transition Probabilities, Service Use Factors, and Duration of Disability for
 Individuals with Disabilities 39

Appendix 2: Regression Analysis Used to Develop Coefficients for Estimating Life Expectancy
 and Use of Services for Nursing Home Residents Moving to a Community Setting..... 45

References..... 47

List of Figures

Figure 1: Prevalence of Disability, by Age.....	15
Figure 2: Annual Incidence Rates of Becoming Disabled, by Gender and Age.....	16
Figure 3: Lifetime Probability of Developing a Disability, by Age and Gender.....	16
Figure 4: Use of Services before Current Residence in an Assisted Living Facility (ALF) or Nursing Home (NH).....	20
Figure 5: Illness Classification at Baseline.....	22
Figure 6: Expected Lifetime Community-Based Long-Term Care Costs, by Service Type.....	26

List of Tables

Table 1: Characteristics of Privately Insured Home-Based and Nursing Home Claimants.....	9
Table 2: Characteristics of Insured Sample by Life Expectancy, Care Hours, and Baseline Classification.....	24
Table 3: Expected Service Costs for Community-Dwelling, Disabled Older Persons Who Wish to Remain in the Community throughout Their Lifetime	28
Table 4: Predicted Life Expectancy and Service Costs Associated with Caring for the Nursing Home Population in the Community, Community-Dwelling Older Persons with Disabilities, and Both Populations Combined	31
Table A: Probabilities for Transitioning between Illness Categories by Baseline Classification	39
Table B: Probabilities for Transitioning between Illness Categories by First and Second Transition Phases	40
Table C: Transition Matrix Illustrating the Percentage Change in Hours of Care by Transition Category and Service Type	42
Table D: Regression Models for Estimating Life Expectancy and Number of Hours of Care Received by Home-Based Disabled, Older Persons	46

I. Background

Over the next several decades, the United States will face the challenge of providing for and financing the long-term service needs of nearly 76 million baby boomers who will soon begin to retire. Recent evidence has shown declines in age-specific rates of disability. If these rate declines continue, they will offset at least to some degree the increase in the absolute numbers of persons in older age categories, where disability is more frequent. However, estimates of the magnitude and nature of the recent declines in disability vary, and there is little agreement on what disability rates to project 20 to 50 years into the future (Manton et al., 1997; Manton and Gu, 2001; Schoeni et al., 2001; Waidmann and Liu, 2000). As a result, there is a lack of consensus about the degree to which the number of individuals projected to need long-term services—home and community-based or institutional-based—in the future is expected to increase. Under the most optimistic assumptions, there will not be a substantial increase in the number of older persons needing long-term services; under the most pessimistic assumptions, the level might increase to several times the number of older people who currently require long-term services.

Whatever the specific number, it will place significant demands on the service delivery and financing sectors. In 2002, roughly \$140 billion was spent on the direct costs of nursing home and home health care, with 24 percent of these costs paid out of pocket (O'Brien and Elias, 2004). This total does not include some personal care services spending, and most of the costs of assisted living. Also not counted in this figure are indirect costs, such as wages lost when an employed family caregiver takes time away from work to provide unpaid care. Because about 60 percent of individuals with disabilities rely on family sources for their care, this opportunity cost is significant. Long-term care costs, therefore, pose a

serious threat to living standards if individuals do experience a need for such care¹ (AARP, 2002; ACLI, 2001; MetLife, 2001).

Although individuals use Social Security, pensions, and savings to maintain living standards throughout retirement, studies consistently show that most individuals do not seriously consider the possibility that they will face high long-term care costs. Many individuals who eventually need long-term services, but who cannot afford to pay for them, must turn to public sources, primarily Medicaid, for support. After “spending down” their assets to qualify for Medicaid, many then find it necessary to receive these services as nursing home residents. Given the nature of current public financing programs, it is not surprising that older persons and their families bear a large part of the financial risk and services burden associated with long-term care.

Most people say they would prefer to remain living in their own homes, even if they develop a disability.² For these individuals it is useful to have some understanding of the resource levels required to ensure that if long-term services are necessary, they can avoid having to receive them in a nursing home. Clearly, the costs of these services for a specific person cannot be known with certainty. Not only do they depend on whether the person develops a disability in the first place, but the actual level of costs will likely differ from the average, and in particular may be much greater than the average level of expected costs for those few persons who require extensive services for a long time.

¹ Evidence suggests that current savings may not be adequate for a “healthy” retirement, let alone one with significant periods of disability (Purcell, 2003; ASEC, 1999; EBRI, 1999; Moore and Mitchell, 1998).

² It is important to note that not all individuals may wish to remain in their homes throughout a course of disability. Some may prefer assisted living or the medical oversight available in nursing homes.

Estimating even average cost levels is not an easy task, however.³ Although much data and a great deal of information are available about current service use patterns and costs across various care settings, such information is inadequate for this objective. This is because observed patterns of service use are a function of the structure of public financing programs, private insurance, and individuals' abilities to pay for care. We do not know whether the level of services that individuals with disabilities receive is adequate to meet current needs, let alone sufficient to keep them out of an institutional setting. Also, little information is available on the specific services that individuals receive in nursing homes, which could form the basis for determining what would be needed to maintain such individuals in the community. For these reasons, new data and methods are needed to estimate the monetary costs that will allow individuals with disabilities to avoid nursing home placement and instead live out their lives in their own homes. This paper describes data and a methodology for making such estimates, then provides these estimates.⁴

II. Purpose

As individuals begin planning for their retirement, it is useful that they have a *benchmark* for what it might cost them to remain independent in their homes in the presence of significant long-term service needs. This analysis was designed to answer the following research questions:

- What is the lifetime probability of becoming disabled and needing long-term care services among older individuals?

³ An individual can never know in advance the precise liability associated with their long-term care, given the wide variation in costs incurred by individuals with varying characteristics, and differences in service settings and geographic location.

⁴ Because of a comparative lack of data on lifetime use, this analysis does not include assistive living residences, the use of which reflects a combination of service need and lifestyle preference. The types of service need found in the residents of such facilities are included in this analysis in the mix of persons provided services in their homes.

- What is the expected trajectory by age and gender of disability and service needs for individuals with disabilities?
- What would it cost for community-dwelling, older persons to remain living at home in the presence of significant functional and/or cognitive disabilities, and how does this vary by age and gender?
- What would it cost to provide needed services in the community for persons who are currently in nursing homes?

Our intent in this analysis is not to presume that *everyone* will or can avoid nursing home admissions, but instead to estimate the costs associated with doing so for individuals who desire such a course.

III. Method and Analytic Models

To answer these questions, we first performed three analyses. We (1) estimated the lifetime risk of developing a disability, (2) determined the level of services required to meet the needs of community-dwelling individuals (i.e., those living at home) with disabilities and allow them to remain in their homes, and (3) determined the level of services necessary to maintain currently institutionalized individuals in the community. We used a number of data sources to perform these analyses, including the 1994 National Long-Term Care Survey (NLTCS) and the 1999-2000 National Database for Long-Term Care Insurance Claimants.⁵ We then used published data from government and trade association sources to obtain information on the cost of such home care service providers such as home health aides, nurses, and therapists.

⁵ Because there were a number of reported data errors in the 1999 NLTCS when this research was performed, we relied on the 1994 NLTCS for elements of the analysis. This data set has been used widely by a variety of researchers, and its variables have been validated. With regard to disability status (in terms of ADLs), there are few differences between the two data sets.

Estimating the Lifetime Risk of Developing a Disability

Disability is measured by an individual's inability to perform certain activities of daily living (ADLs), such as dressing, bathing, using the toilet, without assistance from another person. Individuals who are cognitively impaired (as measured by the Short Portable Mental Status Questionnaire) and therefore require assistance or supervision also are considered to have a disability. In this analysis, we define disability as requiring help with two or more ADLs for at least 90 days or being cognitively impaired.

To determine lifetime risk, we used a technique known as a "double decrement life table," which focuses on the annual probability of developing a disability and the annual probability of dying. The model also accounts for the probability of recovering from a disability.

To estimate this lifetime risk, and to estimate the probability that once disabled, individuals receive care in a home or community-based setting or in a nursing home setting, we examined data from the 1994 National Long-Term Care Survey (NLTC), which was designed to collect data about the health and functioning of the Medicare beneficiary population aged 65 and older. Survey questions identified persons who had certain disabilities or health problems lasting three months or longer. Individuals living in the community who had at least one chronic limitation in either an ADL or an instrumental activity of daily living (IADL), such as doing light housework or shopping) completed a comprehensive survey. The total 1994 NLTC sample consisted of 4,167 individuals. We used only the subset of this sample that met our definition of disability (two or more ADLs or cognitive impairment) to estimate prevalence rates for people aged 65 and older with a

disability. However, prevalence rates convey a cross-sectional estimate for the probability of *having a disability* on any given day; they do not directly tell us the probability of *developing a disability* over a particular time period. Instead, to estimate the lifetime chance of developing a disability one must focus on *incidence* rates, which tell us the probability of developing a disability over a particular time period.

To estimate incidence rates, we relied on additional data from the 1994 NLTCs that allowed us to estimate the probability that an individual will develop a disability during a five-year interval. The survey tracked whether individuals who did not have a disability in 1989 did have a disability five years later, in 1994. The survey also tracked the number of deaths among individuals with disabilities during the interval.

Because the survey only provides individuals' status at two defined times, it did not tell us whether initially healthy individuals who died sometime during the interval also developed disabilities at some point during the interval before they died. We assumed that those who died during the interval had the same annual rate of disability as those who lived throughout the entire interval. Therefore, the estimates presented here may slightly underestimate the probability of developing a disability over the period, because some evidence suggests that people with disabilities have a higher rate of mortality than do those without disabilities (Stallard, 2001).

In addition, individuals who became disabled during the interval and recovered before the end of the five-year interval would not be included in the observed five-year disability incidence rate. We made no adjustments to account for disability and subsequent recovery before the end of the interval. Few individuals who have two or more ADL limitations do

recover during a five-year period; in fact, fewer than 5 percent of persons older than age 70 with a disability in 1989 had recovered five years later.

To generate annual incidence rates, that is, the probability of developing a disability during a single year, for each age in 1989 we took the number of survivors over the interval who became disabled and divided it by the total number of survivors (i.e., the number of lives exposed to the risk of becoming disabled) over the five-year interval. We then used this ratio to estimate the *annualized* incidence, which represents the average *annual* rate (or probability) of becoming disabled over the five year interval.

We then used these annual incidence rates to estimate the lifetime probability of developing a disability, starting at age 60. We did this by joining the estimated annual incidence rates together in a table, and then “aging” a hypothetical cohort of persons by subjecting them to the risks of disability and death over each year of their remaining lifetimes.⁶ The lifetime rate of disability represents the number of people who develop a disability divided by the total number alive at the beginning of the cohort. For persons who died during a period, the probability of developing a disability during each year of that period was assumed to be the same as the probability estimated for persons who survived through the entire period. With this assumption we were able to estimate a probability of developing a disability over their remaining lifetime for all individuals, starting at various ages.

⁶ The death rates are derived from U.S. Lifetables for the United States in 1998 and published in the *National Vital Statistics Report* 48 (18) (February 7, 2001).

Determining the Level of Services Required to Meet the Needs of Community-Dwelling Individuals with Disabilities and Allow Them to Remain in Their Homes

To estimate the level of service needs we examined service use, specifically the number of hours of paid care, in a fully insured environment of individuals with long-term care insurance. In such an environment, individuals do not bear the costs of care because insurance pays for it. This is true for both community-based services as well as for institutional care. Therefore, for the most part, the cost of care does not influence service use, and observed patterns of care in such an insured environment are likely to represent what individuals perceive they must have to meet their care preferences and needs.⁷

To estimate future service use, we first examined the case files contained in the 1999-2000 National Database for Long-Term Care Insurance Claimants, a nationally representative sample of long-term care insurance claimants, from which we used data for 700 home-based care claimants and 400 institutional claimants with long-term care insurance policies (Cohen et al., 1999). Information on these individuals was collected through in-person assessments from nurses and social workers trained in geriatric assessment. The Department of Health and Human Services and the Robert Wood Johnson Foundation funded development of this data set, which had a combined response rate of 85 percent. Randomly sampled from eight major long-term care insurance companies, this cross-sectional database provides information about the sociodemographic characteristics of long-term care insurance claimants; their medical, functional, and cognitive status; their use of services, both paid and unpaid; and their

⁷ For purposes of this research, we assume that the privately insured do not face supply constraints, that they are able to obtain the services they need, and that the provisions of the insurance policy do not present impediments to or distortions in the choice of service setting. The one caveat we mention is that since a typical long-term care insurance policy includes a maximum level of spending per day, the use of services in the community may be constrained in some instances where extremely resource-intensive care is indicated.

satisfaction with their long-term care insurance policy. Combined, these companies pay benefits to more than 80 percent of all individuals receiving benefits under long-term care insurance policies throughout the United States. The characteristics of the home-based and nursing home claimants are summarized in Table 1.

Table 1: Characteristics of Privately Insured Home-Based and Nursing Home Claimants

	Home-Based Claimants (n= 698)	Nursing Home Claimants (n=343)
Average Age	79 years ^{***}	81 years
Gender		
Male	33%	34%
Female	67%	66%
Marital Status		
Married	46%	44%
Unmarried	54%	56%
Education Level		
Less than high school	35%	40%
High school or greater	65%	60%
Annual Income		
Less than \$30,000	51%	49%
\$30,000 or greater	49%	51%
Proportion Cognitively Impaired ⁸	40% ^{***}	83%
Has Personal Hygiene Problems	11% ^{***}	28%
Exhibits Abusive Behaviors	3% ^{***}	6%
Average ADL Limitations ⁹	3.3 limitations ^{***}	4.7 limitations
Primary Diagnosis		
Diabetes	3% ^{**}	5%
Stroke	25% ^{***}	2%
Fracture	12% [*]	16%
Parkinson's	4% ^{***}	18%
Cardiac	7% ^{**}	3%
Respiratory	4% [*]	2%

Source: Authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

Notes: The values for home-based claimants and nursing home claimants were compared for each characteristic and tested for statistically significant differences, indicated as follows: * Significant at the .10 level; ** significant at the .05 level; *** significant at the .001 level. The majority of those who were cognitively impaired also had a diagnosis of dementia or Alzheimer's disease.

⁸ This is based on failing the Short Portable Mental Status Questionnaire, having a cognitive diagnosis, or not being oriented to person, place, or time.

⁹ The levels of disability among the insured population in the nursing home may be higher than those found among the noninsured institutionalized population. Because the insured may be able to remain in the community longer with higher levels of disability than can the noninsured, they may enter the nursing home more disabled than their noninsured counterparts.

While the 1999-2000 National Database for Long-Term Care Insurance Claimants also contains data for persons who received services in assisted living residences, the data for these persons were not used in constructing the service-need profiles for persons in the community, and our estimates do not include this type of residential service setting. There are several reasons for this decision. Many observers (both insurers and researchers) have more difficulty cataloguing the specific services that are actually used in assisted living residences, and with what frequency, than in the home where individual services are more generally prescribed (and therefore easily identified) on a service-by-service basis. Also, as a result of regulations some individuals may have some services performed on their behalf in assisted living residences for activities that they could do on their own. In addition, examination of the data for persons receiving services in assisted living residences indicated that these persons were no more disabled than those receiving services in their homes – the housing aspects as much as the service aspects of assisted living seemed to have attracted people before they become too disabled. Finally, no lifetime risk estimate for moving to an assisted living facility has been published.

In order to determine expected service need in the home, a clinical panel comprised of two nurses next reviewed the medical, functional, and cognitive profiles of the 700 community-dwelling claimants and the services they were receiving at the time they were interviewed. For each individual, the clinical review yielded estimates of: (1) the claimant's remaining life expectancy, and (2) the expected trajectory of disability and service use over the person's remaining lifetime. The estimation of life expectancy was based on an analysis of longitudinal data derived from the 1994 NLTCs, a review of the mortality literature, and

clinical experience garnered from making such estimates in the private insurance setting.¹⁰ In making predictions about individuals' life expectancy, the clinicians took into account their age, medical history, functional status, and cognitive status. An upper estimate for each disabled individual was 95 percent of the age-specific life expectancy of a healthy individual. Put another way, in the cases analyzed, disabled individuals were predicted to have, at most, 95 percent of the life expectancy of similarly aged but healthy individuals.

Regarding the trajectory of service use, it is well known that individuals' disability status and service needs rarely remain constant. This often translates to changes in specific services. For each individual claimant, baseline status was classified into one of the following four illness categories:

- 1. *Recovering from Acute Illness:*** This category included individuals who had sustained an acute "event," such as new-onset cerebrovascular accident (e.g., stroke), surgical procedure, fracture, cancer, or other illness from which the individual might be recuperating. It is important to note that even in this category almost all persons analyzed had substantial underlying limitations and resulting care needs apart from the acute illness episode.
- 2. *Illness Stabilized:*** This category included individuals who might have either leveled off in terms of rehabilitation from an acute illness or who had a chronic illness, such as diabetes or chronic obstructive pulmonary disease (COPD). Review of the case file indicated that the illness had been maintained at a steady state over at least a one-year period.
- 3. *Chronic Illness, Now Deteriorating:*** This category included individuals whose known illness showed a steady decline in health and function, but who were not necessarily in a terminal stage. This included people with Alzheimer's or Parkinson's disease or people who had a chronic illness that was no longer being held in check. The individual showed progressive decline in health and functioning, often as a result of progressing cancer, cardiac or respiratory problems, multiple and recurring fractures, or strokes.

¹⁰ On behalf of private insurance companies, the clinicians involved in this study estimate the life expectancies of disabled individuals who are interested in purchasing insurance to pay for care for as long as it is needed. Thus, the insurer must estimate how long a disabled individual is likely to live in order to set a premium for the insurance policy. The setting of this premium is based in part on the same type of estimate for life expectancy developed by the clinical panel used in this study.

4. ***Terminal Illness:*** This category included individuals whose illness had a fairly predictable likelihood of death within the next 12 to 18 months. For purposes of this study, this category typically included terminal stages of cancer, Alzheimer’s disease, and Parkinson’s disease.¹¹

After reviewing each of the cases and the services that individuals were receiving at the time they were initially interviewed (that is, the individuals’ baseline status), the clinical panel estimated a trajectory for disability and service needs (monthly hours of care) over the remaining lifetime for each of these individuals. This trajectory was defined as a series of transitions among the four illness categories described above. The specific sequence of categories, the time spent in each category, and the hours of care for various services while in that category were determined on a case-by-case basis. This classification and need analysis was based on the individual’s medical diagnosis, functional and cognitive status, and disease staging. The point of reference for this estimation of the trajectory of services needed over the remaining lifetime was the amounts and types of care—both paid and unpaid—provided at baseline for each individual.

Once the lifetime hours of care for various service categories were estimated, unit costs were ascribed to each service type. These unit costs of care were based on published national data. Summing up these costs over all types of service and all years yields the total lifetime costs of long-term care services for an individual. Costs are presented in 2002 dollars, without explicit adjustments for increases in service costs in the future and without the discounting of the costs of services that occur in the future. (The discounting of future costs embodies the general perception that costs expected in the more distant future represent

¹¹ That Alzheimer’s and Parkinson’s are in both categories three and four suggests that other information and comorbidities play an important role in the individual’s ultimate classification.

less of a burden today than if the same level of costs were actually incurred today.) We assume that the rate of increase in service costs is offset by the rate of discount of future costs.

A more complete description of the results of this trajectory classification process is found in Appendix 1, which presents summary transition probabilities for persons who started in each of the four illness states as well as the average length of time (in months) in each state. These summary data are aggregated from the specific trajectories produced by the panel for each individual. All trajectories end in death, with most individuals expected to transition to a chronic-deteriorating state that ends in death, usually within two to three years.

Determining the Level of Services Necessary to Maintain Currently Institutionalized Individuals in the Community

To determine this level of services, we developed two regression equations. Based on the sample of community-dwelling, disabled older persons from the 1999-2000 National Database for Long-Term Care Insurance Claimants, we estimated the relationship between future life expectancy (derived from the clinical review panel) and sociodemographic and health characteristics. Similarly, we also estimated the relationship between the number of hours of care that persons were projected to receive in the community (again derived from the clinical review panel) and sociodemographic and health characteristics. The regression equations and explanation of variables are summarized in Appendix 2. The relationships estimated in these regression equations (showing the effects of various explanatory variables on life expectancy and care requirements for individuals with disabilities in the community) were then used to predict the life expectancy of nursing home residents as well as the monthly

hours of care they would incur in the community, given their sociodemographic, health, and functional status.

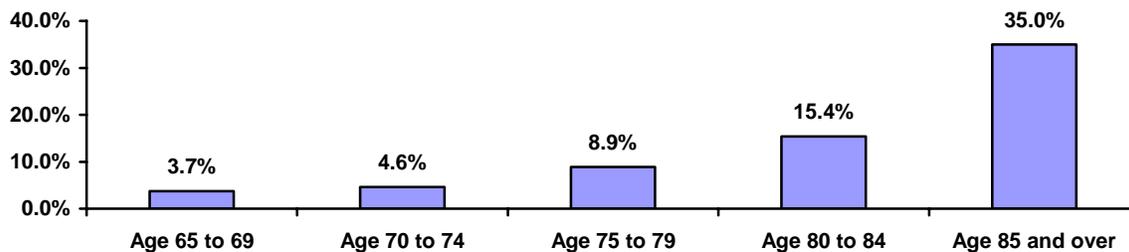
To develop an overall estimate of the costs associated with keeping community-dwelling, disabled individuals in the community plus the service costs associated with having currently institutionalized, disabled older persons receive care in the community, we combined estimates from each population to create a weighted average. The weights were based on information about the distribution of disabled individuals living in the community and in nursing homes (Spector et al., 1998).

IV. Findings and Discussion

Lifetime Risk of Disability

This section presents three figures that report our findings on the lifetime risk of developing a disability. These findings are derived from, first, calculating disability prevalence rates, then estimating the probability of developing a disability (incidence) over a specific time interval. The prevalence rate measures the number of people who have a disability at a particular time, defined as having at least two limitations in activities of daily living (ADLs) that have lasted 90 days or more, or being cognitively impaired as measured by the Short Portable Mental Status Questionnaire (SPMSQ). Figure 1 highlights the age-specific prevalence rates for individuals with disabilities. These prevalence rates include individuals living in the community as well as those living in nursing homes. Data are derived from the 1994 NLTCs.

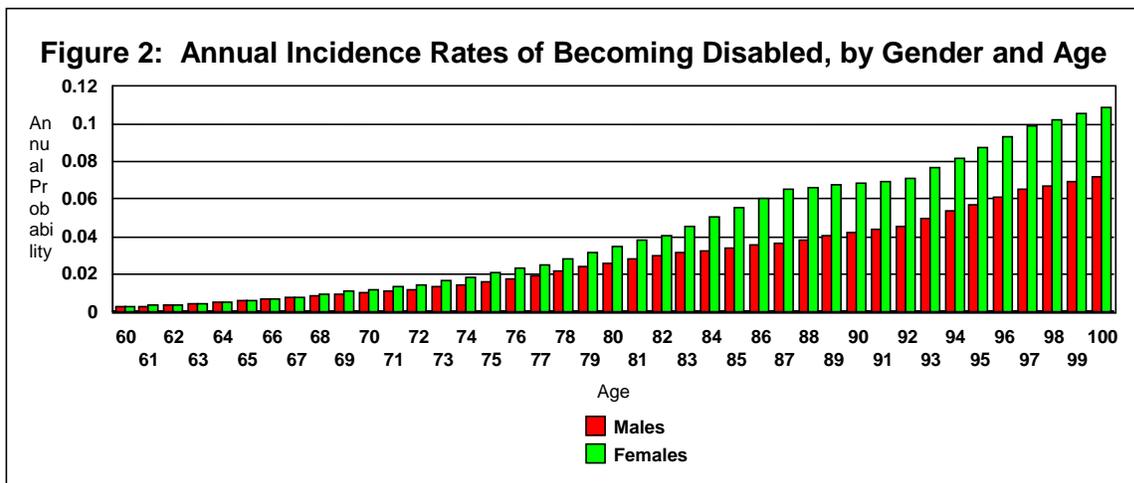
Figure 1: Prevalence of Disability, by Age



Source: Stallard, 2001.

As shown, the likelihood of having a disability increases greatly with age: For example, the likelihood of a person 85 years or older having a disability (35 percent) is more than seven times greater than that of a 70- to 74-year-old (4.6 percent). These data suggest that if everything else is held constant, improvements in life expectancy should lead to greater numbers of individuals requiring assistance in ADLs simply because they live to a point when disability is more prevalent. In other words, individuals who live long enough are more likely to experience some level of functional or cognitive disability before they die than are those who die at younger ages. (On the other hand, one could argue that because greater life expectancy could be the result of better physical and mental health, individuals might have fewer disabilities, or have them for a shorter period of time, and therefore have less need for long-term services in later years).

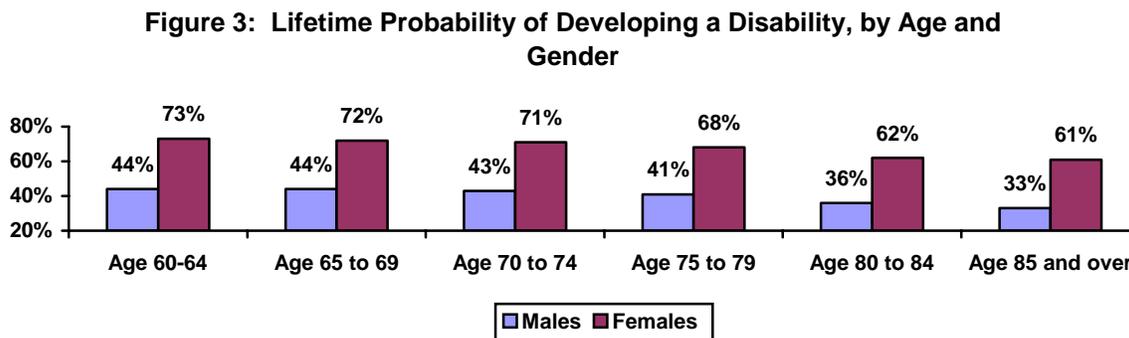
Figure 2 displays the results of the next analytic step, that is, determining the annual probability of becoming disabled by gender for those ages 60 and older. As shown, at all ages the risk of disability is greater among females than among males, with the difference becoming more pronounced after age 80.



Source: Authors' calculations based on the 1994 National Long-Term Care Survey.

Note: Disability is defined as requiring either stand-by or hands-on assistance with two or more ADLs or having a cognitive impairment as measured by making at least three errors on the SPMSQ.

Cumulating the incidence rates, as described in the methods section, yields Figure 3, which summarizes the remaining lifetime probability of developing a disability, by gender and age category.



Source: Authors' calculations based on the 1994 National Long-Term Care Survey.

Note: Disability is defined as requiring either stand-by or hands-on assistance with two or more ADLs or having a cognitive impairment as measured by making at least three errors on the SPMSQ.

The lifetime probability of developing a disability for an individual at age 65 is 44 percent for males and 72 percent for females. Although a majority of women are estimated to develop a disability, in that they will require help in two or more ADLs (for at least 90 days) or will be

cognitively impaired, slightly less than half of all males are estimated to reach this level of need.¹² In general, after age 70, the lifetime probability of developing a disability declines slightly with advancing age. This is due in part to the fact that a person has fewer remaining years during which to face the annual probability of developing a disability. Also, because chronic disability is associated with higher mortality, those who live into their 80s “disability-free” may be more likely to die from acute illnesses before experiencing chronic conditions that require personal care assistance. Put another way, they may be more likely to die before experiencing significant functional or cognitive declines. They may still experience more moderate levels of functional disability, however.

Across all ages shown, women are much more likely to develop a disability than are men. In fact women face a lifetime probability of developing a disability that is at least 60 percent higher than for men across most ages. In part, this is related to the fact that women are more likely to live long enough to experience disability, but it also has to do with the fact that age-specific incidence rates are higher for women than for men. This may also be related to the fact that men are more likely to die from heart disease and other acute illnesses, whereas women live long enough to experience more chronic illnesses.

It is important to note that these risk estimates are based on the experience of cohorts that were ages 65 and older in 1994. To the extent that subsequent cohorts have improved health histories, as evidenced by lower disability rates, then these estimates may overstate the lifetime probability of disability. Even so, modest improvements in disability will not alter

¹² Sensitivity analysis shows that if we assumed instead that the rate of disability among those who died during the interval was only half that of those who became disabled and lived throughout the entire interval, then the lifetime risk estimates for a 65 year old would fall by 14% for females – from 72% to 62% -- and by 18% for males – from 44% to 36%.

the general picture of a majority of individuals experiencing some level of disability before they die.

Lifetime Probability of Using Services

A great deal of research has focused on predicting the probability that an individual turning age 65 will use *a particular service*. For example, in a new study exploring the lifetime risk of needing nursing home care, Spillman and Lubitz (2002) project that 44 percent of individuals turning age 65 will access nursing home care at some point during their lifetime. They also demonstrate that given predicted changes in the structure of the population, this figure is expected to rise to 47 percent over the next 20 years. Others have estimated the overall risk to be closer to 49 percent (Alexih, 2000). These findings closely parallel previous work by Murtaugh et al. (1990) and Cohen et al. (1986). The underlying assumption of these estimates is that service use rates will remain constant. Yet, the long-term care service system has experienced dramatic changes over the last decade, including changes in both community-based and nursing home care. Thus, estimates based on current and past use rates will necessarily be somewhat inaccurate if they do not take into account changing roles and continuing shifts in the function and use of specific service modalities. For example, much of nursing home care has shifted to short-term postacute care, so that the probability of using a nursing home now includes more than the probability of needing its services on a *long-term basis* (Bishop, 1999). It now includes the need for certain short-term subacute and rehabilitation services.

It is important to note that all published estimates for the lifetime risk of service use rely on data from the late 1980s and early 1990s, and do not take into account changes over

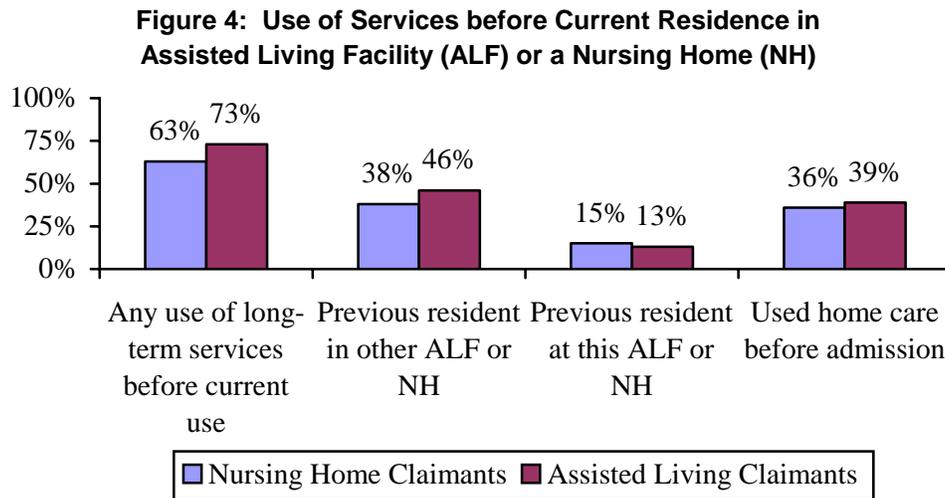
the last decade in the types of services available and service use. As noted above, assisted living facilities have emerged as a factor in the care sector for older Americans, yet few data have been collected systematically at the client level, and the definition of assisted living is not uniform across the states. Also, the use of assisted living facilities reflects a combination of both lifestyle preference and current or expected service need. Thus, no lifetime risk estimate for moving to an assisted living facility has been published, so we do not include this type of residential service setting in our estimates of service use.

The decision to use a particular long-term care service is complex and depends on a variety of factors, including (but not limited to) personal wealth, availability of publicly financed services, private health or long-term care insurance coverage, trends in the provider environment, family mobility, family structure and labor force participation, service availability in a specific area, access to alternative advanced technologies, and individual preferences for specific services. Thus, all predictions about the future use of services tend to hold these factors constant and take a retrospective approach to quantifying risk and projecting it forward on a population. At best, researchers take into account the changing age and gender composition of the population to refine somewhat their estimates for the risk of using specific types of services. They may also present an array of possible futures based on different use patterns to show the sensitivity of their analyses to different possibilities.

Another difficulty with estimating the risks associated with using specific types of services is that the risks are not mutually exclusive. An individual can use home care, then move to an assisted living facility, and ultimately end up using nursing home care. For example, Alecxih (1997) predicted that an individual turning 65 has a 72 percent chance of at some point during his or her life using long-term care other than nursing home care, such as

formal home care. But one cannot simply add up the individual risks of using each of these services to obtain a composite risk of service use. Nationally collected data do not permit easy identification of the overlap in service use.

To illustrate the point, Figure 4 shows whether a sample of privately insured nursing home and assisted living claimants received any home- or community-based services or whether they lived in other long-term care institutions before their current residence. As shown, many nursing home residents received home care or had been in an assisted living facility before their current stay in a nursing home. Similarly, most assisted living residents had used some form of home health or nursing home care before moving to an assisted living facility. Thus, individuals may experience many transitions between and among different types of care. As providers develop additional services or combinations, it will be even more difficult to accurately predict the lifetime risk of using any one particular service.



Source: Cohen and Miller, 2000.

The implication of these findings is that projecting specific service use patterns is much less precise than predicting disability itself. This is because disability rates do not vary with changes in the provider system, individual preferences, family structure, and other exogenous factors. However, disability status and use of long-term care services are strongly linked. We know that individuals who have at least two or more ADL limitations or are cognitively impaired are very likely to require long-term care services, from either family members, paid caregivers, or both.

In the following sections, we base our estimates of the costs associated with maintaining individuals with significant disabilities in the community on: (1) the amount of time a person is estimated to remain disabled, and (2) the costs associated with providing specific services to meet individuals' needs in a community setting. We used the data from our primary database for individuals who already have a disability and are receiving assistance in the community and for the characteristics of institutionalized persons who are also represented in this database. For these currently institutionalized persons, we estimated the costs associated with caring for them in the community. Finally, we reweighted these two sets of estimates to generalize the results to the general population, based on our estimates of the probability of developing a disability by age and gender.¹³

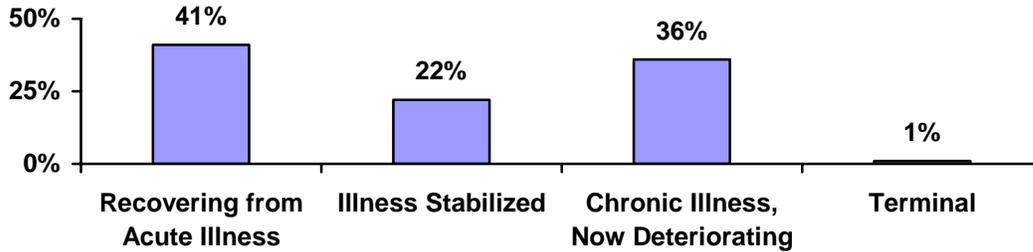
Use of Services by Privately Insured, Community-Dwelling Older Persons

In this section, we present the findings from our analysis of baseline levels of service used by community-dwelling individuals with disabilities and project their life expectancies.

¹³ This combined weighted estimate may slightly underestimate the true costs, given that a small percentage of currently institutionalized persons who require around-the-clock care may have their community-based care costs underestimated as a result of the per diem cost limits contained in the long-term care policies that provide reimbursement for the community-based sample.

Figure 5 summarizes the baseline classification for all of the community-dwelling, privately insured older persons with disabilities in the National Database for Long-Term Care Insurance Claimants sample.¹⁴

Figure 5: Illness Classification at Baseline



Source: Authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

n=698.

Note: A small number of individuals identified as having cognitive impairment (see Table 1) have co-morbidities that dominate their current condition. Most of these individuals have been classified as recovering from an acute illness.

As shown in Figure 5, slightly more than two in five people were recovering from an acute illness. About one in three had a chronic illness and was in deteriorating health. On average, at the time of the interview individuals had been receiving services for one year. Those recovering from acute illness had a disability for the least amount of time, whereas those classified with a chronic illness had a disability the longest.

Table 2 shows the distribution of the privately insured, community-dwelling sample by average projected life expectancy with a disability, by the number of hours of care received each month at baseline, and by the baseline classifications. The resulting relationships and patterns between projected life expectancy and other variables were

¹⁴ These individuals have at least two ADL limitations or are cognitively impaired.

predictable. The clinical projections of average life expectancy show that life expectancy is inversely related to age, disability, and cognitive impairment. In addition, males with disabilities in this sample are predicted to live somewhat shorter lives than are females with disabilities.

The actual hours of paid and unpaid care at baseline varied with individuals' characteristics. For example, married individuals received greater amounts of unpaid family care but less paid care than did their single counterparts. Similarly, individuals with higher levels of disability required greater levels of both paid and unpaid care. Males received twice as much unpaid care as did females. Given males' higher likelihood of being married, as well as their spouse's greater probability of outliving them, this is not surprising.

Table 2: Characteristics of Insured Sample by Life Expectancy, Care Hours, and Baseline Classification

Characteristic	Disabled Life Expectancy (years) ¹	Weekly Hours of Care at Baseline ²		Baseline Classification ³			
		Paid	Family	Class 1	Class 2	Class 3	Class 4
Sample Average	5.3	36	24	41%	22%	36%	1%
Age							
65-69	8.1	34	41***	38%	25%	38%	---
70-74	6.8	36	36	46	27	28	---
75-79	6.1	37	22	40	23	37	---
80-84	4.6	35	23	45	22	33	---
85+	3.5	38	17	35	21	44	1
Gender							
Male	5.0	35	37***	46%	22%	32%	---
Female	5.5	38	18	39	23	37	---
Marital Status							
Married	5.4	33***	40***	46%	20%	34%	---
Unmarried	5.5	41	11	36	26	38	---
ADL Limitations							
0-1 ⁴	6.4	21***	9***	49%	21%	30%	---
2-3	6.1	32	18	48	30	22	---
4 or more	4.5	46	35	35	20	45	1
Cognitively Impaired							
Yes	4.1	42***	32***	20	11	68	---
No	6.3	33	19	52%	33%	15%	1

Source: Clinical analysis and authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants. (Services are not necessarily received during the entire period of disabled life expectancy.)

Note: Statistical tests are for significant variation within the entire category in that column, even though the asterisks are placed on just the first entry in the category. * Significant at the .10 level; ** significant at the .05 level; *** significant at the .001 level. We only conduct significant tests for weekly hours of care at baseline, which are based on empirical data and not clinical projections.

¹ These figures represent the total amount of time these individuals are expected to be disabled before death. The estimate is based on clinical staff projections. ² Sample characteristics. ³ Clinical staff assignments. ⁴ These persons comprise a small group who are cognitively impaired, and almost all have one ADL limitation.

In terms of paid care, neither gender nor age is a significant differentiator of the amount of care received. On the other hand, disability and marital and cognitive status are

associated with the amount of paid care received at baseline. Greater disability is associated with higher levels of paid care at baseline. Advancing age and the number of unpaid care hours received at baseline have a negative relationship. For example, a disabled individual aged 65 to 69 received 41 hours per week of family care on average, whereas an 85-year-old received only 17 hours of such weekly care.

Expected Lifetime Costs of Care to Maintain an Individual in the Community

To estimate the cost of maintaining individuals in the community, one must project the number of hours of care (by service type) required—should they develop a disability—as they move through various illness transitions. These hours are then multiplied by the associated hourly cost of care. Based on a compilation of public and private data sources, we estimated the hourly cost of care in 2002 for each of the major home and community-based care services as follows:¹⁵

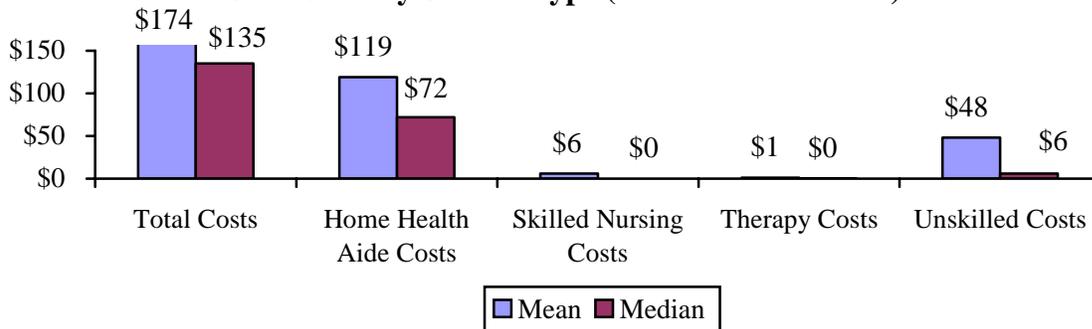
<u>Service</u>	<u>Hourly Cost</u>	<u>Typical per Visit Cost</u>
Home Health Aide	\$19	\$ 75
Skilled Nurse	\$63	\$126
Therapy Service	\$67	\$133
Unskilled Service	\$15	\$ 45

(While LTC insurance does pay for some therapy services if certain triggers are met, most therapy services are covered by an individual’s health coverage, not the LTC insurance data that are used here to produce estimates.)

¹⁵ Note: These figures are based on 1997 charges to Medicare, which do not reflect final Medicare payments. They represent charges that have been increased by 3 percent per year between 1997 and 2002. This reflects changes in the consumer price index for medical care services. The base home health visit charges in 1997 were \$64 for an aide visit, \$109 for skilled nursing, and \$115 for therapies. Charges for unskilled services were about \$39 per visit. Source: HCFA Office of Strategic Planning analysis of sample data files used in *A Profile of Medicare Home Health Chart Book*. Health Care Financing Administration. Washington, D.C., August 1999.

Estimates of the lifetime costs of caring for a person with a disability in the community are derived by multiplying the projected hours of care by the cost per hour over an individual’s remaining lifetime. The resulting dollar estimates are based on our sample of claimants. However, we want to produce estimates that are representative of all persons living in the community who develop disabilities after age 65. Because the lifetime costs of community-based services for a disability that occurs after age 65 are in part a function of when the disability occurs and a person’s gender, we reweighted our estimates to represent the average costs over the actual range of ages at which disability occurs and for men versus women (see Figure 3). Thus, the resulting estimates are representative of the service costs for those persons among the community-dwelling U.S. population who become disabled after age 65. Figure 6 summarizes these projected lifetime costs, given the development of disability, of community-based care by service type. The costs are in 2002 dollars and include an assumption that service cost increases will balance out the discount rate. The estimates also presume that individuals will receive enough care to enable them to remain in the community while they have a disability, have their needs met, and not enter an institution.

Figure 6: Expected Lifetime Community-Based Long-Term Care Costs by Service Type (thousands of dollars)



Source: Authors’ analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

Note: This figure is based on 2002 dollars. Skilled nursing and therapy costs are so low both because these individuals need these services infrequently, and because health insurance typically pays for a portion of them.

Table 3 summarizes the mean and median costs of care, by various sociodemographic factors, for community-dwelling older persons who become disabled and remain in the community. A number of sociodemographic characteristics relate to the level of expected lifetime costs. For example, individuals who develop a disability at younger ages generally have much higher lifetime costs than do individuals who develop a disability when they are older, because the former live longer with their disability due to lower mortality rates at younger ages, their disability notwithstanding. Also, females, those who are unmarried, and those with more significant functional impairments will spend more on assistive services over their lifetime.

Table 3: Expected Services Costs for Community-Dwelling, Disabled Older Persons Who Wish to Remain in the Community throughout Their Lifetime

Characteristic	Lifetime Costs		Monthly Costs
	Mean	Median	Mean
Total Costs	\$174,000	\$135,000	\$2,924
Age			
65-69	\$225,000***	\$123,000	\$2,378
70-74	\$222,000	\$165,000	\$2,708
75-79	\$192,000	\$159,000	\$2,659
80-84	\$169,000	\$134,000	\$3,028
85 and over	\$144,000	\$116,000	\$3,411
Gender			
Male	\$159,000***	\$119,000	\$2,713
Female	\$180,000	\$149,000	\$3,003
Marital Status			
Married	\$146,000***	\$107,000	\$3,370
Unmarried	\$195,000	\$168,000	\$2,371
Annual Income ¹⁶			
Less than \$30,000	\$154,000	\$117,000	\$2,524
\$30,000 or greater	\$177,000	\$144,000	\$3,145
Functional Disability			
0-1 ADL Limitations	\$115,000***	\$75,000	\$1,631
2-3 ADL Limitations	\$167,000	\$130,000	\$2,604
4-6 ADL Limitations	\$204,000	\$169,000	\$3,954
Cognition ¹⁷			
Cognitively impaired	\$171,000	\$139,000	\$3,603
Not cognitively impaired	\$174,000	\$127,000	\$2,436

Source: Authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

Note: Tests of significance are for column categories. For example, mean expected lifetime cost differences by age are statistically significant. Numbers rounded to nearest thousand.

* Significant at the .10 level; ** significant at the .05 level; *** significant at the .001 level.

¹⁶ Roughly 25 percent of the sample did not provide information on income. Those with missing income information are excluded from the calculations by income category.

¹⁷ Information related to cognitive impairment could not be collected for 10 percent of the sample, thus there are missing values. Those with missing cognitive impairment data are excluded from the calculations by cognition category.

As shown, community-dwelling individuals, if they are disabled, can expect to spend, on average, \$174,000 in paid care designed to meet their needs and keep them in the community for the remainder of their lifetime. Because the distribution of service use is highly skewed, the median cost—the point where half of the people spend more than this amount and half spend less—is \$135,000. Most of the costs are for home health aide and unskilled services such as homemaker, companion, and chore services. The mean total cost of \$174,000 translates to a monthly cost of care of about \$2,924 over these individuals' remaining lifetime.

Although the monthly costs of caring for an individual with cognitive impairment are much higher than the costs of caring for the noncognitively impaired, individual total lifetime costs are not higher. This is because higher monthly service costs are offset by the lower life expectancy.

Expected Costs of Caring for Currently Institutionalized Older Persons in the Community

Thus far, we have estimated the service costs associated with remaining at home for a community-dwelling individual who becomes disabled. These costs are lower on average than what it might cost to care for a currently institutionalized older person in the community. This is because nursing home residents tend to be somewhat more functionally disabled, have fewer available family caregivers, and are more likely to have cognitive impairment.

As described earlier and as presented in detail in Appendix 2, we estimated the cost of caring in the community for a currently institutionalized older person on the basis of the coefficients in two regression equations that were estimated using the sample of community-dwelling, disabled older persons from the National Database for Long-Term Care Insurance

Claimants. The first equation predicts future life expectancy; the second predicts hours of care in the community. Using these two equations, we estimated the future life expectancy of nursing home residents and the number of hours of care they would require were they to receive care in the community, based on their sociodemographic and health characteristics and functional status. Using an average cost per service hour based on the community (about \$19), we then estimated total service costs.

Table 4 shows the predicted life expectancy and service costs associated with caring for currently institutionalized individuals in the community, along with the results for individuals with disabilities currently living in the community. The mean expected lifetime costs of care for a nursing home resident are slightly higher than those for an individual with a disability already living in the community—\$179,000 compared to \$174,000.¹⁸ Nursing home residents are typically more disabled and have higher average monthly costs (roughly \$4,000), but they also have shorter life expectancies than do individuals with disabilities in the community.

¹⁸ National data suggest that the average stay in a nursing home is approximately 2.5 years (Wiener and Spence, 1990). The estimate for life expectancy in the community for the institutionalized older persons in this sample is closer to 3.7, 1.2 years higher than this average. However, it is important to note that the sample of institutionalized older persons in this analysis is cross-sectional, indicating that long-stayers may be overrepresented.

Table 4: Predicted Life Expectancy and Service Costs Associated with Caring for the Nursing Home Population in the Community, Community-Dwelling Older Persons with Disabilities, and Both Populations Combined

	Both Populations Combined (weighted estimates)	Community-Dwelling Disabled Older Persons	Nursing Home Population
Mean Life Expectancy	4.7 years	5.0 years	3.7 years
Mean Monthly Service Costs	\$3,145	\$2,924	\$4,031*
Mean Lifetime Service Costs	\$175,000	\$174,000	\$179,000*

Source: Authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

Note: These figures are based on the age, gender, and marital status distribution of disabled older persons in the United States who are living in the community and in nursing homes.

*These are the estimated costs of providing services to the nursing home population *in the community* and as such do not include any room and board charges.

Total Costs of Receiving Care in the Community

Table 4 also presents weighted averages that combine the service needs of individuals with disabilities currently living in the community with those associated with caring for currently institutionalized individuals in the community. Based on national data, as well as trends in the use of services that show four times as many individuals with disabilities living in the community as living in nursing homes, we generated these weighted averages by assigning a

weight of 80 percent to estimates for individuals in the community and 20 percent for individuals in nursing homes (Spector et al., 1998).¹⁹

As shown in the far left column of Table 4, the combined mean lifetime service costs associated with ensuring that all individuals who become disabled can remain in their homes and can have their needs met amount to \$175,000.²⁰ This amount could be viewed by individuals as a lump sum that would cover the mean costs of services needed for a disability developed after age 65. But since this amount is often incurred over several years, it could also be viewed as a stream of costs that could be matched to income and/or other sources.

Study Limitations

In this paper, we have provided an estimate of the costs of continuing to live at home in the face of significant functional or cognitive disability. It is important to reiterate that there is a wide distribution of potential liabilities around the point estimates developed here. The variation is in part a function of individual characteristics, characteristics of specific service settings, and geographic location. For many individuals who develop a disability after age 65, this estimate will be *too much*, whereas for others it will be *too little*, either because their actual monthly costs differed from the average or because paid disability service needs were needed for shorter or longer periods than average.

Individuals cannot know how much the costs of disability services will be for them, or whether they will even develop a significant disability at all in later life. Given this

¹⁹ Data from the 1994 National Long-Term Care Survey indicate that 73 percent of those with any disability in 1994 were in community care settings. Given changes in the use of the nursing home and shifts toward greater use of community alternatives, we make the simplifying assumption that the proportion of community-dwelling older persons with disabilities would increase from 73 percent to 80 percent over the 20-year period from 1994 to 2014.

²⁰ Again, we make the simplifying assumption that service costs will increase at the same rate as the discount rate over the period.

uncertainty, there are many plausible ways to deal with potential future long-term care liabilities. Individuals might save and generate assets to meet future needs, mix assets with available income, count on public financing to pay for some portion of future liabilities, or purchase private insurance. The suitability of each of these for an individual depends importantly on her/his levels of assets and income. It also rests in part on rates of return on investment and inflation in the costs of services, both of which are difficult to predict. In this paper, we do not examine the optimal savings or planning strategy for individuals, which is also a function of preferences in addition to financial capacity.

Although we have attempted to estimate the service costs associated with keeping all individuals with significant disabilities in their homes, we recognize that there will always be some individuals who need nursing home care, regardless of their desire to remain at home. Serious cognitive impairment, high levels of functional disability, lack of family support, poor housing, supply constraints on home care, and geographic and social isolation are just some of the non-financial factors that would lead someone to require or even prefer nursing home care. Thus, the intent here is not to presume that *everyone* would avoid nursing home admissions, but instead to estimate the costs associated with doing so. We also recognize the appropriateness of rehabilitation stays in skilled nursing facilities before returning home to community-based care.

The database on which baseline service packages are summarized and then projected forward is derived from a sample of individuals with private long-term care insurance. Clearly, these individuals differ in relevant, and potentially unmeasurable, respects from the general older population. For example, actuaries who price long-term care insurance policies generally assume that these individuals live longer than does the general population. In the

projections made for the general population of individuals aged 65 and older, we made adjustments to account for differences in the age, gender, and marital status of insured and noninsured individuals. What we cannot account for, however, are differences in the *preferences* of insured individuals. The services chosen by these individuals that we observed at baseline may be very different from those chosen by individuals in the general population, even when controlling for income. We could not control for preferences, so the service cost projections should be viewed with this in mind.

A major component of the service cost estimate is based on the results of the clinical panel's projection of disability and resulting changes in the observed baseline mix of services. The panel's projections are not based on a detailed longitudinal database, but rather on clinical judgment and experience. Because there are no agreed-upon norms of practice vis-à-vis levels and intensity of home health care for individuals with varying degrees of disability, nor are there reliable empirical data on disability trajectories, clinical expertise is all one can rely on. Estimates regarding the length of disability are bounded by empirical data on mortality, which represent an upper limit estimate on disability duration. Disease staging and cognitive and functional status are also taken into account. However, significant levels of unpaid care are provided on average by family members and friends to the claimants in our sample at the same time that they are receiving services paid for by their insurance coverage, and we assume this provision of unpaid care will continue. In sum, the projections are necessarily imprecise; this aspect of the projection may be as much art as science. Nevertheless, human judgments with repeated observations can be subjected to significance testing, and we did find that the magnitudes and directionality of estimates were reasonable and sensible.

The underlying database of insured disabled individuals in the National Database for Long-Term Care Insurance Claimants is cross-sectional in nature. The information gleaned from this data set is certainly representative of what one would observe at a point in time for insured individuals with disabilities. As is the case with all cross-sectional data, however, they would not be representative of all insured disabled individuals viewed over a longer period. Cross-sectional data tend to over-represent those individuals whose duration of disability may be somewhat longer than the average. This will necessarily lead to a somewhat higher estimate for service costs if applied to all individuals across all spells of disability.

The data used in this analysis are primarily from the 1990s. To the extent that people turning 65 more recently have better health histories, as evidenced by declining disability rates, the estimates here may somewhat over-estimate the lifetime probability of disability. However, the lifetime risks would still be significant even under the most optimistic scenario.

Finally, given the dramatic changes in the service system, it is difficult to predict future care patterns, even if we could accurately predict levels of disability. The analysis presented here is grounded in a baseline set of services consumed by individuals with disabilities, but a “baseline” set of services five years from now may look very different, even for insured individuals. To be more specific, the data set did not permit an analysis of individuals who may be accessing assisted living services. This has been one of the fastest-growing long-term care services, and increasing numbers of older persons are expected to receive their care in this setting in the years ahead. Although national data on costs are difficult to obtain, there is consensus that assisted living costs less than nursing home care but more than home care—primarily because assisted living includes a housing component. As use of assisted living grows, the distribution of service use between home care and nursing

home care may change. This will affect aggregate estimates of costs as well. Thus, one should understand that the estimates presented here have a high degree of variation due both to characteristics of individuals and those of the service system.

V. Conclusions

Many older people express a strong preference for remaining at home should they develop a disability. Therefore, quantifying the potential service-related expenses of avoiding nursing home residence in the event of disability is important for fulfilling this desire. The costs associated with ensuring that an individual who develops a disability after age 65 can receive a level of service that meets his or her needs in the community are significant; on average they are \$175,000 (in 2002 dollars) over the remaining lifetime. The median level of costs for those currently living in their own homes is \$135,000, which is lower than the mean, but still a substantial figure. Not only are these levels of costs substantial, but these estimates assume that the levels of unpaid care observed in the source data will continue. For persons who develop a disability after age 65, the average age at which paid services begin to be needed for such a disability is 82, and in most cases these services result in costs that are incurred over several years.

To cover these costs, an individual would need to have saved regularly over a period of years or have adequate income to pay for costs as they occur. Also, many individuals have the option of purchasing long-term care insurance. But for many other people of modest means, publicly funded programs, mainly Medicaid, may be the only option.

We have focused on the *mean* costs of the services that allow a person to remain in the community for the rest of his/her life, should they develop a disability after age 65. But no

single measure can summarize the entire set of service need possibilities. If an older person does not develop a disability, then the costs of such services will be zero. For those who do develop a disability, the median cost (representing the point where half of the people spend more than this amount and half spend less) is lower than the mean cost, because the distribution of service use is highly skewed. We have focused on the mean because, to the degree that people are risk-adverse, they may want to acknowledge that their disability services cost experience may end up somewhere in the top half of the people who develop disabilities after age 65. Focusing on mean costs provides some of this acknowledgement of risk aversion, and some persons might want to prepare for costs that even exceed the mean.

Whichever measure one chooses to focus on, the magnitude of the cost of needed services is more than many people can accommodate through either income or savings. Some of this need may be accommodated through increased unpaid care provided by family and friends. However, while unpaid care involves no monetary transactions, it nevertheless often results in real costs for the caregivers. Public policy therefore needs to focus on various forms of risk-sharing arrangements—that is, private sector products or public sector programs that involve the pooling of risks with regard to the payment for community-based long-term care services. Some programs are available in the private sector (long-term care insurance), but there is little in terms of government programs that provide pooling for the financial burden of community-based long-term care services. While Medicaid does provide a safety net for services to assist with disabilities, such services are provided primarily in nursing homes, not in the community. Given most individuals' stated desire to remain living independently in their own homes throughout their lifetime, it is important to recognize that a lack of private saving for long-term care needs and/or the absence of alternative publicly supported programs

significantly increases the possibility of institutional nursing home care. Thus, the need to think about and act on a strategy for addressing potential long-term care risks and costs—some aspects of which have been quantified in this paper—is crucial.

**Appendix 1: Transition Probabilities, Service Use Factors,
and Duration of Disability for Individuals with Disabilities**

Tables A and B show the individually projected trajectory and transition probabilities for each of the four illness states as well as the average length of time individuals are projected to be in each state.

Table A: Probabilities for Transitioning between Illness Categories by Baseline Classification (mean and median number of months in parentheses)

Baseline Classification	First Transition Classification			
	Illness Stabilized	Recovering from Acute Illness	Chronic Illness, Now Deteriorating	Terminal
Recovering from acute illness	87% (mean=34 months) (med=30 months)	----	13% (mean=33 months) (med=29 months)	----
Illness stabilized	----	1% (mean=24 months) (med=24 months)	99% (mean=36 months) (med=33 months)	----
Chronic illness, now deteriorating	----	----		100% (mean=12 months) (med=12 months)

Source: Clinical analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.

Table B: Probabilities for Transitioning between Illness Categories by First and Second Transition Phases (mean and median number of months in parentheses)*

First Transition Phase	Second Transition Classification			
	Illness Stabilized	Recovering from Acute Illness	Chronic Illness, Now Deteriorating	Terminal
Recovering from acute illness	-----	----	100% (mean=66 months) (med=65 months)	-----
Illness stabilized	-----	-----	100% (mean=31 months) (med=24 months)	----
Chronic illness, now deteriorating	-----	-----	-----	100% (mean=12 months) (med=12 months)

Source: Clinical analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.
 * When “Chronic illness, now deteriorating” is the final state, this table assumes that this state ends in death.

For example, in Table A, of those who are “Recovering from Acute Illness” at baseline (the top row), 87 percent are estimated to transition into the “Illness stabilized” category in their first transition, and the remaining 13 percent are estimated to transition into the “Chronic illness now deteriorating” category. Moving to Table B, of those 87 percent who transitioned into the “Illness stabilized” category, 100 percent are estimated to then transition into the “Chronic illness, now deteriorating” category, at the end of which they will die.

As an individual transitions between these illness categories, the level of care needed tends to change, typically among one or more of the following care providers: home health aide, skilled nursing, skilled therapists, nonskilled providers, and nonpaid/family caregivers. Thus, as a person’s condition is projected to worsen, he or she would be expected to require more care than what was required at baseline. Table C summarizes how the transition factors

were used to adjust the levels of care as individuals transition through these illness categories.
Again, these were based on the clinical experience and judgment of the clinical panel.

Table C: Transition Matrix Illustrating the Percentage Change in Hours of Care by Transition Category and Service Type

	HHA	Care Manager	Skilled Nursing	Skilled Therapists	Nonskilled
Base: Illness stabilized					
Transitions:					
1=Recovering from acute illness	1.50	1.50	2.00	1.75	.50
2=Illness stabilized	1.00	1.00	1.00	1.00	1.00
3=Chronic illness, now deteriorating	1.00	.75	1.25	.75	1.40
4= Terminal illness	1.25	1.00	1.50	.80	.80
Base: Recovering from acute illness					
Transitions:					
1=Recovering from acute illness	1.00	1.00	1.00	1.00	1.00
2=Illness stabilized	.75	.25	.25	.10	1.50
3=Chronic illness, now deteriorating	.80	.50	.40	.40	1.75
4= Terminal illness	1.30	.75	.80	.70	.50
Base: Chronic Illness, now deteriorating					
Transitions:					
1=Recovering from acute illness	1.00	.80	1.50	1.30	.75
2=Illness stabilized	.75	.50	.50	.20	1.30
3=Chronic illness, now deteriorating	1.00	1.00	1.00	1.00	1.00
4=Terminal illness	1.00	1.25	1.25	1.20	.50
Base: Terminal Illness					
Transitions:					
*1=Recovering from acute illness	1.50	1.00	1.50	1.50	1.00
*2=Illness stabilized	1.00	.80	.50	.50	1.50
3=Chronic illness, now deteriorating	1.00	.70	.70	.20	1.50
4=Terminal illness	1.00	1.00	1.00	1.00	1.00

*Such a transition rarely occurs.

The following example demonstrates how these factors are applied to an individual with a baseline classification of “recovering from an acute illness” and who is projected to transition to a classification of “chronic illness, now deteriorating.” At the baseline status, we observed the set of services that the person is receiving, one of which is home health aide care. When the person transitions to the new illness classification—“chronic illness, now deteriorating”—we projected that he or she would require fewer hours of home health aide care. To be more specific, in this example the person would receive 20 percent fewer hours of home health aide (HHA) care than he or she received during his or her baseline classification. Similarly, if nonskilled services were in place at baseline, once the individual transitions to the new classification, he or she would be projected to need 1.75 times more hours of nonskilled services. The upper estimate for care received for all services is 24 hours per day. The transition matrix enables us to project the number of hours of care for specific service categories that would be required by an individual to stay in the community over his or her remaining lifetime. The overall estimate was constrained by the projected life expectancy for each individual.

An important underlying assumption is that, at baseline, people receive a level of services commensurate with their need. Theoretically, features of the insurance policy (e.g., low daily benefit amounts, limits on how long a policy pays benefits, and others) could lead an individual to obtain less care than he or she needs. We assume that in the aggregate, those with the insurance coverage analyzed here receive care commensurate with their level of need, in light of their disability and family situation. Given the fact that in our data insurance pays for the vast majority of costs, income is assumed not to be a factor constraining use of services. Thus, unless there are constraints on supply, or on the willingness of people to

accept needed levels of service, which may occur in some cases, these individuals ought to be accessing a level and intensity of care that meets (or comes close to meeting) their needs.

Appendix 2: Regression Analysis Used to Develop Coefficients for Estimating Life Expectancy and Use of Services for Nursing Home Residents Moving to a Community Setting

The results of these regression analyses of life expectancy and service use are presented in Table D. The model adequately explains the variance in the “Life Expectancy” dependent variable (e.g., adjusted R^2 of 65 percent) but is less robust for explaining difference in the monthly amount of care (e.g., adjusted R^2 of 25 percent). The data show that advancing age is positively associated with the need for more hours of care but negatively associated with life expectancy. This is also true of functional disability. On the other hand, cognitive impairment does not influence the hours of care but is negatively related to life expectancy. An interesting finding is that although certain medical diagnoses do affect life expectancy, they do not have a discernable effect on the amount of monthly care required. This is because it is *how* these illnesses affect functioning that is important (not just the presence or absence of disease), and this is captured by the disability measures in the equation. The same is true regarding cognitive impairment: If such impairment does not result in ADL needs or the need for oversight or supervision, it has little effect on the amount of monthly care required. Finally, marital status is negatively related to hours of paid care but does not affect life expectancy estimates.²¹

²¹ We did not model the effect of behavioral problems on life expectancy because, in the presence of other variables in the equation, there was no reason to believe that these variables would have an independent effect on life expectancy.

Table D: Regression Models for Estimating Life Expectancy and Number of Hours of Care Received by Home-Based Disabled, Older Persons (standard errors in Parenthesis)

Independent Variables	Dependent Variable:	
	Monthly of Hours of Care	Life Expectancy (in months)
	Coefficient	Coefficient
Age	4.52 ^{***} (.86)	-3.36 ^{***} (.12)
Gender (0=male)	12.35 (13.97)	4.52 ^{***} (1.89)
Marital status (0=unmarried)	-79.44 ^{***} (13.88)	-2.61 (1.87)
Number of ADL impairments	42.23 ^{***} (3.53)	-6.51 ^{***} (.46)
Presence of cognitive impairment (0=no)	.16 (16.17)	-17.67 ^{***} (1.96)
Exhibiting abusive behavior (0=no)	66.57 [*] (33.56)	N.A.
Having personal hygiene issues (0=no)	-49.70 ^{**} (20.78)	N.A.
Being a threat to self or others (0=no)	27.52 ^{**} (17.15)	N.A.
Oriented to person (0=no)	-51.59 ^{***} (21.96)	-4.47 (2.94)
Diagnosis of Parkinson's (0=no)	-35.48 (31.98)	22.10 ^{***} (4.32)
Diagnosis of Cancer (0=none)	17.82 (24.38)	-12.06 ^{***} (3.29)
Diagnosis of stroke (0=no)	21.30 (14.04)	-6.99 ^{***} (1.89)
Constant	-293.72 ^{***} (74.81)	361.8 ^{***} (9.95)
Adjusted R ²	25%	65%

Source: Authors' analysis of 1999-2000 National Database for Long-Term Care Insurance Claimants.
 Note: * Significant at the .10 level; ** significant at the .05 level; *** significant at the .001 level.

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