



Changes in Elderly Disability Rates and the Implications for Health Care Utilization and Cost

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**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

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CHANGES IN ELDERLY DISABILITY RATES AND THE IMPLICATIONS FOR HEALTH CARE UTILIZATION AND COST

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EXECUTIVE SUMMARY

Background

Recent research has provided promising evidence that aggregate age-adjusted disability among older Americans has decreased. There also is evidence that cognitive impairment and physical limitations, such as lifting 10 pounds, walking short distances, and climbing a flight of stairs, which may be precursors to disability, may have declined in recent years. On the other hand, some studies show increases in chronic disease, increases in the use of paid long term care, and increasing disability levels within the disabled population. This study was undertaken in order to better understand these trends and their potential implications for use of acute and long term care.

Study Questions

Studies to date have primarily examined aggregate age-adjusted trends. In this study aggregate trends are decomposed into trends in underlying aspects of disability. Specific questions addressed are the following:

- How has the prevalence of chronic disability among the elderly changed since the mid-1980s?
- Does the trend in disability differ for specific components of disability, such as disability only in basic activities necessary for independent living or in use of equipment?
- Do declines differ for younger ages and older cohorts?
- Are there particular activities which have declined more than others or which appear to be more amenable to independence with special equipment or other environmental/social factors?
- What are the implications for future costs?

Data and Methodology

Data are from four waves of the National Long Term Care Survey (NLTC) representing three five-year periods between 1984 and 1999. The NLTC is conducted

by the U.S. Census Bureau under the direction of researchers at the Center for Demographic Studies (CDS) at Duke University.

Chronic disability (defined as lasting at least 3 months) was examined in the aggregate and then decomposed along two dimensions. The first distinguishes the use of human help--long term care--from the use of assistive devices to perform basic activities. The second distinguishes disability only in instrumental activities of daily living (IADLs), which are activities such as money management and meal preparation that are associated with the ability to maintain independence at home, from disability in activities of daily living (ADLs), which are basic personal care activities such as dressing and eating that indicate a higher level of disability or frailty.

The relationship between age-adjusted declines in disability and the actual prevalences in a steadily aging elderly population also were examined, as well as trends for individual IADL and ADL activities and for the mean number of disabilities among the disabled elderly in the community and in institutions.

Major Findings

- The aggregate prevalence of chronic disability among the elderly declined significantly over the 15-year period, from 22.1 percent in 1984 to 19.7 percent in 1999.
- The decline was the result of two countervailing factors--a 3.9 percentage point decline in the percent of the elderly receiving help from someone for ADLs or IADLs and a 1.4 percentage point increase in the percent of the elderly who managed chronic ADL disability in the community with assistive devices only.
- More than 80 percent of the 3.9 percentage point decline in the percent of the elderly receiving human help for a chronic disability was due to a decrease (from 7.4% in 1984 to 4.2% in 1999) in the percent of elderly persons receiving human assistance for IADLs only.
- The percent independent with IADL equipment in the community (0.7 percent) for the one IADL for which we could measure independent equipment use was stable and did not contribute to the disability decline.
- The prevalence of institutional residence, the most costly form of long term care, was about 5 percent of the elderly throughout the period.
- Population aging moderated the decline in the prevalence of chronic disability.

- Nearly all individual IADLs declined over the period, but the most dramatic change was a 3.7 percentage point drop in help with money management between 1984 and 1989, when Social Security direct deposit became the norm, raising a question whether IADL declines reflect improvements in health or improvements in the physical environment.
- No individual ADLs declined in prevalence over the period.
- The mean number of IADLs among the disabled in the community declined over the 15-year period, but the mean number of ADLs for which assistance was received increased for the disabled in both the community and institutions.

Conclusions

The disabilities that saw the most improvements over the 15-year study period were not ones that necessarily imply better health and lower health and long term care costs among the elderly. Rather, a substantial part of disability declines may reflect improvements in the external environment that make it easier to perform such activities as managing money, shopping, and telephoning, regardless of physical state. Help with ADLs changed only slightly from the beginning to the end of the study period. For those receiving ADL help in the community, the total number of chronic disabilities, which is correlated with hours of long term care, fell initially but had returned to its 1984 level by 1999. These findings suggest a need to examine directly both Medicare costs and hours of paid and unpaid long term care for different subgroups of the elderly and the elderly disabled in order to understand the cost implications of disability changes since the mid 1980s.

The growth in the percent of persons who manage various ADL activities with only equipment also suggests the need to know more about which types of equipment are being used and whether the equipment substitutes for or supplements hours of human assistance. Only for bathing was the increase in the prevalence of equipment use accompanied by a decline in the prevalence of human help, but it remains to be seen whether those who manage some activities with equipment use fewer hours of long term care.

Better understanding of the real implications of aggregate disability changes is not an academic exercise as policymakers consider changes in Social Security and Medicare to ensure their long-range financial health. Many argue that declines in disability need to be taken into account in projecting future spending. Until there is a better understanding of these trends and their cost implications, however, it is not clear how they should be taken into account.

INTRODUCTION

Since the mid-1980s, there has been a concern that increased longevity and the aging of the Baby Boom generation will result not only in a larger elderly population, but also in an increased prevalence of disability. Increased survival could mean more years of disability and higher long term care and other medical costs if medical interventions are able to prolong life, but not health and independence.

Recent findings using a number of different data sources have provided evidence to the contrary. These studies suggest that there has been a decrease in the age-adjusted prevalence of disability among the elderly since the early 1980s (Waidmann and Manton, 1998; Waidmann and Liu 2000; Manton and Gu 2001), an increase in disability-free life expectancy (Crimmins, Saito, and Ingegneri, 1997), and a decrease in physical limitations, such as lifting 10 pounds, walking short distances, and climbing a flight of stairs, which are related to onset of disability (Freedman and Martin, 1998). Some studies have found declines but not a consistent downward trend in some aspects of disability and a concentration of declines at lower levels of disability (Waidmann and Liu 2000; Schoeni, Freedman, and Wallace 2001). For example, Schoeni et al. found that disability declined among the noninstitutionalized population aged 70 or older between 1982 and 1986, but fluctuated between 1986 and 1996, ending the period essentially unchanged. Other studies have found that the use of formal long term care services has increased (Spillman and Pezzin 2000; Liu, Manton, and Aragon 2000) and that the level of disability among those receiving help with chronic disability, including those in institutions, has increased (Spillman and Pezzin 2000; Sahyoun, Pratt, and Lentzner 2001; Rhodes and Krauss 1999). This could suggest higher mean long term care costs among the disabled, which could work against declines in the cost of disability, even with a declining prevalence.

Clearly, a better understanding of the underlying structure of changes in the prevalence of disability is needed in order to assess likely short and long-term cost implications of disability declines and to understand how disability is likely to change as the population continues to age through mid-century. This study uses data from four waves of the National Long Term Care Survey to look beneath aggregate trends and examine more closely the nature of the declines and potential implications for service use and costs

The following questions are addressed:

- How has the prevalence of chronic disability among the elderly changed since the mid-1980s?
- Does the trend in disability differ for specific components of disability, such as disability only in basic activities necessary for independent living or in use of equipment?

- Do declines differ for younger ages and older cohorts?
- Are there particular activities which have declined more than others or which appear to be more amenable to independence with special equipment or other environmental/social factors?
- What are the implications for future costs?

DATA AND METHODS

Data for this analysis are from the 1984, 1989, 1994, and 1999 waves of the National Long-Term Care Survey (NLTCS), which is conducted by the U.S. Census Bureau under the direction of the Center for Demographic Studies at Duke University (CDS). The NLTCS is a nationally representative survey of persons aged 65 and older designed to identify those who are chronically disabled, as defined by activities of daily living (ADLs) or instrumental activities of daily living (IADLs) and to collect detailed data on their disability, service use, family support, and health and demographic characteristics. The samples are drawn from Medicare enrollment files and represent both community and institutional residents. The longitudinal component is refreshed in each wave with a new sample of persons who turned 65 since the previous survey, and in 1994 and 1999, a supplemental sample of those aged 95 or older was added to increase precision of estimates for the very old. There were about 21,000 respondents in 1984, 16,000 in 1989, and 17,000 in 1994 and 1999. Although the survey began in 1982, the 1984 survey is the base year for this analysis because it was the first wave in which detailed information about the disabled in institutional settings also was collected.

The NLTCS is a complex survey, but the complexity generally represents a strength for detailed examination of disability patterns. The survey uses a very broad definition of disability to screen the full population for detailed interview. This broad definition can then be narrowed progressively using information from the subsequent detailed interviews. Specifically, a screening interview identifies those who have a “problem” performing any of six ADLs without help or equipment, who are incontinent, who have difficulty going outside without help or equipment, or who are *unable to perform* any of seven IADL activities without help because of a health or disability problem. In order to be eligible for a detailed interview--to “screen in”--the respondent must have had or *expect to have* at least one of the problems or inabilities for three months or more. Those who are in an institution or who received a detailed interview in a previous survey year are automatically interviewed without a new disability screen. There were about 7,600 detailed respondents in 1984, and about 6,000 in the remaining years.

Disability Measures

Chronic disability in this analysis is defined as receiving help or using equipment to perform at least one ADL, or inability to perform at least one IADL without help for at least 3 months, as reported at the detailed interview. ADLs are basic activities necessary for personal care and generally are an indicator of a greater level of disability or frailty than IADLs, which are activities more related to the ability to live independently. The ADLs included in this analysis are eating, getting in and out of bed (transfer), getting around

inside (indoor mobility), toileting, bathing, and dressing. The IADLs are light housework, laundry, meal preparation, grocery shopping, getting around outside, taking medications, managing money, and using the telephone. Going outside of walking distance (transportation) is not included as an IADL in this analysis. While the screening interview asks about having a problem or difficulty with ADLs, the detailed interview focuses on whether the respondent received active human help or supervision with each activity or used equipment to perform the activity.¹ With one exception, the IADL questions at the detailed interview also focus only on ability to perform the activity without help. The exception is getting around outside, for which respondents may report use of equipment without human help or supervision. The small group for whom this was the only reported disability is included in the chronic disability estimates that follow, but is reported separately.

Distinguishing Long-Term Care

This study's ultimate concern is with the implications of disability trends for the cost of long term care, which is the receipt of help or supervision. Therefore, data were edited to distinguish between those receiving any human help for at least 3 months, implying use of paid or unpaid services, from those who received no help but used disability-related equipment for at least three months. For each ADL or IADL, individuals were coded as receiving help if they reported help, regardless of whether they also used equipment with the activity. They were coded as using equipment for an activity only if they reported equipment use but no human help. The disability classification used in the tables presented below was then created by combining the individual disabilities hierarchically to distinguish those receiving long term care from those who were independent with equipment as follows. Those who reported receiving help with *any* of the six included ADL activities for at least 3 months were classified as receiving human help with ADLs. Those remaining were classified as receiving human help with IADLs if they reported help with any of the eight included activities for at least 3 months. All institutional residents were

¹ The reference period for ADLs is "during the last week." This reference period technically would miss persons who chronically receive help or supervision or use equipment, but did not during the last week. It seems reasonable to assume that few persons who are chronically disabled in these basic activities would fail to be picked up by a one-week reference period. For those who did not perform activities, such as bathing and dressing at all during the last week, which might be more affected by differences in individual preferences, either the main question or the probe about the duration of failure to do the activity, or both, refer to ability to perform the activity. Thus, for example, the primary question for bathing asks whether the person received help, or was the person "*unable* to bathe at all." For those who did not bathe, the duration question asks, "About how long has ... been *unable* to bathe?" No time dimension is included in the IADL questions, which ask whether the person "usually" performs the activities. Further probes identify whether inability to perform the IADLs is due to health problems or disability.

included as receiving human help.² The remaining group who reported no human help lasting 3 months with any activity was classified as using equipment with ADLs if they reported equipment use for any ADL for at least 3 months. The small remaining group whose only reported chronic disability was use of equipment to get around outside was classified as IADL equipment only. Thus, individuals classified as receiving help based on any activity may also use equipment for that or other activities, but individuals are classified as “equipment only” only if they have not received chronic help with any activity. The remainder of the analysis sample, who reported no chronic help or equipment use, was classified as not chronically disabled. Individuals in all chronic disability classifications also may have reported human help or equipment use for other activities that did not meet the 3-month criterion for chronic care.

Unless otherwise noted, estimates discussed are significant at the 5 percent level of significance in a two-tailed test.³

² The institutional interview elicited information about human help and equipment use for ADLs, but did not collect information on IADLs. In each survey year, all institutional residents for whom ADLs were reported received help with at least one ADL. No equipment or help with any ADL was reported for a small proportion of institutional respondents in each survey year (8 percent or less).

³ The complex design of the survey must be taken into account in computing standard errors. Because the variables required to identify clustering and strata used in drawing the sample are not on public use files, statistical packages that compute standard errors corrected for the complex design of the survey could not be used. Census Source and Reliability Statements available on the Duke University Center for Demographic Studies web site (<http://www.cds.duke.edu>) provide general variance function (GVF) formulas and parameters to compute standard errors for estimated numbers or proportions. However, the GVF parameters were not updated for the 1994 and 1999 surveys. An investigation of the implied design effects (defined as the ratio of the survey design-adjusted variance to the variance under simple random sampling) suggested that design effects were less than 1 in both years, compared with design effects of about 1.4 for 1984 and 1.1 in 1989. Therefore for 1994 and 1999, standard errors are computed as the standard error under simple random sampling multiplied by the square root of the design effect for 1984. The larger estimated average design effect was chosen so that conclusions about the significance of results would be more conservative in the absence of accurate standard errors. In fact, significance conclusions were affected very little because there were few marginal cases.

THE TREND IN THE PREVALENCE OF DISABILITY

There is a clear downward trend in the percent of the elderly population who are chronically disabled (Exhibit 1). Chronic disability was reported by 22.1 percent of the elderly population in 1984. By 1999 the prevalence had dropped to 19.7 percent, an average 0.16 percentage point per year, or 0.8 percent annual decrease over the 15-year period. The largest decline per year (0.24 percentage points, or 1.17 percent) occurred between 1989 and 1994, consistent with the findings of Manton et al. (1997). The 0.4 percentage point decline between 1994 and 1999 was not statistically significant.

In some ways, the trend in the lack of disability is as interesting as the trend in chronic disability. Through 1994, a constant 73 percent of the elderly population reported being free of difficulty or disability in any ADL or IADL. In 1999, this proportion rose to 74.7 percent. Another 5 to 7 percent of the elderly population in each year fell into a gray area of persons who report difficulty or disability but ultimately fail to meet the definition of chronically disabled.⁴

Underlying the downward trend in aggregate disability is a pattern of steadily increasing equipment use and declining human help with disabilities. Use of equipment for ADLs with no human assistance increased 1.4 percentage points (from 1.6 percent to 3.0 percent) over the 15-year period. Conversely, the prevalence of human help with any disability declined from 19.8 percent in 1984 to 15.9 percent in 1999. This is an average decline of 0.26 percentage points, or 1.4 percent per year, again with a slightly larger average annual decline (0.32 percentage points or 1.8 percent) between 1989 and 1994.

Declines in IADL-only disability account for most of the decline in human assistance. The prevalence of help with only IADLs in the community dropped 3.2 percentage points over the 15-year period, from 7.4 percent in 1984 to 4.2 percent in 1999. Most of the IADL decline occurred between 1984 and 1989, with much smaller declines thereafter. On the other hand, the combined prevalence of help with ADLs or institutional residence, which are associated with a higher level of disability or frailty, actually rose over the 1984-1989 period, and began to show a decline from the 1984 level only after 1994. Although the 0.2 percentage point decline in the percent receiving help with ADLs in the community

⁴ This 5 to 7 percent comprises three groups of persons who have provided some evidence of difficulties either in the current or a previous survey year and may be in poorer health and at higher risk of chronic disability, even though they are not currently chronically disabled. Less than 1 percent of the elderly in each year reported some type of problem in the screening interview but did not expect it to last for 3 months. A larger group screened into the survey in the current or a previous year but reported no disability during the detailed interview. This group ranged from 4.1 percent to 5.6 percent of the elderly, depending on survey year but showed no upward or downward trend. Another 0.5 percent in each year reported help or equipment use at detailed interview but did not meet the 90-day duration requirement.

between 1994 and 1999 is not significant, the 0.8 percentage point decline from the peak in 1989 is significant, and implies an average annual decline of slightly less than 0.1 percentage point, or 1.1 percent between 1989 and 1999.

Community and Institutional Residence

Further complexities in the underlying pattern of long term care are indicated by the trend in community and institutional residence. With the exception of a small increase in the prevalence of institutional residence in 1989, the trend has been relatively flat at about 5 percent of the elderly population.⁵ Besides the implication that there are aspects of disability that are not improving, the persistence of institutional residence, the most costly type of long term care, suggests that declining disability may not translate to similar declines in costs.

The essentially constant prevalence of institutional residence also is consistent with the concentration of declines at the lower levels of disability as evidenced by the dominant role of the IADL declines. The percent of the elderly who were disabled and residing in the community declined an average 0.2 percentage point annually in each of the first two 5-year periods, from 17 percent in 1984 to 15 percent in 1994. This was primarily due to the large declines in IADL-only disability moderated by the rising prevalence of equipment use for ADLs with no human help. IADL declines account for more than 80 percent of the overall 3.9 percent decline in human assistance in the community over the 15-year period.

Age and Chronic Disability

The results seen in the previous tables are consistent with underlying declines in *age specific* disability rates that have been reported elsewhere (Manton and Gu 2001), but aging of the elderly population since 1984 has moderated the age-specific declines. Exhibit 2a shows the age-specific prevalence of chronic disability for those age 65-74, 75-85, and 85 or older. A downward trend in overall disability is evident for every age group, with the largest absolute declines in the two older age groups. This is not surprising because the prevalence of disability is far lower among the young elderly. Only 12.2 percent of those age 65 to 74 in 1984 and 9.2 percent in 1999 were chronically disabled, less than one-fifth the rates for those age 85 or older. In percentage terms, however, the

⁵ Although an analysis of the NLTCs by Manton and Gu (2001) reported a sharp decline in institutional residence in 1999, those estimates are not comparable. Unlike the weights for the previous survey years, the 1999 weight was not post-stratified to Census estimates of the institutional population. For the current study, the 1999 weight was post-stratified using methodology consistent with that used in the previous years. The 1984 weight released by CDS is similarly incomparable with the 1989 and 1994 weights and was adjusted for the current study. Details of the methodology are in the Appendix.

declines are smallest for those age 85 or older. Overall disability declined at a rate of less than 1 percent per year for the oldest group compared with 1.5 to 2 percent per year for the two younger groups.

The composition of declines is somewhat more mixed within age groups. For example, the youngest age group saw a small though insignificant *decline* in independence with equipment between 1994 and 1999, resulting in no net change over the 15 year period, while the largest increases for the two older groups occurred during the 1994-1999 period. As for the elderly as a whole, the age-specific prevalence of IADL only help was roughly halved over the 15 year period, and drives the overall decline in human assistance. However, for all groups the largest improvement in IADL help occurred between 1984 and 1989. In fact, the youngest age group had a significant decrease only between 1984 and 1989, with no significant decline between 1989 and 1999. The within-age-group prevalence of human help with ADLs and institutional residence declined far less, and in fact, although declines appear to be larger for the oldest group, the change over the 15 year period was not significant for those age 85 or older. As for the elderly as a whole, significant declines in the prevalence of ADL help and institutional residence occurred only after 1989 for all age groups.

The age-specific declines in disability were moderated by the upward shift in the age distribution of the elderly population over the 15-year period (Exhibit 2b). Those age 65 to 74 declined from 60 percent of the elderly population in 1984 to 53 percent in 1999, while those age 85 and older, with their extremely high disability rate, increased from about 9 percent to 12 percent of the elderly population (not shown). Those chronically disabled in the two younger age groups represent declining proportions of the elderly population over the 15 year period, but the disabled age 85 or older actually make up a slightly larger proportion of the elderly because of the combined impact of growth in the size of this age group and their far higher disability rate relative to the younger groups. This demonstrates how the increasing age of the population can lessen the impact of disability declines on observed cross-sectional prevalence rates. In fact, through 1994, the increase in the proportion of the elderly who were 85 or older and receiving human help with ADLs or institutionalized (0.7 percentage points) was sufficient to overcome a similar decline for the youngest age group. The result was the essentially flat prevalence of ADL help between 1984 and 1994 seen in the earlier tables.

Exhibit 3 illustrates the tradeoff between declines in age-specific disability and aging of the elderly population over the 15-year period. The solid line shows the actual prevalence of aggregate chronic disability, any human help, ADLs with help in the community, and institutional residence, and the dashed lines show what these prevalences would have been if the age distribution among the elderly had not changed since 1984. Clearly, all actual trends are flatter than their age-standardized counterparts. The 1.5 percent annual rate of decline in the age-standardized trend for aggregate chronic disability is nearly twice the 0.8 percent that actually occurred (Exhibit 4). This same

moderating impact of aging is evident for the components of disability most associated with greater frailty. The actual prevalence of ADL help in the community, which began to decline only after the peak in 1989, fell at a rate of 0.5 percent per year, while the standardized trend shows a 1.1 percent per year decline. Similarly, actual institutional residence declined at a rate of 0.3 percent per year, while the standardized trend declined 1.5 percent per year. Interestingly, disability in only IADLs and ADL equipment use are fairly insensitive to upward shifts in the age distribution. In fact, the actual upward trend in equipment was slightly greater than the age-standardized trend.

TRENDS IN INDIVIDUAL ACTIVITIES

Given that the trends for underlying components of disability differ from the overall downward trend in aggregate chronic disability, it is reasonable to also ask whether trends for individual activities also show variation and whether any variation provides insights into the sources of disability decline. A central unanswered question regarding disability declines is whether they indicate improvements in health or environmental changes that promote greater independence for any given level of frailty. Exhibit 5 examines the trends over the 15-year period for individual IADLs, ADLs with equipment only, and ADLs with human help that underlie the overall trend in disability. It is clear that just as the overall trend in disability is driven by declines in help with only IADLs, nearly all declines in the prevalence of help with individual disabilities occurred for these activities, with almost no change in the prevalence of individual ADL items.

Because IADL information was not collected for the 5 percent of the elderly who were in institutions, the number of persons with individual IADLs includes only community residents. Therefore, for each IADL item, total population prevalence may be understated by as much as 5 percent. In all cases activities are ordered by prevalence in 1984 from highest to lowest. It should be recalled that persons categorized in the previous tables as receiving help with at least one IADL or ADL may also have other ADLs for which they use only equipment. For this reason, the prevalence of some equipment ADLs, notably use of equipment for getting around inside, exceeds the percent of the elderly who use ADL equipment but receive no human help with any activity. However, for each ADL reported, individuals were categorized as *either* using help *or* using equipment without help. Thus, the sum of the percent using ADL equipment and the percent using ADL help for each activity equals the total population prevalence of disability in that activity.

IADL Disabilities

There was a downward trend in the prevalence of all IADLs except getting around outdoors and taking medication, but the most striking declines are for managing money, grocery shopping, and laundry. The first two activities intuitively could reflect the increasing range of services and accommodations generally available in the economy over the period, such as telephone and electronic banking and shopping. The pattern seen for shopping is consistent with such a phenomenon, with steady, 1 percentage point declines in the first two periods and a much larger decline between 1994 and 1999. However, nearly all the 4.5 percentage point decline in help with money management occurred between 1984 and 1989, with far smaller declines in the subsequent 5-year periods.

The precipitous drop in help with money management may well reflect a change in the way Social Security makes payments, more than an improvement in cognitive or physical health. The Social Security Administration in 1987 adopted direct deposit as the default method of Social Security payments, which represent at least half of income for two-thirds of the elderly (Social Security Administration 2000). The policy was altered in 1988 so that new beneficiaries were offered either payment by check or direct deposit, but SSA continued to encourage direct deposit, and about 80 percent of benefits currently are paid by direct deposit.⁶ This change almost certainly contributed to the pattern seen for money management. This may suggest that some of those reporting difficulty in managing money, which is usually associated with cognitive difficulties (Spector and Fleishman 1998), were truly reporting physical difficulty with getting out to cash or deposit checks. It is also possible that direct deposit encouraged greater use of banks and bank-based money management services, including automatic bill payment.

Neither of these possibilities would necessarily imply that the decline in this IADL is due to an improvement in the health or cognitive functioning of the elderly. Freedman, Aykan, and Martin (2001), using the 1993 Assets and Health of the Oldest Old and the 1998 Health and Retirement Survey found a decline in the proportion of persons age 70 or older who were cognitively impaired and speculated that improved functioning may contribute to the decline in IADLs observed in other data sources. Improvements in cognitive functioning cannot be investigated using the NLTCS because cognitive functioning was not assessed for the full population in the NLTCS prior to 1994, and in 1999, questions dealing with cognitive function changed so significantly that comparisons between 1994 and 1999 cannot be made. Within the chronically disabled population, there was a significant increase in cognitive impairment between 1984 and 1994, from 34 percent to 40.1 percent (Spector et al. 2000). Clearly, this could be observed even in the presence of a decline in cognitive impairment in the population at large.⁷

It may be more generally true that technology advances and greater availability of services in the economy reduce the reliability of a link between declines in IADLs and improvements in health. Respondent perceptions may also have changed for activities that are facilitated by environmental changes. In order to be classified as independent in an IADL activity, respondents to the NLTCS must either do the activity or be able to do it if they had to. Using grocery shopping as an example, in order for telephone or Internet shopping to have resulted in a decline in reported disability in this activity, a respondent who orders groceries and has them delivered would have to consider that as *doing* their

⁶ SSA historian Larry DeWitt provided the information on Social Security direct deposit. The Debt Collection Improvement Act of 1996, which requires most federal payments to be made electronically, essentially returned Social Security payments to default direct deposit effective January 2, 1999.

⁷ In fact, over this period, full or partial proxy response, which is often due to cognitive impairment, rose slightly among detailed questionnaire respondents, from 45 percent in 1984 to 46.8 percent in 1994, while overall proxy response, including those who screened out of the survey, fell from 23 percent to 16.1 percent.

grocery shopping, rather than *having it done* for them. Technology almost certainly has contributed to declines in other IADL help, but again, the implication is not necessarily better health. For example, meal preparation is likely to have been affected by growth in the availability of prepared foods and appliances such as the microwave oven, which make it both easier and safer to perform without help, *at any given level of health*. Telephones with amplifying devices, touchtone dialing, and possibly wider use of hearing aids almost certainly contribute to the decline in the prevalence of help with telephoning. On the other hand, despite technological advances, there was no downward trend in getting around outdoors, with 6 to 7 percent of the elderly getting help in this activity in each year. Similarly, assistance with taking medications remained about 5 percent in all years.

ADL Disabilities

In contrast to the finding for individual IADLs, there was no pattern of consistent declines in the prevalence of individual ADLs. In fact, there were few significant differences. It was seen earlier that an increasing percent of the elderly manage their ADL disability solely with the use of equipment. This appears to be attributable to only three activities: bathing, getting in and out of bed, and toileting.⁸

The overall prevalence of help with ADLs increased between 1984 and 1989 and fell thereafter, but this pattern did not occur for individual ADL items. There were significant increases in institutional help with bathing, dressing, getting in and out of bed, and toileting over the 1984-1989 period, but only bathing showed a significant decline after 1989. The significant 0.5 percent increase in institutional help with dressing over the 15-year period was offset by a similar decline in community help for no overall change in the prevalence of dressing help. Only help with bathing shows an overall significant decline over the 15-year period, as the result of a 0.6 percent decline in the prevalence of community help. This decrease was more than offset by a 1.3 percentage point increase in the prevalence of independence with equipment, however, so that the overall prevalence of disability in bathing did not change significantly. This is the single ADL activity for which increases in equipment use were accompanied by decreases in human help or supervision. The overall prevalence of disability in getting in and out of bed and toileting increased, due to the combination of the significant increase in the prevalence of institutional help with toileting and significant increases in equipment use in the community for these two activities.

⁸ Independence in toileting with equipment is not available for institutional residents in 1984 and 1989. In those two years, questions about use of equipment were not asked if the sampled person received no help.

Mean Number of Disabilities

The ability to understand the nature of disability declines and the potential cost implications depends not only on the prevalence of disability but also on the level of disability. For example, Spector and Fleishman (1998) found that hours of long term care received by chronically disabled community residents increased with the number of IADL and ADL disabilities for which help was received and that the total number of IADL and ADL disabilities predicted hours of care better than the number of ADLs alone. This section examines mean IADLs, mean ADLs, and, for relevant populations, total mean disabilities over the 15-year study period. The decline in the prevalence of most IADLs suggests that the mean number of IADL disabilities probably declined between 1984 and 1999. On the other hand, the lack of a downward trend in the prevalence of help with individual ADLs, coupled with the slightly lower overall prevalence of help with any ADL suggests that the mean number of ADLs with help among those with chronic disabilities is likely to have increased. The trend in the mean number of IADL disabilities is shown in Exhibit 6, and the trend for mean ADLs with help is shown in Exhibit 7, for relevant populations from Exhibit 5. Because IADLs are measured for the community disabled population only, IADL means shown in Exhibit 6 are based only on community residents.

The mean number of IADLs shows the expected downward trend for all community disabled, with the largest 5-year decrease between 1984 and 1989. The picture is less clear for the subsamples of community residents with IADL help only and those with ADL help. Although the mean number of IADLs for those with IADL help only is significantly lower in 1999 than in 1984, there was no downward trend prior to 1999. For community residents receiving ADL help, there was a decrease in mean IADLs between 1984 and 1989, but no trend since 1989. (The apparent slight increase in mean IADLs for this group since 1989 is not statistically significant.)

As expected, mean ADLs rose over all, for the community disabled, for community residents receiving ADL help, and for institutional residents, with the largest increase occurring for institutional residents. For those receiving ADL help in the community, there appears to have been no trend prior to 1999, but both the overall increase in mean ADLs between 1984 and 1999 and the increase between 1989 and 1999 are significant.

Finally, the declines in mean IADLs appear to have moderated these increases in mean ADLs for the two subgroups--all community disabled and community residents with ADL help--for which mean total disabilities in IADL or ADL activities can be measured meaningfully. For all community disabled residents, the mean number of disabilities declined gradually from 4.5 to 4.2 over the 15-year study period, although only the cumulative decline over the whole period was significant (not shown). Conversely, for those receiving ADL help in the community, there was a significant drop in mean ADL and IADL disabilities between 1984 and 1989, from 7.8 to 7.3, due primarily to the precipitous drop in mean IADLs over that period. This decline was followed, however, by a steady

increase through 1999, so that the total number of disabilities for which community residents with ADL help received help had returned to the 1984 level of 7.8 in 1999.

DISCUSSION

Research in recent years has converged to the conclusion that aggregate disability has declined, at least over some periods. By decomposing the aggregate trend shown in one data source closely associated with this conclusion, this study highlights that much remains to be understood before disability declines can convincingly be associated with savings in either Medicare or long term care spending and before it can be concluded that the rate of improvement seen in recent years will continue.

The results presented support the need to look further into underlying causes of observed aggregate declines in chronic disability and to look directly at how service use and costs have changed. Most of the change in disability between 1984 and 1999 was due to improvements at the lower end of disability, specifically among those reporting only IADL help, confirming the findings of research using other data (Schoeni, Freedman and Wallace 2001; Waidmann and Liu 2000). The prevalence of institutional residence did not show a downward trend, and the prevalence of ADL help declined much less than the prevalence of IADL help and only after 1989. This may imply that not all of the downward trend in aggregate disability reflects improvements in health. Rather, at least some of the observed improvements likely reflect improvements in the environment that affect both the ability of the elderly to cope with activities associated with independent living and whether they perceive themselves to be disabled. The increase in mean ADLs among the disabled reinforces the need for caution in predicting decreased long term care costs.

As noted earlier, the use of paid services among disabled community residents, including those with informal caregivers, increased between 1984 and 1994 (Spillman and Pezzin 2000; Liu, Manton, and Aragon 2000), consistent with the possibility of increasing mean costs among the disabled. This affected all payers. The percent of disabled elderly persons with formal caregivers who reported Medicare as a payment source rose from 16 percent in 1982 to more than a quarter in 1994 (Liu, Manton, and Aragon 2000), and Medicaid programs also greatly increased spending on community long term care over the period. Out-of-pocket payments for free-standing home health care agencies increased rapidly, from about \$500 million in 1984 to \$6 billion in 1994 (Letsch, Lazenby, Levit, and Cowan 1992; Braden, Cowan, Lazenby, et al. 1998). Since then, Medicare home health spending has fallen in absolute terms due to a combination of fraud and abuse detection and payment system changes in the Balanced Budget Act of 1997 (McCall, Komisar, Petersons and Moore 2001), and growth in spending by all other payers also slowed (Cowan et al. 2001). However, although growth may be slower, the decline in Medicare home health spending is likely to have been a temporary outcome of the Interim Payment System recently replaced by the new prospective payment system. Moreover, home health services represent only a fraction of all paid community long term care. Further analysis is needed to examine directly whether increases in use of paid long term care continued after 1994 and who paid for such care.

The results here also suggest a need to understand better the relationships among disability, chronic conditions, and Medicare spending. Historically those identified as chronically disabled have had higher Medicare costs than those without chronic disability. If, however, declines at the low end of disability and particularly among the IADLs, as found here, reflect a more forgiving physical environment as everyday technologies advance rather than actual improvements in health, there is no reason to believe that total or per capita Medicare costs would decline. That is, a smaller proportion of any group defined by chronic conditions or health status may report difficulties if it is simply physically easier to perform various activities because of changes in the external environment.

Freedman and Martin (2000) found *increases* in various chronic conditions associated with disability, coupled with a decline in physical limitations such as reaching above the head or carrying a bag of groceries. They concluded that while some conditions that have increased in prevalence, such as osteoporosis, appeared to have become less debilitating, earlier diagnosis and improved treatment may account for some of the apparent decline in the rate of disability associated with these conditions. However, earlier diagnosis and improved treatments do not necessarily imply lower costs and may imply higher costs. For example, such mobility enhancing procedures as hip and knee replacements have risen dramatically in recent years, raising the possibility that disability improvements may have been purchased with higher Medicare spending. The finding here, however, is that the overall prevalence of mobility problems increased and then declined resulting in no net change at the end of the 15-year period examined. This pattern was entirely due to changes in the prevalence of equipment use. The prevalence of help with mobility was constant. Thus, the potential for a link between Medicare spending and chronic disability that might intuitively be made is not evident.

Waidmann and Liu (2000) found evidence that disability declines were associated with smaller *increases* in per capita Medicare costs between 1992 and 1996. However, they caution that the relationship between disability and acute care utilization is complex, so that, for example, expectation of a longer active life may prompt greater spending for restorative procedures, such as cataract surgery and joint replacements. More direct analysis of the relationship between Medicare spending, chronic conditions, and disability is warranted. The NLTCs, which can be merged to a long Medicare claims history, is particularly well suited for such analysis, since it can be used both to examine repeated cross-sections and to analyze successive cohorts over time.

Finally, the results with respect to both equipment use and IADLs warrant further examination, in part because they may reflect a margin of disability where policies to promote environmental improvements can be effective in reducing dependence on help. The proportion of persons who manage all ADL disabilities with equipment increased, as did the overall prevalence of equipment for bathing, getting in or out of bed, and toileting among the elderly. However, the increased use of equipment was accompanied by a lower prevalence of human assistance only for bathing. It would be worthwhile to examine

whether use of equipment is associated with reductions in hours of care among those who receive help but manage some activities independently with equipment and what distinguishes those who are independent with equipment from those who are not. Agree and Freedman (1998) found that equipment use was positively related to disability level, more common among those using informal care, and most common among those using formal care. They found some evidence that simple devices, such as canes and walkers, substituted for informal care and supplemented formal care. An earlier analysis of the 1984 and 1994 NLTCs showed a decline in informal care, and an increase in the use of formal care, even among those receiving some informal care (Spillman and Pezzin 2000). More needs to be known about trends in equipment and the relationship between specific types of equipment and the amount of long term care.

Similarly, the strong downward trend in IADLs, which accounts for nearly all the observed decline in disability, needs more careful study. In addition to examining the role of underlying health and physical limitations in the decline in IADLs, more needs to be known about factors such as education, which have been found to be significantly related to disability declines in recent studies using other data (Waidmann and Liu 2000; Schoeni, Freedman, and Wallace 2001). The prevalence of IADLs was seen in this study to be far less sensitive than ADL disability to aging of the elderly population, even though there is a substantial physical component to several of the activities. There also are some inconsistencies that are puzzling. For example, outdoor mobility, a physically-oriented activity, and managing medications, which is more associated with cognitive difficulties or frailty, did not decline, while grocery shopping and money management did.

CONCLUSION

Better understanding of the real implications of aggregate disability changes is not an academic exercise as policymakers consider changes in Social Security and Medicare to ensure their long range financial health. Many argue that declines in disability need to be taken into account in projecting future spending. Until there is a better understanding of these trends, however, it is not clear how they should be taken into account. Spillman and Lubitz (2000) analyzed acute and long term care costs after age 65 and found that, *holding the relationships among age, disability, and utilization patterns constant* at the levels of the mid 1990s, longevity after age 65 *per se* will have modest impacts on Medicare spending for cohorts turning 65 over the next 20 years. Impacts on long term care costs were larger, though still modest. The impacts, however, due to the increase in the number turning age 65, reflecting a combination of larger birth cohorts and increasing survival to retirement age, were large.

The current and other recent studies have shown that the relationship between age and disability has not been constant. There also is evidence of changing utilization patterns for long term care. Changes in demographics, such as female labor force participation and other factors are likely to further reduce the supply of informal care in the future. Changes in behavior that appear to be resulting in greater use of paid long term care services and in greater use of higher technology, more costly, acute care also must be taken into account in estimating effects of disability declines for health care and long term care costs and utilization.

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EXHIBIT 1. Percent of Elderly Population Meeting NLTCS Chronic Disability Criteria, 1984-1999

	1984	1989	1994	1999	5-Year Change			10-Year Change		15-Year Change
					1984-1989	1989-1994	1994-1999	1984-1994	1989-1999	1984-1999
Number of Elderly (000s)	27,968	30,871	33,125	34,459	10.4%	7.3%	4.0%	18.4%	11.6%	23.2%
Percent Distribution										
S No disability ¹	73.0	73.0	73.1	74.7	0.0	0.1	1.6*	0.1	1.7*	1.7*
S Evidence of disability but not now chronically disabled ²	4.8	5.7	6.8	5.6	0.8*	1.1*	-1.2*	2.0*	0.0	0.8
S Chronically disabled³	22.1	21.3	20.1	19.7	-0.7	-1.2*	-0.4	-2.0*	-1.6*	-2.4*
S Community IADL equipment only	0.7	0.7	0.7	0.7	0.0	0.0	0.0	0.0	0.0	0.0
S Community ADL equipment only	1.6	2.1	2.5	3.0	0.5*	0.4*	0.5*	0.9*	0.9*	1.4*
S Any human help	19.8	18.5	16.9	15.9	-1.3*	-1.6*	-0.9	-2.9*	-2.5*	-3.8*
S Community human help with IADLs only	7.4	5.3	4.7	4.2	-2.0*	-0.6*	-0.5	-2.7*	-1.1*	-3.1*
S Community human help with at least one ADL activity	7.4	7.7	7.1	6.9	0.3	-0.6	-0.2	-0.3	-0.8*	-0.5
S Institutional resident	5.0	5.5	5.1	4.8	0.4	-0.3	-0.3	0.1	-0.6*	-0.2

NOTE: Estimates may not sum to column or row totals because of rounding.

* Statistically different from zero at the 5% level in a two-tailed test.

1. Defined as being a community resident and (1) having no problem requiring human help or special equipment with any of six ADLs (eating, transfer, indoor mobility, dressing, bathing, and toileting), incontinence, or outside mobility and (2) being able to perform all of eight IADLs (meal preparation, laundry, light housework, grocery shopping, getting around outside, money management, taking medicine, making phone calls).
2. This group includes those who reported difficulty with ADLs or inability to perform IADLs on the screening interview or were disabled in a previous round of the survey but either failed to meet the 3-month criterion for chronic disability or reported no ADL or IADL disability on the detailed interview.
3. ADL help, supervision, use of special equipment, or need for help, or inability to perform IADLs has lasted 3 months or longer at time of detailed interview, or person is an institutional resident.

EXHIBIT 2a. Age and Chronic Disability 1984-1999: Percent of Age Group										
	1984	1989	1994	1999	5-Year Change			10-Year Change		15-Year Change
					1984-1989	1989-1994	1994-1999	1984-1994	1989-1999	1984-1999
65-74	12.2	10.8	10.4	9.2	-1.4*	-0.5	-1.2*	-1.8*	-1.7*	-3.1*
S Community IADL Equipment Only	0.5	0.5	0.5	0.5	0.0	0.0	0.0	0.0	0.0	0.0
S Community ADL Equipment Only	1.1	1.4	1.9	1.4	0.3	0.5*	-0.4	0.8*	0.1	0.3
S Any Human Help	10.6	9.0	8.0	7.2	-1.7*	-0.9	-0.8	-2.6*	-1.8*	-3.4*
S Community human help with IADLs only	4.4	2.9	2.7	2.5	-1.6*	-0.2	-0.2	-1.7*	-0.4	-1.9*
S Community human help with at least one ADL activity	4.6	4.5	4.0	3.5	-0.1	-0.5	-0.5	-0.6	-0.9*	-1.1*
S Institutional resident	1.6	1.6	1.3	1.2	0.0	-0.3	-0.1	-0.3	-0.4*	-0.4*
75-84	29.1	27.6	24.3	23.4	-1.4	-3.3*	-0.9	-4.8*	-4.3*	-5.7*
S Community IADL Equipment Only	1.1	1.1	1.0	0.8	0.0	-0.1	-0.2	-0.1	-0.3	-0.3
S Community ADL Equipment Only	2.3	2.8	3.3	4.5	0.5	0.5	1.2*	1.0*	1.7*	2.2*
S Any Human Help	25.7	23.7	20.0	18.0	-2.0*	-3.7*	-2.0*	-5.7*	-5.7*	-7.7*
S Community human help with IADLs only	10.3	7.5	5.9	5.0	-2.7*	-1.6*	-1.0*	-4.3*	-2.6*	-5.3*
S Community human help with at least one ADL activity	9.0	9.7	8.5	8.0	0.7	-1.2*	-0.5	-0.5	-1.7*	-1.0
S Institutional resident	6.4	6.5	5.6	5.1	0.1	-0.9	-0.5	-0.8	-1.4*	-1.3*
85 and Older	62.0	61.7	57.3	55.5	-0.3	-4.4*	-1.8	-4.7*	-6.2*	-6.5*
S Community IADL Equipment Only	1.1	1.1	1.2	1.3	0.0	0.1	0.1	0.1	0.2	0.2
S Community ADL Equipment Only	1.9	3.8	3.4	5.7	1.9*	-0.4	2.4*	1.4*	1.9*	3.8*
S Any Human Help	59.0	56.7	52.7	48.4	-2.3	-4.0*	-4.3*	-6.3*	-8.3*	-10.6*
S Community human help with IADLs only	16.6	12.5	11.1	9.8	-4.1*	-1.5	-1.3	-5.5*	-2.7*	-6.8*
S Community human help with at least one ADL activity	19.9	19.7	18.4	18.5	-0.2	-1.4	0.1	-1.5	-1.2	-1.4
S Institutional resident	22.5	24.5	23.3	20.1	2.0	-1.2	-3.2*	0.8	-4.4*	-2.4

NOTE: Estimates may not sum to column or row totals because of rounding.
* Statistically different from zero at the 5% level in a two-tailed test.

EXHIBIT 2b. Age and Chronic Disability 1984-1999: Percent of All Elderly

	1984	1989	1994	1999	5-Year Change			10-Year Change		15-Year Change
					1984-1989	1989-1994	1994-1999	1984-1994	1989-1999	1984-1999
65-74	7.3	6.2	5.8	4.8	-1.1*	-0.4	-1.0*	-1.5*	-1.4*	-2.5*
S Community IADL Equipment Only	0.3	0.3	0.3	0.3	0.0	0.0	0.0	0.0	0.0	0.0
S Community ADL Equipment Only	0.7	0.8	1.1	0.8	0.1	0.3*	-0.3*	0.4*	0.0	0.1
S Any Human Help	6.4	5.2	4.5	3.8	-1.2*	-0.7*	-0.7*	-1.9*	-1.4*	-2.6*
S Community human help with IADLs only	2.6	1.7	1.5	1.3	-1.0*	-0.1	-0.2	-1.1*	-0.3*	-1.3*
S Community human help with at least one ADL activity	2.8	2.6	2.3	1.9	-0.2	-0.3	-0.4*	-0.5*	-0.7*	-0.9*
S Institutional resident	1.0	0.9	0.7	0.6	0.0	-0.2	-0.1	-0.2*	-0.3*	-0.3*
75-84	9.0	9.0	8.0	8.2	0.0	-1.0*	0.2	-1.0*	-0.8*	-0.8*
S Community IADL Equipment Only	0.3	0.4	0.3	0.3	0.0	0.0	0.0	0.0	-0.1	-0.1
S Community ADL Equipment Only	0.7	0.9	1.1	1.6	0.2	0.2	0.5*	0.4*	0.7*	0.9*
S Any Human Help	7.9	7.7	6.6	6.3	-0.2	-1.1*	-0.3	-1.3*	-1.4*	-1.6*
S Community human help with IADLs only	3.2	2.4	2.0	1.8	-0.7*	-0.5*	-0.2	-1.2*	-0.7*	-1.4*
S Community human help with at least one ADL activity	2.8	3.1	2.8	2.8	0.4	-0.4	0.0	0.0	-0.3	0.0
S Institutional resident	2.0	2.1	1.8	1.8	0.1	-0.3	-0.1	-0.1	-0.3	-0.2
85 or Older	5.8	6.1	6.3	6.6	0.3	0.2	0.4	0.5	0.6	0.9*
S Community IADL Equipment Only	0.1	0.1	0.1	0.2	0.0	0.0	0.0	0.0	0.0	0.1
S Community ADL Equipment Only	0.2	0.4	0.4	0.7	0.2*	0.0	0.3*	0.2*	0.3*	0.5*
S Any Human Help	5.5	5.6	5.8	5.8	0.1	0.2	0.0	0.3	0.2	0.3
S Community human help with IADLs only	1.5	1.2	1.2	1.2	-0.3*	0.0	0.0	-0.3*	-0.1	-0.4*
S Community human help with at least one ADL activity	1.9	1.9	2.0	2.2	0.1	0.1	0.2	0.2	0.3	0.4*
S Institutional resident	2.1	2.4	2.5	2.4	0.3	0.1	-0.1	0.5*	0.0	0.3

NOTE: Estimates may not sum to column or row totals because of rounding.

* Statistically different from zero at the 5% level in a two-tailed test.

EXHIBIT 3. Actual and Age-standardized Chronic Disability

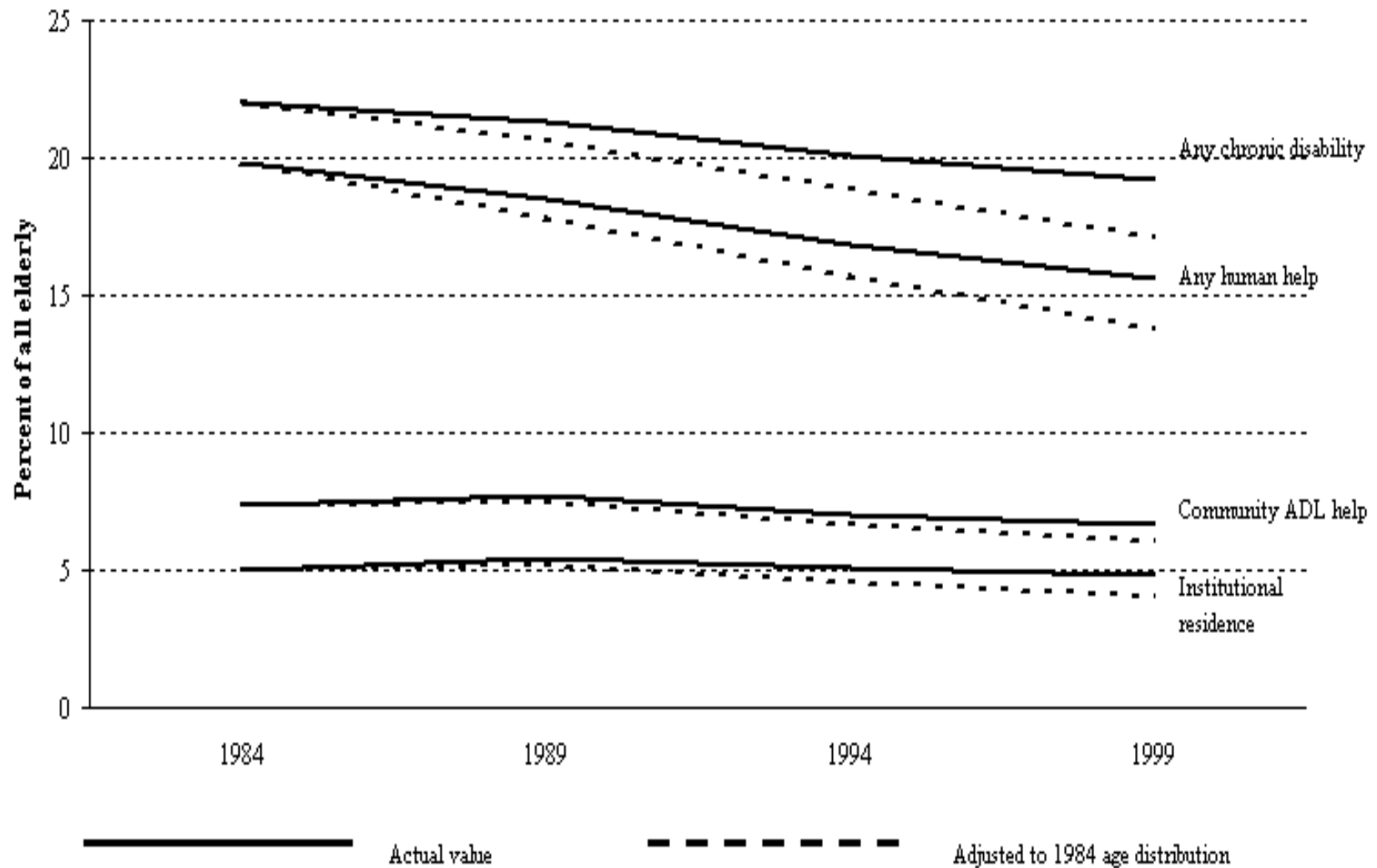


EXHIBIT 4. Actual and Age-standardized Annual Percentage Rates of Change in Components of Chronic Disability		
	Age-standardized (1984 age distribution)	Actual Trend
Any disability	-1.7%	-0.9%
Community ADL equipment	3.7%	4.1%
Any human help	-2.4%	-1.6%
S Community help IADLs only	-4.4%	-3.8%
S Community help ADLs	-1.4%	-0.7%
S Institutional resident	-1.5%	-0.3%

EXHIBIT 5. Prevalence of Individual IADL and ADL Disabilities, 1984-1999										
	1984	1989	1994	1999	5-Year Change			10-Year Change		15-Year Change
					1984-1989	1989-1994	1994-1999	1984-1994	1989-1999	1984-1999
Community IADL Help										
S Grocery shopping	10.9	9.9	8.8	7.1	-1.0*	-1.0*	-1.7*	-2.1*	-2.8*	-3.8*
S Managing money	8.4	4.7	4.4	3.8	-3.7*	-0.3	-0.6*	-4.0*	-0.9*	-4.6*
S Laundry	7.9	7.1	6.3	5.3	-0.8*	-0.8*	-1.0*	-1.6*	-1.8*	-2.6*
S Outdoor mobility	7.1	6.6	6.2	6.8	-0.5	-0.4	0.6	-0.9*	0.2	-0.3
S Meal preparation	5.6	5.2	5.0	4.3	-0.4	-0.2	-0.7*	-0.7*	-0.9*	-1.3*
S Taking medication	4.9	5.1	4.6	5.0	0.2	-0.5	0.4	-0.2	-0.1	0.2
S Light housework	4.8	4.3	4.2	4.1	-0.4	-0.1	-0.1	-0.5*	-0.2	-0.7*
S Using the telephone	3.2	2.9	2.3	2.2	-0.4	-0.6*	-0.1	-0.9*	-0.7*	-1.1*
Community ADLs with Equipment Only										
S Getting around inside	4.0	4.3	4.3	4.0	0.3	0.0	-0.3	0.3	-0.3	0.0
S Bathing	2.4	2.8	2.8	3.5	0.4*	0.0	0.7*	0.4*	0.8*	1.2*
S Getting in and out of bed	1.8	2.1	1.9	2.5	0.3	-0.2	0.6*	0.1	0.4*	0.7*
S Toileting	1.7	2.3	2.8	2.6	0.6*	0.5*	-0.3	1.2*	0.3	0.9*
S Dressing	0.1	0.2	0.2	0.1	0.1	0.0	0.0	0.1	0.0	0.0
S Eating	0.0	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Community ADLs with Human Help										
S Bathing	6.6	6.6	6.4	5.8	0.1	-0.3	-0.6*	-0.2	-0.9*	-0.8*
S Dressing	4.2	4.2	3.9	3.8	0.0	-0.4	-0.1	-0.4	-0.4*	-0.5*
S Getting around inside	4.2	4.4	4.1	4.2	0.2	-0.3	0.0	-0.1	-0.3	0.0
S Getting in and out of bed	3.8	3.8	3.6	3.9	0.0	-0.2	0.3	-0.2	0.1	0.1
S Toileting	3.4	3.2	3.2	3.3	-0.2	0.0	0.1	-0.2	0.1	-0.1
S Eating	2.2	2.1	2.2	2.3	-0.1	0.1	0.1	0.0	0.2	0.1
Institutional ADLs with Equipment Only										
S Getting around inside	1.2	1.7	1.2	1.0	0.5*	-0.5*	-0.2	0.0	-0.6*	-0.1
S Getting in and out of bed	0.7	0.7	0.5	0.6	0.0	-0.2*	0.1	-0.2	-0.1	0.0
S Bathing	0.2	0.2	0.3	0.3	0.0	0.0	0.0	0.1	0.0	0.0
S Eating	0.0	0.1	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.1
S Dressing	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
S Toileting ¹	n.a.	n.a.	0.3.	0.3.	n.a.	n.a.	n.a.	0.0.	n.a.	n.a.
Institutional ADLs with Human Help										
S Bathing	4.5	5.0	4.6	4.3	0.5*	-0.4	-0.2	0.1	-0.7*	-0.1
S Dressing	3.6	4.2	4.0	4.1	0.6*	-0.2	0.0	0.4*	-0.1	0.5*
S Getting in and out of bed	3.2	3.6	3.6	3.5	0.4*	0.0	-0.1	0.4*	-0.1	0.3
S Toileting	3.1	3.5	3.5	3.4	0.4*	0.0	0.0	0.4*	-0.1	0.4*
S Getting around inside	2.9	2.8	3.1	3.2	-0.1	0.3	0.1	0.2	0.3	0.3
S Eating	2.1	2.4	2.2	2.1	0.3	-0.2	-0.1	0.1	-0.3	0.0

	1984	1989	1994	1999	5-Year Change			10-Year Change		15-Year Change
					1984-1989	1989-1994	1994-1999	1984-1994	1989-1999	1984-1999

NOTE: Estimates may not sum to column or row totals because of rounding.

* Statistically different from zero at the 5% level in a two-tailed test.

1. Independence in toileting with equipment cannot be ascertained for institutional residents in 1984 and 1989 due to a skip logic error. Those who did not receive help with toileting were not asked about equipment in those years.

EXHIBIT 6. Mean ADLs: Chronically Disabled Community Elderly, 1984-1999

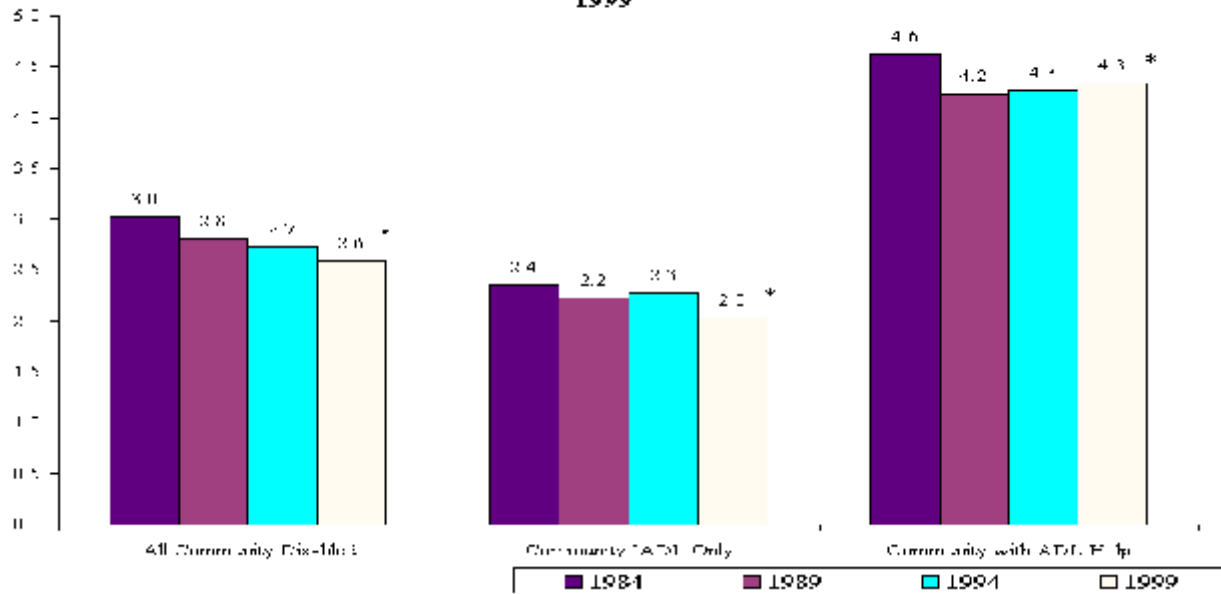
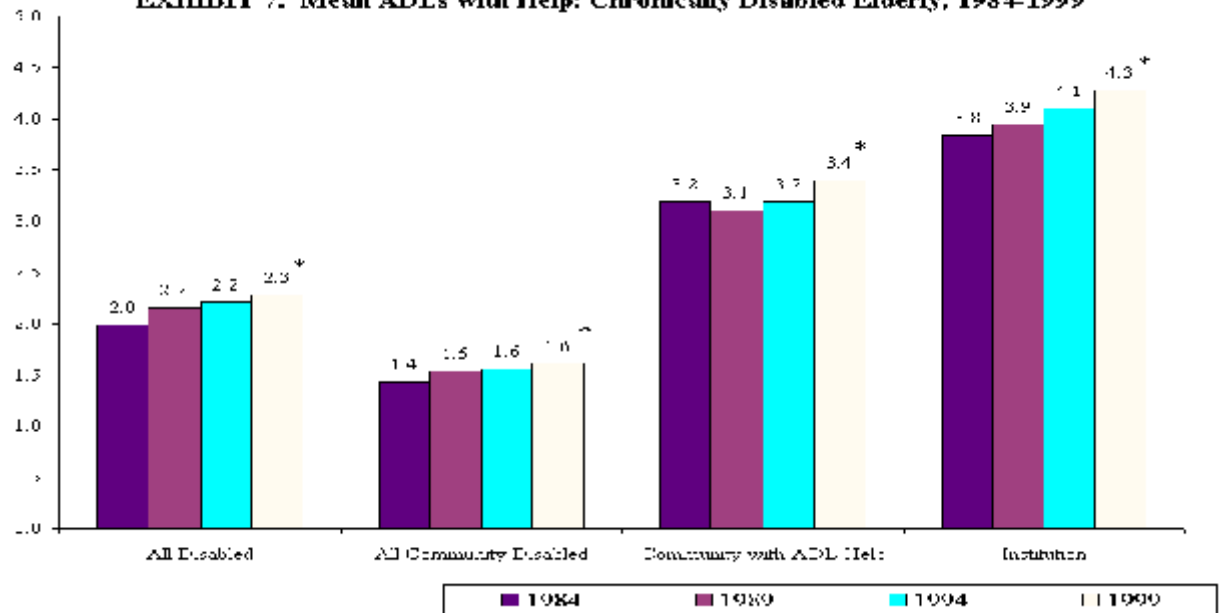


EXHIBIT 7. Mean ADLs with Help: Chronically Disabled Elderly, 1984-1999



APPENDIX: WEIGHT ADJUSTMENTS FOR THE 1984 AND 1999 NLTCS

The weights provided on the public use files for the 1984 and 1999 waves of the NLTCS are not comparable to the weights for 1989 and 1994 because they do not include the same post-stratification of the institutional population used in the two intermediate waves of the survey.⁹ This leads to a distortion in the estimated trend in institutional residence over time if the publicly released survey weights are used. To a lesser degree, it also affects disability trends. This appendix describes how the weights released for 1984 and 1999 differ from weights for the other two years and how they were adjusted for the present study to make estimates comparable over the four waves of the survey.

The NLTCS public use files are constructed by the U.S. Census Bureau, under the direction of the Center for Demographic Studies (CDS) at Duke University, which then distributes the data files. In 1989, the author and other researchers at the then-Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality) who were working with the 1984 NLTCS observed that the nursing home estimate (a subset of the NLTCS institutional questionnaire population) was large relative to other available estimates. Public use file weights were post-stratified by age, gender, and race to external institutional and noninstitutional control totals provided by Census. The institutional questionnaire sample was post-stratified to the institutional control total, and the community questionnaire sample was post-stratified to the noninstitutional control total. After investigating the definition of institutional residence used to produce the Census institutional control total, it was determined that this definition was broader than the definition used to assign NLTCS respondents to the institutional questionnaire. NLTCS respondents are assigned to the institutional questionnaire if they live in group quarters (three or more unrelated individuals) that have daily medical supervision, whereas the Census definition included such settings as “rest homes for the aged” with no requirement for number of residents or medical supervision.¹⁰ This mis-match had the effect of overstating the size of the institutional questionnaire population by weighting too narrow a subset of respondents to the institutional control total. Similarly, community population estimates were distorted because the noninstitutional control total was spread over too many respondents.

⁹ See “1994 Long-Term Care Survey Weighting Specifications for Cross-Sectional Estimates,” www.cds.duke.edu/pdf/94_CrossSectionalWeightings.pdf, and various versions of the “1999 Long-Term Care Survey Weighting Specifications for Cross-Sectional Estimates” available from Center for Demographic Studies (CDS) staff for more details.

¹⁰ See U.S. Bureau of the Census, 1980 Census of the Population, PC80-1-D1-A, Appendix B, p. B-2, and U.S. Bureau of the Census, 1980 Census of Population, v. 2, Subject Reports, “Persons in Institutions and Other Group Quarters,” PC80-2-4D, 1984, Appendix A, p. A-4.

After discussions with staff at Census, researchers at AHCPR developed a strategy for selecting a sample more comparable to the institutional control total definition that would then be post-stratified to this control total. This strategy was later adapted by Census and used in construction of public use file weights for the 1989 and 1994 waves of the NLTCS. The adjustment expands the sample post-stratified to the institutional control total to include two groups besides institutional questionnaire respondents. The two groups are:

- Persons living in noninstitutional group settings that do not include daily medical supervision, provided they receive help with ADLs, on the assumption that this reasonably replicates “homes for the aged” which are included in the control total but not in the NLTCS institutional questionnaire sample, and
- All persons living in quarters identified as institutional but not providing medical supervision, since medical supervision is not a requirement for the control total.

The rest of the sample receiving the community questionnaire and not in one of these groups then is post-stratified to the noninstitutional control total. The effect of the adjustment is to reduce the estimate of the size of the institutional questionnaire population and increase the estimate size of the community questionnaire population. In 1984, the adjustment reduced the institutional questionnaire population from 1.55 million persons to 1.41 million persons, and the nursing home population (a subset of the institutional questionnaire) from 1.51 million to 1.37 million.

In 1999, CDS staff felt that the institutional control total originally provided by Census was too large and instructed Census to omit *any* post-stratification to an external institutional control total. For this reason, the 1999 institutional population estimate using weights distributed by CDS is far smaller in magnitude and incomparable to those for previous years. Therefore, for the current study, the 1999 data also were post-stratified according to the method outlined here.¹¹

The results of the reweighting are shown in Table A-1, which compares published estimates for all years from the NLTCS using weights on the public use files or analytic files provided by CDS with the estimates presented here.

Other than weights, the estimates within each year differ analytically only with respect to the IADLs included in the IADL-only category, defined as having at least one chronic IADL limitation and no ADL limitation. In the present study, IADLs exclude heavy housework and going outside of walking distance (transportation). In the estimates published in *Older Americans 2000* (Federal Interagency Taskforce on Aging Statistics 2000), both heavy housework and transportation are included, while in Manton and Gu

¹¹ Detailed specifications for the 1999 reweighting are available from the author.

(2001) transportation, but not heavy housework, is included. The impact of this analytic difference can be seen by focusing first on the 1989 and 1994 estimates, for which both sets of estimates use the NLTCS cross-sectional file weights. The institutional population estimates are identical, with both based on respondents to the institutional questionnaire. Within the community population, all of the difference between the estimates in 1994, and all but 0.2 percent in 1989, is due to the difference in the IADL-only estimate.

The impact of the weighting adjustments can be seen in the 1984 and 1999 estimates. Considering 1984, as noted, the adjustment of the population post-stratified to the institutional control total, has the effect of reducing the estimate of the institutional questionnaire population, from 5.5 percent to 5.0 percent of the elderly. The larger difference between ADL status in the community likely results from the tendency of the reweighting to increase the weights of those in the community who are not in the marginal groups included in the institutional post-stratification and who may reasonably be expected to be less disabled. This is true in part because the larger of the two marginal community groups included in the institutional sample as defined for reweighting--disabled elders in group settings without medical supervision--is selected in part based on having ADL disability.

Three sets of 1999 estimates are presented. The first are the published estimates from Manton and Gu (2001), the second was constructed using the cross-sectional file weights most recently distributed by Duke, and the third uses the post-stratified weight used in the current study. In this case, because the CDS weights include no post-stratification to an external institutional control total, the 1999 estimate of the nursing home population increases, from just over 4 percent in the first two estimates, to the 4.8 percent reported in the present study. Both the community estimates using the weight distributed by CDS and the estimates using the post-stratified weight are immaterially different from those published in Manton and Gu, except for the IADL-only difference discussed above.

Going forward, it would be desirable to have a consistent set of weights across all the survey years. While the adjustment here makes the estimates more comparable, a better approach to being able to compare the NLTCS estimates over time would be to have a set of weights produced by one source using identical methodology over all years. One strategy would be to remove all post-stratification, allowing the survey to generate an independent estimate of facility use. If the estimates are to be post-stratified, identically defined control totals and post-stratification methodology should be used over all years. In addition, because estimates from the nearest Census were not available at the time weights for the surveys originally were produced, new post-stratified weights should reflect the nearest Census information for those years (1989 and 1999) that are contemporary to a new decennial Census, and Census information from the two bracketing Censuses for the years between Censuses (e.g. 1980 and 1990 for 1984) to take into account changes now known to have occurred between Censuses.

TABLE A-1. Comparison of NLTCS Estimates in *Older Americans 2000*¹ and *Manton and Gu (2001)* with Estimates in Current Project

	1984			1989			1994			1999				
	Older Americans 2000 ²	Spillman	Diff.	Older Americans 2000 ²	Spillman	Diff.	Older Americans 2000 ²	Spillman	Diff.	Manton and Gu (2001) ³	Spillman (CDS final weight)	Diff.	Spillman Post-stratified Weight ⁴	Diff.
Community														
S IADL only	5.8	5.2	-0.6	4.7	3.4	-1.3	4.3	3.1	-1.2	3.2	2.6	-0.6	2.6	-0.6
S 1-2 ADLs	6.5	6.2	-0.3	6.3	6.2	-0.1	5.8	5.8	0.0	6.0	5.8	-0.2	5.8	-0.2
S 3-4 ADLs	2.9	2.7	-0.2	3.5	3.3	-0.2	3.2	3.1	-0.1	3.5	3.4	-0.1	3.4	-0.1
S 5-6 ADLs	3.1	3.0	-0.1	2.8	2.9	0.1	2.8	2.9	0.1	2.9	3.1	0.2	3.1	0.2
S Any ADL	12.5	11.9	-0.6	12.6	12.4	-0.2	11.8	11.8	0.0	12.4	12.3	-0.1	12.3	-0.1
All Community	18.3	17.1	-1.2	17.3	15.8	-1.5	16.1	14.9	-1.2	15.6	14.9	-0.7	14.9	-0.7
Community and Institution	23.8	22.1	-1.7	22.8	21.3	-1.5	21.2	20.0	-1.2	19.8	19.0	-0.8	19.7	-0.1
Institution														
S All	5.5	5.0	-0.5	5.5	5.5	0.0	5.1	5.1	0.0	4.2	4.1	-0.1	4.8	0.6
S IADL only	-	0.2		-	0.2		-	0.2		-	0.1	-	0.1	-
S 1-2 ADLs	-	0.9		-	0.8		-	0.7		-	0.3	-	0.4	-
S 3-4 ADLs	-	1.0		-	1.1		-	1.0		-	0.9	-	1.1	-
S 5-6 ADLs	-	2.9		-	3.4		-	3.3		-	2.7	-	3.2	-

NOTE: IADL only means inability to perform at least one IADL, but no help or equipment use for any ADL. Those with ADLs may be using equipment or receiving either active or standby help.

1. Federal Interagency Task Force on Aging-Related Statistics (2000). <http://www.agingstats.gov>.
2. Spillman estimates include light housework, laundry, meal preparation, grocery shopping, getting around outside, financial management, using the telephone, and taking medications. Estimates from *Older Americans 2000* apparently also include transportation and heavy housework.
3. IADLs apparently include all in *Older Americans 2000* except heavy housework.
4. The final weight is post-stratified to Census totals using methodology consistent with that described in Census weighting specifications for the 1989 and 1994 survey waves. Those who are neither in an institutional residence nor disabled at screen and those who receive the community questionnaire but are not in any type of group quarters are adjusted to the age, gender and race distribution of the Civilian Noninstitutional Population and to that control total. Those who are disabled and living in noninstitutional group quarters (i.e., living with three or more unrelated individuals), those living in an institutional setting that does not have medical staff on duty daily, and those receiving the institutional questionnaire (i.e., those living in group quarters, including institutional settings, that have medical staff available daily) are adjusted to the race, and gender distribution of (Civilian Population--civilian noninstitutional population--correctional population) and to that control total. Those in correctional facilities are out of scope.

