



**More Older People with Disabilities
Living in the Community:
Trends from the National
Long-Term Care Survey, 1984–2004**

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Research Report

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FOREWORD

Over the 20 years covered by the National Long-Term Care Survey (NLTCs), disability rates among older Americans have declined substantially. If 1984 age-specific rates had remained unchanged, 1.3 million more older persons would have experienced a disability in 2004. If rates of institutional use among older persons with disabilities had remained constant, three-quarters of a million more older people would have been in institutions. And had these changes not occurred, federal and state Medicaid spending on nursing homes would have been \$24 billion higher. The new and detailed analyses of the NLTCs data in this report provide insight into the factors driving these changes.

EXECUTIVE SUMMARY

I. INTRODUCTION

The popular media are full of headlines highlighting the projected growth in the number of older persons and predicting a tsunami of demand for long-term services and supports (LTSS) to address the needs of increasing numbers of older persons with disabilities. Implicit in these headlines are three assumptions:

- A growing population of older persons translates into corresponding growth in the number of persons with disabilities.
- Growing numbers of persons with disabilities will result in growing demand for LTSS, particularly for institutional services.
- Growing demand for institutional services will result in higher costs for public programs such as Medicaid, which currently is the major payer for most nursing home residents.

This report challenges these assumptions, using newly available data from the five complete waves of the National Long-Term Care Survey from 1984 to 2004 to provide a detailed picture of disability trends among the older population and the relationship between those trends and the demand for institutional services. Specifically, the report documents trends in the older population related to—

- Declining disability rates
- Declining institutional use
- Increasing numbers of older persons with disabilities in community settings
- Variations resulting from gender, marital status, living arrangements, and socioeconomic status

II. METHODOLOGY

To measure trends in disability rates and use of LTSS, the AARP Public Policy Institute analyzed estimates from the National Long-Term Care Survey (NLTCS). Conducted in six waves beginning in 1982, the NLTCS is a nationally representative survey of the institutional and community-dwelling population aged 65 and older. This report uses data from the five waves beginning in 1984 and conducted every five years afterward until 2004/2005 because those waves have comparable detailed data on the disabilities of the institutional as well as the community populations.

The NLTCS measures disabilities related to two types of activities: instrumental activities of daily living (IADLs) and activities of daily living (ADLs). IADLs are measured in eight activities related to managing a household and living independently: light housework, laundry, meal preparation, shopping, getting around outside, managing money, taking medications, and using the telephone. ADLs are measured in six basic personal care activities: bathing, dressing, toileting, getting in or out of bed, indoor mobility, and eating. The National Long-Term Care Survey defines chronic disabilities as

receiving help or supervision or using equipment to perform an ADL for at least three months, or being unable to perform an IADL without help because of poor health or disability for at least three months.

AARP's Public Policy Institute (PPI) staff produced the analyses in this report based on data tables provided under contract by Brenda Spillman of The Urban Institute and building on previous work published by PPI (Gibson et al. 2003; Liu, Manton, and Aragon 2000; Redfoot and Pandya 2002; Spillman and Black 2005). Additional analyses based on the NLTCs data tables, interpretations, and conclusions are those of the authors.

III. FINDINGS

The major findings can be summarized by seven trends that organize the report. The first three trends relate to the overarching changes in the older population regarding disability, institutional use, and living in the community with disabilities. The subsequent four trends explore in greater detail how these overarching trends have played out among different subgroups in the older population by gender, marital status, living arrangements, and economic status.

Trend #1: The number of older persons has increased rapidly—but disability rates have decreased just as rapidly

The rate of increase in the older population was largely offset by the declining rate of disability during the twenty years of the NLTCs. After increasing from 6.2 million to 7.1 million between 1984 and 1989, the number of older persons with disabilities remained relatively constant, increasing by only 1.4 percent between 1989 and 2004 despite a 17 percent increase in the older population during that period. The United States would have had 1.3 million more older people with disabilities in 2004 if age-specific rates of disability had remained constant between 1984 and 2004. The distribution of disabilities changed markedly as the percentage of older persons reporting only IADL disabilities declined dramatically, while the percentage reporting ADL disabilities remained relatively unchanged.

Data Highlights

- ***The overall rate of chronic disabilities, including IADLs and ADLs, declined from 22.8 percent to 18.9 percent when age-adjusted to the 1984 population—a relative decline of 17 percent over the twenty-year history of the survey.***
- Declining age-adjusted disability rates were particularly pronounced among those reporting IADL disabilities only (-42 percent) and those reporting disabilities in all six ADLs (-20 percent).
- The percentage of the older population with two or more ADL disabilities remained remarkably constant throughout the twenty years of the study—declining only slightly in age-adjusted terms, from 11.4 percent in 1984 to 11.2 percent in 2004.

Trend #2: Institutional use is declining at all ages and at all levels of disability

The most dramatic change documented by the NLTCS is the declining rate of institutional use by older persons at all ages and at all levels of disability. After increasing from 1.6 million to 2.0 million between 1984 and 1989, the number of older persons living in institutions declined to 1.4 million in 2004. Most of the decline cannot be explained by declining rates of disability—rather, the decline occurred because increasing numbers of older persons with disabilities were able to continue living in community settings. Declines in institutional use among older persons translated into estimated savings in nursing home costs to Medicaid of roughly \$24 billion in 2004.

Data Highlights

- The age-adjusted rate of institutional use among older persons declined by 37 percent between 1984 and 2004.
- Except for a slight increase among those reporting disabilities in three to four ADLs, the number of people in institutions declined at all levels of disability between 1984 and 2004.
- The absolute number of older institutional residents declined by nearly 600,000, or 29 percent from the highest level in 1989.
- Only one-sixth of the decline in institutional use can be attributed to declining disability rates; five-sixths is due to declining institutional use at every level of disability.
- ***If age-specific rates of institutional use and disability had remained constant since 1984, 52 percent more older people—nearly three-quarters of a million more people—would have been in institutions in 2004.***

Trend #3: Older persons with disabilities are increasingly living in the community—even at the highest levels of disability

The flip side of the dramatic decline in the rate of institutional use has been the substantial increase in the number and percentage of older people living in the community at all levels of ADL disabilities. The number of older persons with disabilities in two or more ADLs in the community increased by two-thirds, or nearly 1.2 million people, between 1984 and 2004.

Data Highlights

- ***The percentage of older persons with two or more ADL disabilities living in the community increased from 57.5 percent in 1984 to 69.5 percent in 2004.*** Among all older persons with any level of disability, the percentage living in the community increased from 75 percent in 1984 to 80 percent in 2004.
- Reflecting the decline in those reporting only IADL disabilities, 52.1 percent of the older population with disabilities in the community reported two or more ADL disabilities in 2004—up from 38.2 percent in 1984.
- In 1984, 1.4 older persons with two or more ADL disabilities were in the community for every person in an institution at that level of disability; by 2004, that ratio had increased to 2.3.

Trend #4: The gender gap in disabilities is growing

Age-adjusted rates of disability and institutional use have always been higher among older women, and the gender gap on both increased somewhat over the twenty years of the NLTCS. Rates of institutional use declined substantially among both men and women, though somewhat more among older men. Growth in the older population living in the community with disabilities has been heavily concentrated among women.

Data Highlights

- In 2004, older women were 1.75 times as likely to have a disability and 2.2 times as likely to be in an institution as older men.
- ***The age-adjusted disability rate declined twice as rapidly among older men (by 24 percent) as among older women (by only 12 percent).***
- IADL-only disabilities declined substantially among both men and women, but ADL disabilities declined slightly only among men while increasing slightly among older women.
- Age-adjusted rates of institutional use declined by 38 percent among men and by 33 percent among women.
- Of the total growth in the older population living in the community with two or more ADL disabilities, 76 percent was due to the increase among women.

Trend #5: Married persons are much less likely to have disabilities or live in institutions

In large part because they were younger on average, disability rates were lower at all levels for married persons compared with those who were widowed or otherwise unmarried in all waves of the NLTCS. However, institutional use has declined more rapidly among those who are widowed or otherwise unmarried, resulting in much more rapid growth in the number of persons with disability in the community who are widowed or unmarried.

Data Highlights

- IADL-only disabilities declined for all marital statuses. ADL disability rates stayed about the same for married persons, increased among widowed persons, and were mixed among persons who were otherwise unmarried.
- Among respondents who reported two or more ADL disabilities, between 1984 and 2004 the rate of institutional use declined:
 - From 18.5 percent to 15.3 percent among those who were married
 - From 52.0 percent to 36.8 percent among those who were widowed
 - From 61.4 percent to 40.7 percent among those who were otherwise unmarried

- *More than half (56 percent) of the total increase in the number of older persons in the community with two or more ADL disabilities was among those who were widowed.*

Trend #6: The growth in assisted living has been a significant factor in the shift from institutional to community settings

Assisted living and other forms of community residential care have been the most rapidly growing options for long-term services and supports in recent decades. This growth appears to be a significant factor in the declining use of institutional services. The decline in the number of older persons with disabilities in institutions was more than offset by the growth in the number of persons in community residential care facilities such as assisted living between 1999 and 2004.

Data Highlights

- The number of older persons in the institutions declined by 174,000, or 11 percent, between 1999 and 2004.
- In contrast, the number of older persons with disabilities in community residential care facilities increased by 229,000, or 74 percent, during the same period.
- The number of older persons with disabilities living in a private residence with others increased by 361,000, or 12 percent, which may be partly due to declining rates of widowhood.

Trend #7: Growing numbers of older persons living in the community with disabilities have low incomes

Growth in the number of older persons with disabilities has been heavily skewed to the lower income quartiles. Three out of five older persons living in the community with two or more ADL disabilities reported annual incomes of less than \$20,000, roughly the individual income eligibility standard for Medicaid assistance in most states in 2004.

Data Highlights

- Thirty-seven percent of the growth in the number of older persons living in the community with two or more ADL disabilities was among those in the lowest income quartile.
- In 2004, 25 percent of older persons with two or more ADL disabilities living in the community reported annual incomes of less than \$10,000; only 21 percent reported an income of more than \$30,000.
- By way of comparison, the 2004 income eligibility standard in most states for LTSS paid for under the Medicaid home and community-based services waiver program was \$20,304 for individuals and \$30,456 for couples.

IV. CONCLUSION

The NLTCs data demonstrate that increasing numbers of older persons do not automatically mean similar increases in the numbers of people with disabilities or those using institutional services. After increasing between 1984 and 1989, the total number of older persons with disabilities remained constant between 1989 and 2004. However, the distribution of disabilities changed since the number of those reporting only IADL disabilities declined significantly while the number of older persons reporting ADL disabilities correspondingly increased. The gender gap in disabilities grew as rates of ADL disabilities increased slightly for women while decreasing slightly for men. Rates of institutional use declined at all levels of disability and among all age groups. As a result, the number of older people living in the community increased at all levels of ADL disabilities, especially among women and those with lower incomes. Expanding the trend toward more community living for older persons with disabilities in the coming decades when the boomers reach advanced old age will require laying the foundation of support for home and community-based services and family caregivers today.

INTRODUCTION

The popular media are full of headlines highlighting the projected growth in the number of older persons and predicting a tsunami of demand for long-term services and supports (LTSS) to address the needs of a population with increasing levels of disability. Implicit in these headlines are three assumptions:

- A growing population of older persons translates into corresponding growth in numbers of persons with disabilities.
- Growing numbers of persons with disabilities will result in growing demand for long-term services and supports, particularly for institutional services.
- Growing demand for institutional services will result in higher costs for public programs such as Medicaid, which currently is the major payer for most nursing home services.

This report examines these assumptions, using newly available data from the five complete waves of the National Long-Term Care Survey (NLTC) from 1984 to 2004 to provide a detailed picture of disability trends among the older population and the relationship between those trends and the demand for institutional services. The report documents declining rates of disability and institutional use among all age groups within the older population, though the report also documents how these trends differ in important ways with respect to types of disability, gender, marital status, living arrangements, and socioeconomic status. Perhaps most significant, the report shows that, due to a marked decline in institutional use, the number of older persons with disabilities living in the community has substantially increased—even at the highest levels of disabilities. A companion report (Houser, Gibson, and Redfoot 2010) uses data from the NLTC to examine how these growing numbers of older people with disabilities in the community are meeting their needs.

The major findings can be summarized by seven trends that organize the remainder of the report. The first three trends relate to the overarching changes in the older population regarding disability, institutional use, and living in the community with disabilities. The subsequent four trends explore in greater detail how these overarching trends have played out among different subgroups in the older population by gender, marital status, living arrangements, and economic status.

Trend #1: The number of older persons has increased rapidly—but disability rates have decreased just as rapidly.

Trend #2: Institutional use is declining at all ages and at all levels of disability.

Trend #3: Older persons with disabilities are increasingly living in the community—even at the highest levels of disability.

Trend #4: The gender gap in disabilities is growing.

Trend # 5: Married persons are less likely to have disabilities or live in institutions.

Trend #6: The growth of assisted living has been a significant factor in the shift from institutional to community settings.

Trend #7: Growing numbers of older persons living in the community with disabilities have low incomes.

A companion to this report (Houser, Gibson, and Redfoot 2010) uses NLTCs data to explore how the growing numbers of older persons with disabilities living in the community are meeting their needs through the informal support of family, the paid help of formal services, and the use of equipment. Together, these two reports provide empirical support for directing more public policy attention toward supporting older persons with disabilities in the home and community settings where they prefer to receive assistance—especially by supporting the caregivers, unpaid and paid, who provide services essential to maintaining independence when disability occurs in old age.

1984–2004: A Period of Great Change for Long-Term Services and Supports

The National Long-Term Care Survey provides an important look at changes in disabilities and the use of institutional care over a twenty-year period that saw major changes in the delivery of services as well as public policies related to long-term services and supports, including the following:

- Implementation of the first Medicaid waiver programs as authorized in 1981, which have become a major way to finance home and community-based services (HCBS) for persons with disabilities who have low incomes
- Implementation of the Medicare Prospective Payment beginning in 1983, which shortened hospital stays and reshaped nursing homes as they adapted to provide short-term, post-acute care
- Passage of the Nursing Home Reform Act in 1987, which eliminated the distinction between skilled nursing and intermediate care facilities and set up the regulatory system under which the nursing home industry lives today
- Passage of the Fair Housing Amendments Act of 1988 and the Americans with Disabilities Act of 1990, which extended important civil rights protections to people with disabilities of all ages
- The phenomenal growth of assisted living as a long-term care alternative to nursing homes beginning in the mid-1980s
- Growth in home care and home health care that has fluctuated as Medicare home health benefits have changed
- Decreasing rates of widowhood and childlessness among the older population

These changes have contributed to an ongoing transformation of long-term services and supports over the past few decades. Data from the twenty years covered by the NLTCs provide insight on the degree to which these changes have altered the experiences of older persons with disabilities.

METHODOLOGY

To measure trends in disability rates, use of long-term services and supports (LTSS), and informal caregiving, the AARP Public Policy Institute analyzed estimates from the National Long-Term Care Survey. Conducted in six waves beginning in 1982, the NLTCS is a nationally representative survey of the institutional and community-dwelling population aged 65 and older. In this report, the terms “older persons” or the “older population” refer to those aged 65 and older. This report uses data from the five waves beginning in 1984 and conducted every five years afterward until 2004/2005 because those waves have comparable detailed data on the disabilities of the institutional as well as the community populations. Each wave of the survey included about 20,000 respondents drawn from the rolls of Medicare beneficiaries.

A systematic review of various measures of health and disability called the NLTCS “one of the best designed surveys for analyzing national disability trends” because of its coverage over an extended period, its inclusion of both the institutional and community-dwelling populations, its use of identical field procedures over multiple surveys, its detailed disability questions, and its low “loss-to-follow-up rates” (Doty and Marton 2006). Because of questions related to the weighting of nonrespondents, use of these data sets was delayed pending a review and reweighting of all waves of the survey by Dr. Brenda Cox, then with the Battelle Centers for Health Care Research and Evaluation. The analyses used in this report come from these reweighted data, reflecting a consistent approach to weighting nonrespondents in all waves of the study.

AARP’s Public Policy Institute (PPI) staff produced the analyses in this report based on data tables provided under contract by Brenda Spillman of the Urban Institute and building on previous work published by PPI (Gibson et al. 2003; Liu, Manton, and Aragon 2000; Redfoot and Pandya 2002; and Spillman and Black 2005). The results are detailed in two companion reports related to—

- Basic trends in disability rates, institutional use, and community living by different segments of the older population, which are discussed in this report, and
- Trends in receiving assistance from formal and informal caregivers, as well as trends in payment sources for formal care services, which are reported in a companion report entitled *Trends in Family Caregiving and Paid Home Care for Older Persons in the Community* (Houser, Gibson, and Redfoot 2010).

How Does the NLTCS Define and Measure “Disability” and “Institutional”?

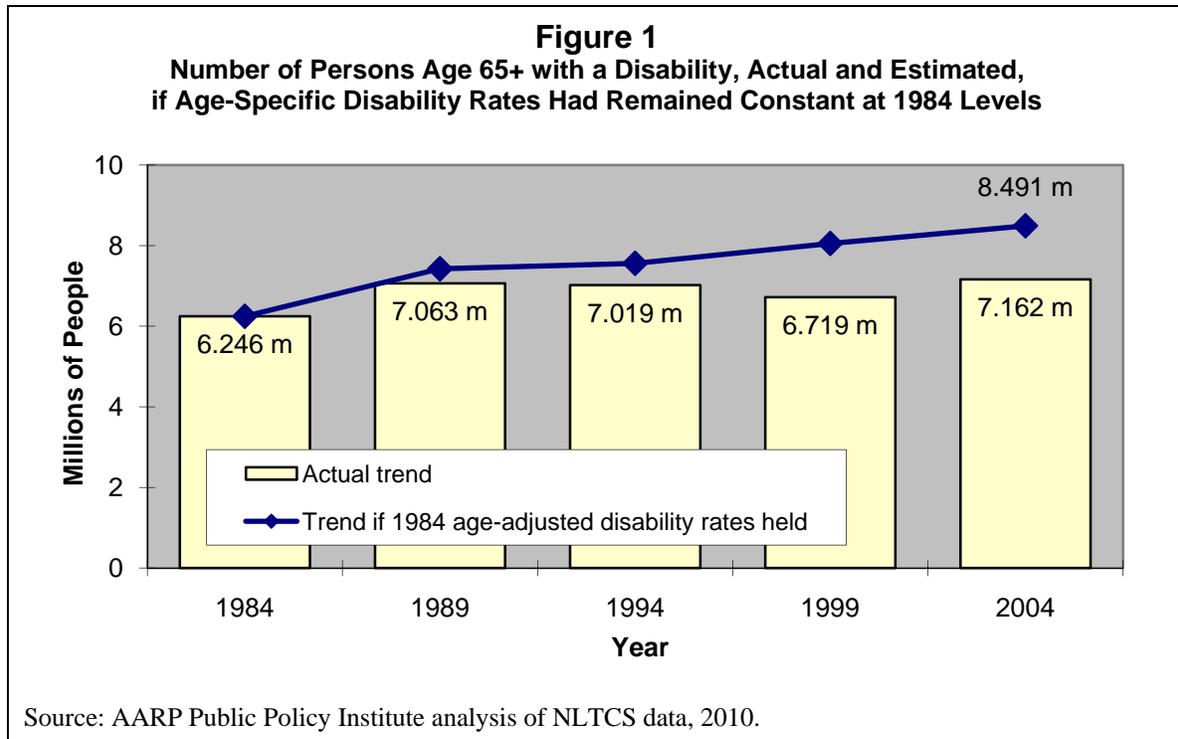
Because much of this report focuses on trends in the rates of disability and institutional use, it is important to understand how the NLTCS defines those terms. Researchers have used the term “disability” to refer to many types, levels, and durations of limitations in the ability to accomplish tasks associated with daily living (Institute of Medicine 2007). Like many other approaches, the NLTCS measures disabilities related to two types of activities: instrumental activities of daily living (IADLs) and activities of daily living (ADLs). IADLs are measured in eight activities related to managing a household and living independently: light housework, laundry, meal preparation, shopping, getting around outside, managing money, taking medication, and using the telephone. The NLTCS measures ADLs in six basic personal care activities: bathing, dressing, toileting, getting in or out of bed, indoor mobility, and eating. The NLTCS defines chronic disabilities as *receiving help or supervision or using equipment* to perform an ADL for at least three months, *or* being unable to perform an IADL without help because of poor health or disability for at least three months.

The NLTCS definition of “institutional” is related not only to characteristics of the setting but also to the types of services received. The survey has two different questionnaires: an institutional questionnaire and a community questionnaire. In all waves of the NLTCS, respondents were assigned to an institutional interview if they lived in a setting with three or more unrelated persons where a health care professional of some sort was on duty every day (Spillman and Black, 2006). In 1999, the survey added questions about residence in assisted living. Respondents who identified that they lived in assisted living and reported that they received “substantial nursing of any kind” were classified as institutional residents. No information was collected on whether the assisted living facility offered nursing services. Assisted living residents who indicated that they did not receive nursing services were given the community survey. Spillman and Black (2006) indicate that 23 percent of assisted living residents were characterized as institutional in 1999, and the rest were characterized as living in the community. As a result, 11 percent of the institutional population in 1999 lived in assisted living settings. The community residential care estimates in this report are limited to assisted living settings considered to be in the community by the NLTCS definition and to other settings such as personal care homes where no health care professionals are on duty daily.

Unlike the community questionnaire, the institutional questionnaire did not obtain information about IADL disabilities. As a result, only ADL disabilities are known for institutional residents. In this report, estimates of disability in only IADLs for the full population include a small proportion of institutional residents for whom no ADL disabilities were reported. Estimates relating only to institutional residents identify this group as having “No ADLs.”

TREND #1: THE NUMBER OF OLDER PERSONS HAS INCREASED RAPIDLY—BUT DISABILITY RATES HAVE DECREASED JUST AS RAPIDLY

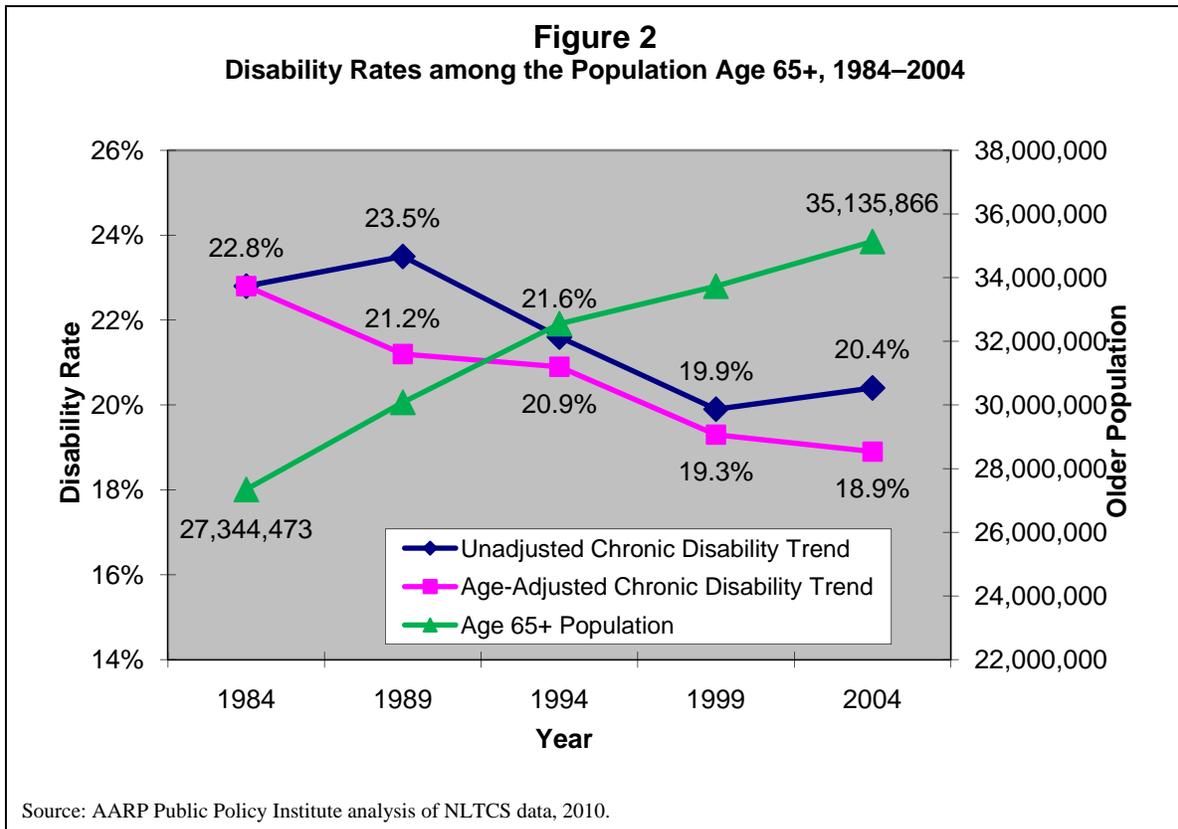
The United States would have had 1.3 million more people age 65 or older with disabilities in 2004 if age-specific rates of disability had remained constant between 1984 and 2004.



DATA HIGHLIGHTS

- *The overall rate of chronic disabilities, including IADLs and ADLs, declined from 22.8 percent to 18.9 percent when age-adjusted to the 1984 population—a relative decline of 17 percent over the twenty-year history of the survey.*
- Declining age-adjusted disability rates were particularly pronounced among those reporting IADL disabilities only (-42 percent) and those reporting disabilities in all six ADLs) -20 percent.
- The percentage of the older population with two or more ADL disabilities remained remarkably constant throughout the twenty years of the study, declining only slightly in age-adjusted terms from 11.4 percent in 1984 to 11.2 percent in 2004.
- After 1989, the number of older persons with a disability remained relatively constant, increasing by only 1.4 percent between 1989 and 2004 despite an increase of 17 percent in the older population during that period.

Disability rates have steadily declined among the older population between 1984 and 2004.



The popular media often assume that the rapid aging of the American population means rapid increases in the number of people with disabilities. As figure 2 indicates, however, the percentage of older persons with any type of disability declined from 1984 to 2004.

- In unadjusted terms, the overall disability rate declined from 22.8 percent to 20.4 percent.
- When the data were adjusted to reflect changes in the age distribution of the population, the disability rate declined from 22.8 percent to 18.9 percent, a 17 percent decrease in relative terms.

The decline in disability rates has been large enough to offset growth of the older population, resulting in little change in the actual number of older persons with a disability in recent years. After increasing by 13 percent between 1984 and 1989, the number of older persons with disabilities increased by only 1.4 percent between 1989 and 2004 despite an increase in the older population of 17 percent during that period.

If age-specific disability rates had remained constant at 1984 levels, we would have expected 8.5 million older people with disabilities in 2004, which is 1.3 million (19 percent) more than the actual number (see figure 1 above).

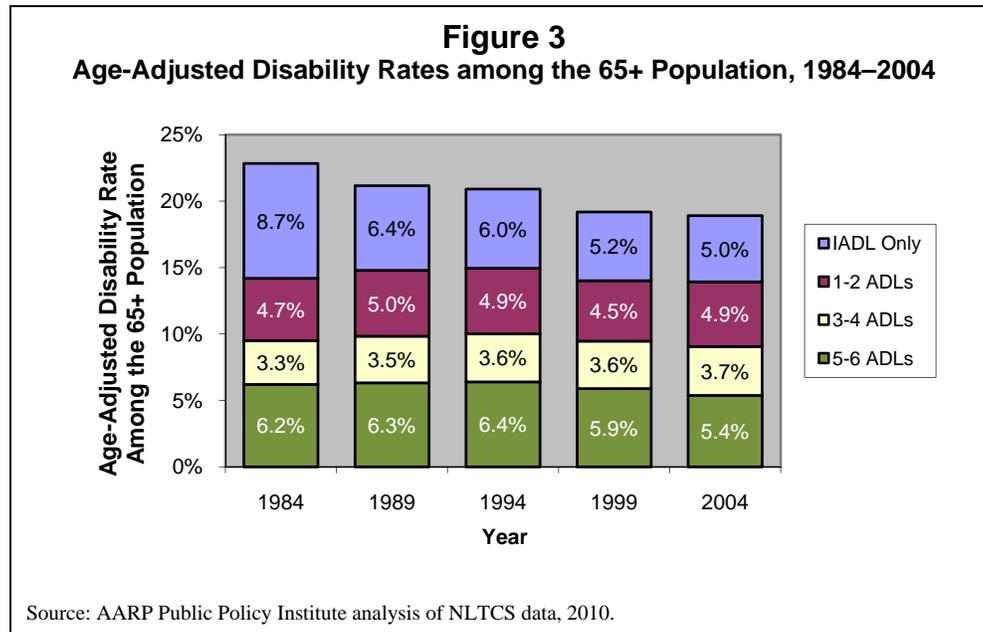
Why Report “Age-Adjusted” Disability Rates?

Disability rates increase substantially with age. When distinguishing the underlying trends in disability rates from changes in the age distribution of the older population, it is necessary to hold the age distribution constant over time. Because growth was most pronounced among those aged 85+ during the twenty years of the NLTCs, we would expect the unadjusted disability rate in the 65+ population to increase simply because the older population was, on average, older. Indeed, the number of young old (65–74) hardly grew at all between 1994 and 2004, even though the older age brackets grew substantially (see table A1 in the appendix).

The pendulum of growth skewed toward the oldest age groups is about to swing in the other direction with the entry of boomers into the 65+ population beginning in 2011. As the Census Bureau projections indicate (see table A1), growth will be much more pronounced among the young old over the next twenty years. While 36 percent of the growth in the older population in the NLTCs was among those aged 65–74 between 1984 and 2004, 65 percent of the growth will be among the young old in the next twenty years. Without adjusting for this rapid change in the age distribution, we would expect declines in the disability rates in the 65+ population simply because that population will become younger on average.

For comparisons of trends on age-sensitive data such as rates of disability or institutional use, this report adjusts the rates to the age distribution that existed in 1984 in order to compare trends without the complicated factor of the changing age distribution. We have identified each time we have made such adjustments, whose effects can be clearly seen in figure 2 when comparing rates in 1999 and 2004. Between those years, the unadjusted disability rate in the 65+ population grew from 19.6 percent to 20.4 percent. Adjusting both years to the 1984 population, however, shows a slight decline from 19.2 percent to 18.9 percent. In other words, the increase observed in the unadjusted percentages can be attributed to the skewing of the growth in the older population toward the oldest age categories. Age-specific disability rates actually declined somewhat.

Disability rates declined only at the lowest (IADL disabilities only) and highest (five or six ADL disabilities) levels.

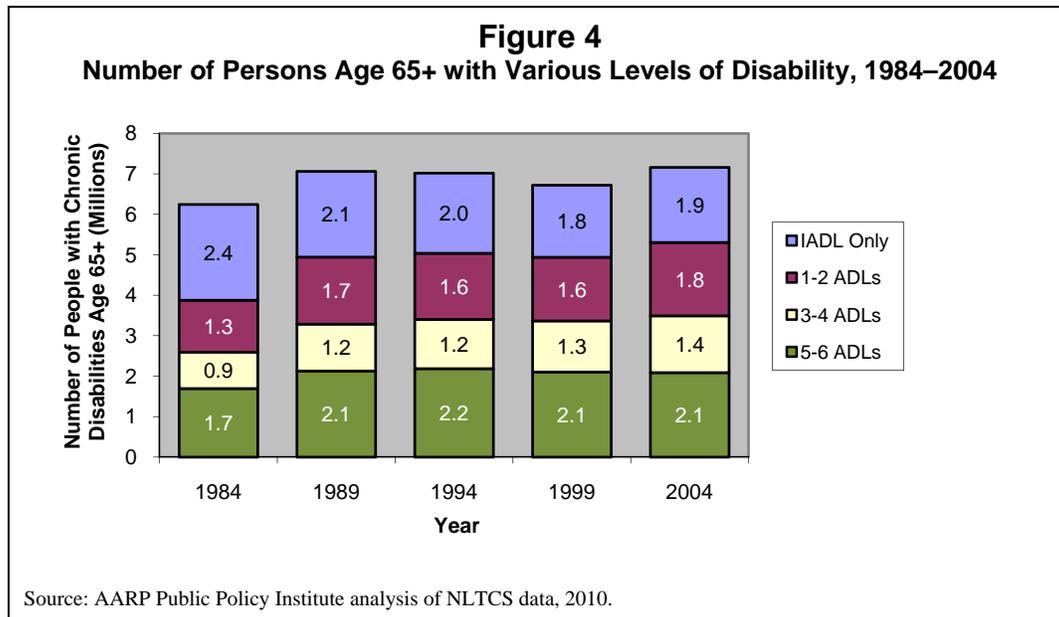


Over the twenty years of the NLTC, the age-adjusted decline in disability rates was most evident among those reporting only IADL disabilities.

- The rate of those reporting only IADL disabilities declined by 43 percent between 1984 and 2004—or by 2.7 percent per year.
- The rate of those reporting two or more ADL disabilities declined by only 1.5 percent between 1984 and 2004—or only 0.1 percent per year.
- At the very highest level of disability (all six ADL disabilities), the rate declined by 20 percent—or at an annual rate of 1.1 percent.

After rising between 1984 and 1989, the total number of older people with disabilities—which includes everyone from those living in the community with one IADL disability to those in institutions with all six ADL disabilities—changed little after 1989. Within this total, however, the distribution of types and levels of disabilities has changed significantly over time (see figure 4). Most of the decline in disability rates was among those reporting only IADL disabilities—half a million fewer older people reported only IADL disabilities in 2004 than in 1984. Earlier analyses of NLTC data have found that the average number of IADL disabilities reported among community-dwelling older persons with only IADL disabilities declined from 2.4 in 1984 to 2.0 in 1999 (Spillman 2004)—which, in most instances, would be a very low level of disability.

On the other hand, the number of people with ADL disabilities increased across all levels of disability. The number with five or six ADL disabilities increased by 430,000 and the number with one or two and three or four ADL disabilities increased by about half a million each. Most of these increases in the number of persons with ADL disabilities occurred between 1984 and 1989, with relatively little change between 1989 and 2004.



Why Have IADL Disabilities Declined So Much More than ADL Disabilities?

Measures of disability are often portrayed as stages on a continuum, with IADL limitations representing a lower level of disability in a progression toward the higher levels of ADL limitations. To the extent that these measures are on a continuum reflecting the underlying health of individuals, one would expect that the trends they measure would move in tandem. The fact that the trends are so different has been an issue for discussion among researchers that has not been entirely resolved. At least three types of explanations could be related to the different trends with these measures.

IADLs and ADLs represent distinct types of disability rather than lying on the same continuum. Landrum, Stewart, and Cutler (2009) challenge the notion that IADLs and ADLs are different stages in a single continuum of disability. They suggest that disabilities be characterized as three distinct types: (1) mobility disability (using mobility measures that cut across the IADL/ADL divide); (2) disability in complex tasks (nonmobility IADLs); and (3) disability in self-care tasks (nonmobility ADLs).

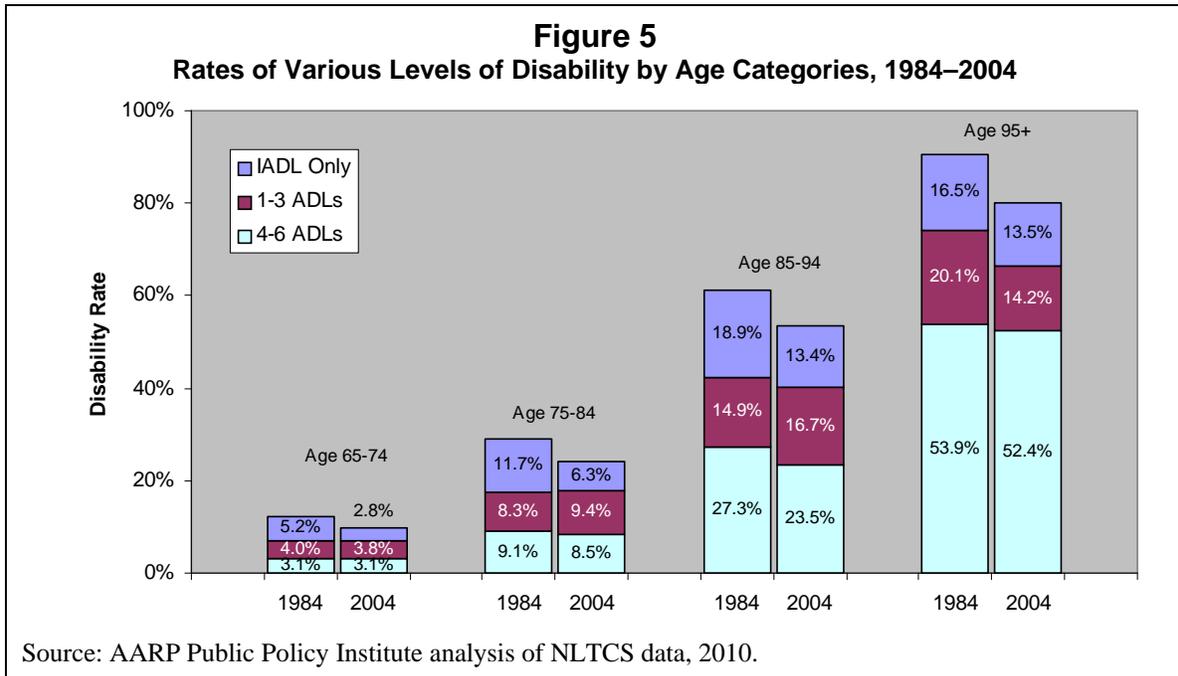
Using data from the NLTCS, these researchers looked at individuals who had recently incurred a disability, along with their underlying clinical disease conditions, arguing that these three types represent distinct clinical pathways to disability. In particular, dementia and organic brain disease, along with heart failure and arrhythmia, were the two leading factors in IADL disabilities, while arthritis played a bigger role in mobility and self-care disabilities. Some research indicates that the prevalence of cognitive impairments has declined (though this research is not conclusive), while arthritis and osteoporosis have increased. These different trends in the prevalence of disabling conditions may explain some of the differences in the trends related to rates of IADL and ADL disabilities (Schoeni, Freedman, and Martin 2008; Wolf, Hunt, and Knickman 2005).

IADL measures are more sensitive to environmental changes. The Institute of Medicine has emphasized that “disability is not an individual attribute but an interaction between the individual and the environment” (Institute of Medicine 2007). As measures of the ability to manage one’s household, IADLs are especially sensitive to the interaction of individuals and their environments. Because technology can facilitate individuals’ ability to deal with environmental challenges, some researchers have argued that technology may be playing a significant role in the decline in IADL disabilities (Spillman 2004; Wolf, Hunt, and Knickman 2005).

Spillman notes that the greatest declines in IADL disabilities between 1984 and 1999 were for money management, shopping for groceries, and laundry. She argues that these declines “may reflect the increasing range of services and accommodations generally available in the economy during this period, such as telephone and electronic banking and shopping.” For example, a marked decline in the IADL measure for money management between 1984 and 1989 coincided with the introduction of direct deposit of Social Security checks in 1987 (Spillman 2004). Similarly, the ability to shop by telephone or computer may be contributing to a decline in the shopping IADL. Other household devices, home modifications, and services may be addressing IADL needs, thereby lowering reported rates of disability by mediating between individuals and their environments even if the health status of those individuals has not improved.

Changes in the social environment may also contribute to changes in reported IADL disabilities (Wolf, Hunt, and Knickman 2005). For example, age-specific rates of widowhood have declined significantly, especially among older women. According to census data, rates of widowhood declined during this period from 39.1 percent to 28.8 percent among women age 65–74 (a relative decline of 26 percent) and from 66.9 percent to 58.8 percent among women age 75 and older (a relative decline of 12 percent). Lakdawalla and Philipson (2002) have argued that the increasing ratio of men to women in old age has been a major factor in the reduction of nursing home utilization rates by increasing the supply of potential caregivers. Increasing numbers of older couples surviving longer and providing support for each other may also be a factor in declining rates of IADL disability. In other words, the presence of a spouse or other caregiver may enable an individual to keep going with IADLs that otherwise would deteriorate. In any case, the role that the supply of caregivers plays in reported disability rates is a factor that should receive more attention from researchers.

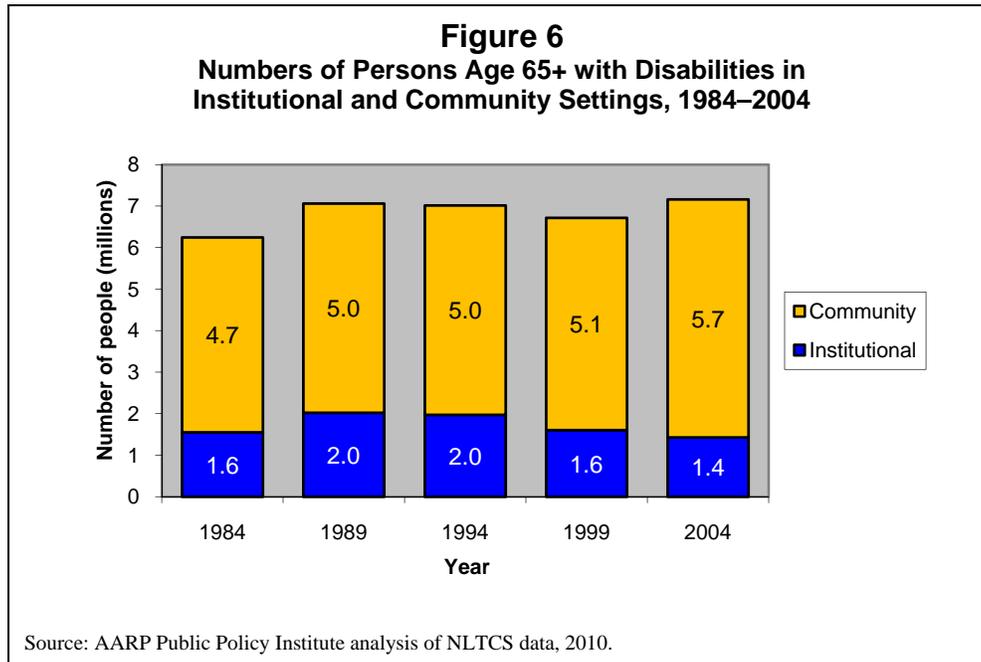
The total disability rate decreased among all age groups in the population age 65+, but the trends vary by age at different levels of disability.



Decreases in disability rates were especially concentrated at all ages among those reporting IADL-only disabilities (except among those age 95+, where the decline was greater among those reporting one to three ADL disabilities). The rate of ADL disabilities remained essentially unchanged between 1984 and 2004 among the 65–74 age group. For the 75–94 age groups, the picture is a bit more mixed. The rate of those reporting one to three ADL disabilities increased somewhat, but decreased for those reporting four to six ADL disabilities. Although the numbers are relatively small, the growing population of respondents aged 95+ saw declines in all levels of disability, though slightly more than half still reported four or more ADL disabilities.

TREND #2: INSTITUTIONAL USE IS DECLINING AT ALL AGES AND AT ALL LEVELS OF DISABILITY.

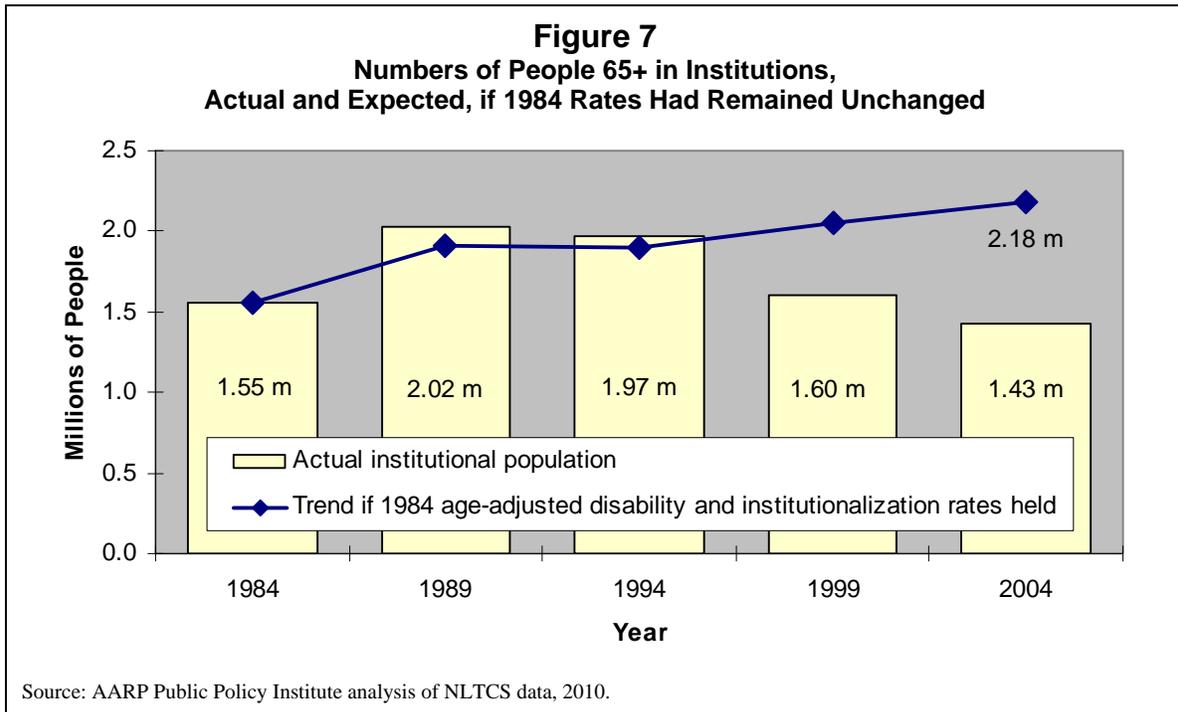
In 2004, declines in institutional use among older persons translated into estimated savings in nursing home costs to the state/federal Medicaid program of \$24 billion.



DATA HIGHLIGHTS

- The age-adjusted rate of institutional use among older persons declined by 37 percent between 1984 and 2004.
- Except for a slight increase among those reporting three to four ADL disabilities, the number of people in institutions declined at all levels of disability between 1984 and 2004.
- The absolute number of older institutional residents declined by nearly 600,000 (29 percent) since the highest level in 1989.
- Only one-sixth of the decline in institutional use can be attributed to declining disability rates; five-sixths is due to declining institutional use at every level of disability.
- *If age-specific rates of institutional use and disability had remained constant since 1984, 52 percent more older people— or nearly three-quarters of a million more people—would have been in institutions in 2004.*

The institutional population has decreased markedly in recent years.



Despite the substantial growth in the older population, the number of people age 65+ in institutional settings was actually 7.8 percent lower in 2004 than it was twenty years earlier. After increasing between 1984 and 1989, the institutional older population decreased by nearly 600,000 (29 percent) between 1989 and 2004. Institutional use rates have declined among all age groups. In 2004, 4.1 percent of Americans age 65+ were living in institutions, down from 5.7 percent in 1984. The age-standardized institutional rate dropped even further, to 3.6 percent.

If age-specific rates of institutional use and disability had remained constant since 1984, the expected rate of institutional use in 2004 would have been 6.2 percent instead of 4.1 percent. We would have expected 52 percent more older people in institutions in 2004 based on 1984 rates (see table A2 in the appendix). ***In other words, there would have been 747,000 more older people in institutions in 2004 if institutional and disability rates had remained unchanged since 1984.***

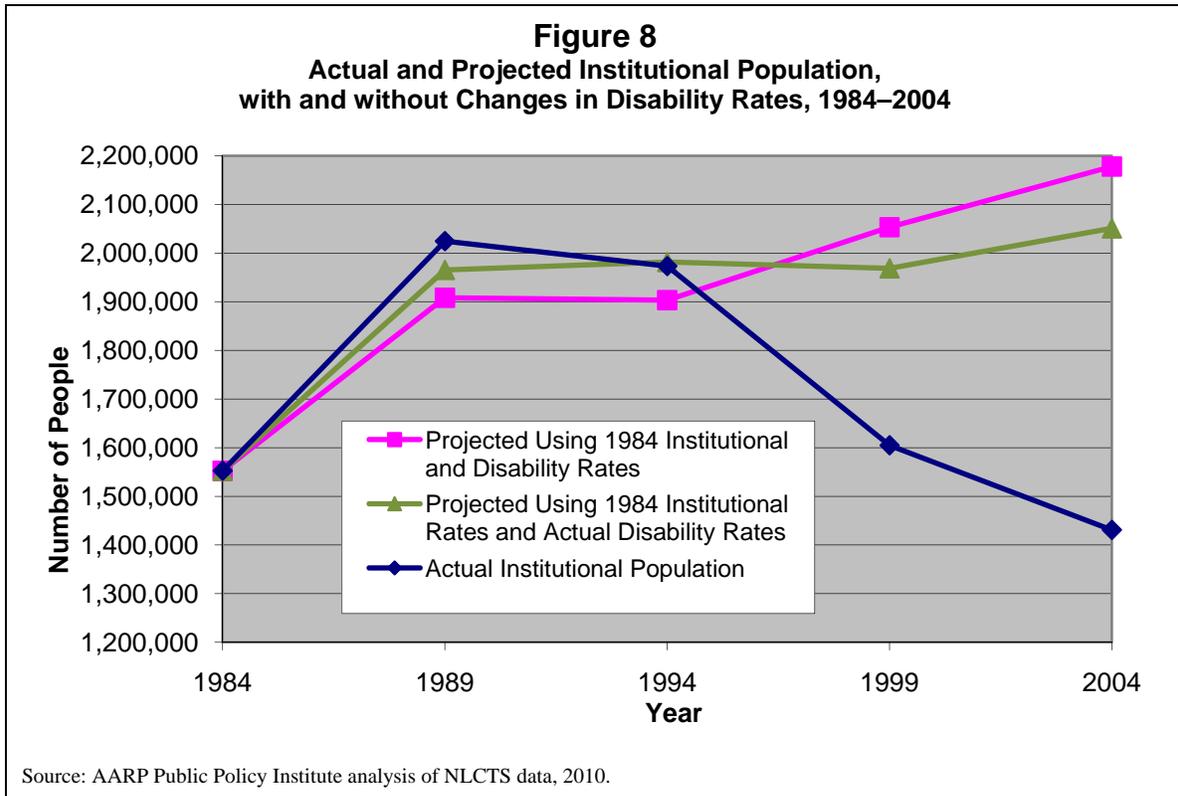
How Do the Trends Regarding Institutional Use from the NLTCS Compare with Other Data Sources?

The dangers of using age projections to predict future demand for long-term services and supports are illustrated by a 1991 report by the Senate Aging Committee entitled “Aging America: Trends and Projections” (U.S. Senate Special Committee on Aging; American Association of Retired Persons; Federal Council on the Aging; U.S. Administration on Aging 1991). This report, which was done in collaboration with AARP’s Public Policy Institute, used data from the 1985 National Nursing Home Survey (NNHS) and census population projections to predict that the older population in nursing homes would soar from 1.3 million in 1985 to 2.1 million by 2005.

However, data from ensuing waves of the NNHS (Alecxi 2006; Jones et al. 2009) indicate that the Senate Aging Committee overshot the actual nursing home population by about 800,000, or 56 percent. According to NNHS data (table A3 in the appendix), the nursing home resident population age 65+ was essentially the same in 2004 as it was in 1985, despite the fact that the 65+ population grew by 24 percent during that time and the 75+ population grew by 55 percent.

Comparing the NLTCS to the NNHS and other data sets is somewhat complicated by the way the NLTCS defines “institutional” (see the discussion of how “institutional” is defined in the Methodology section above). Despite these definitional differences, the findings over the twenty years of the NLTCS (table A3) show remarkably similar trends to those found by the NNHS (table A4) and other research. In addition to the NNHS, a recent analysis of data from the Centers for Medicare & Medicaid Services found that nursing home utilization declined by 19.9 percent between 1997 and 2007 among the population aged 75+ (Wiener, Anderson, and Brown 2009). All of these data sources point to similarly large declines in institutional use in the past two decades.

Declining disability rates explain a relatively small portion of the decline in institutional use.



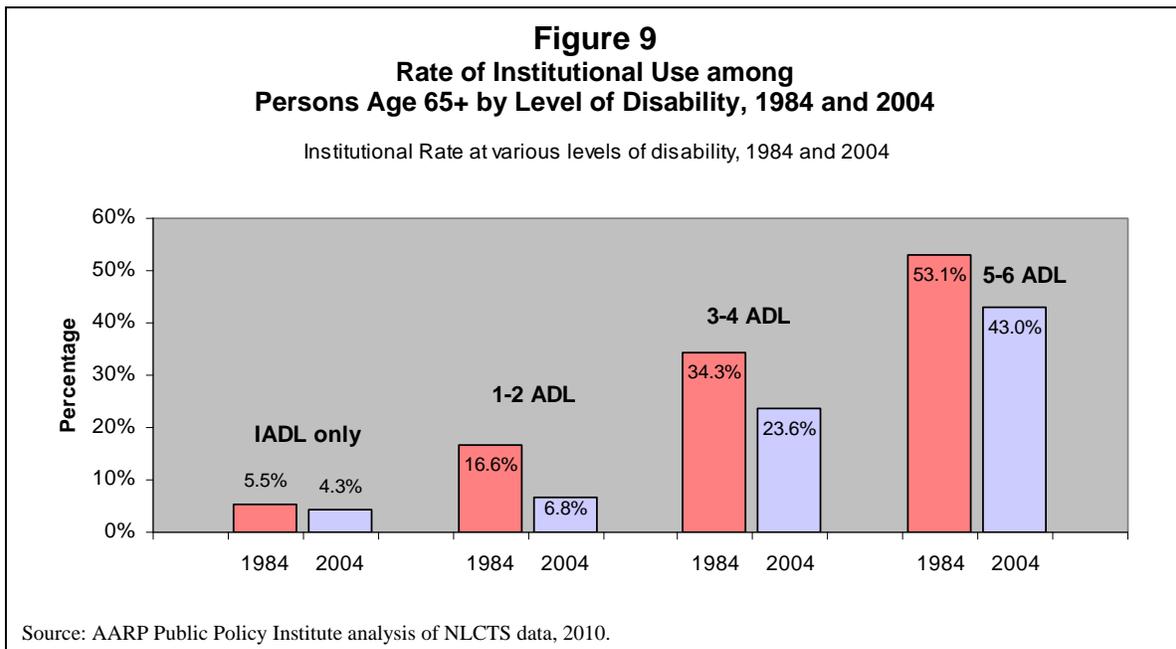
Declining disability rates alone cannot explain the major declines in the use of institutional services noted above. By comparing actual institutional use to the expected use based on 1984 use patterns, we estimate (see also table A5 in the appendix) that only 17 percent of the decline in institutional use can be attributed to declining disability rates. The remaining 83 percent of the decline has come from declining institutional use among older people at each level of disability.

Figure 8 compares the actual number of older persons in institutional settings, as shown in the lower line, with two hypothetical expected numbers. Both lines hold the gender-based age distribution constant. The top line holds both the disability and institutional rates constant at the 1984 levels and applies these rates to the actual age/gender population in the years between 1984 and 2004. The middle line holds the institutional rate constant but uses the actual disability rates to estimate the expected number in institutions. Comparing the two different *expected* institutional numbers—one holding the 1984 disability rate constant and the other using the actual disability rate in each wave—to the *actual* number of older people in institutions allows us to estimate how much of the decline in institutional rates has been due to declining rates of disability.

Many factors other than disability rates have been cited as contributing to declining institutional use. Demographic factors, such as declining rates of widowhood and childlessness in the current oldest cohorts, may have played a role by increasing the supply of informal caregivers (Houser, Gibson, and Redfoot 2010; Redfoot and Pandya

2002). The rapid growth in alternative service options, such as assisted living and home care, have also played a role in replacing or postponing institutional care. Public policy decisions have made a difference, such as increased nursing home eligibility requirements (Mollica and Reinhard 2005) or increased spending for home and community-based services (HCBS) under the Medicaid program (Wiener, Anderson, and Brown 2009). More research is needed on the specific causes underlying these trends that are rapidly transforming the landscape of long-term services and supports, and what they may mean for future demand when boomers reach high-risk ages in a couple of decades.

Institutional use has declined at all levels of disability and at all ages over the twenty years of the NLTCS.



As figure 9 demonstrates, rates of institutional use declined at all levels of disability, especially for those who reported one to two ADL disabilities. Rates of institutional use increased at the lowest and highest levels of disability between 1984 and 1994 and then declined substantially at all levels of disability between 1994 and 2004 (see table A6 in the appendix). The relative declines between 1994 and 2004 have been particularly large at the lowest levels of disability, though the declines in absolute numbers have been most pronounced at the highest levels of disability. One in five older persons with a disability (20.0 percent) was in an institutional setting in 2004, a decline from 24.8 percent in 1984 and 28.1 percent in 1994. Even at the highest levels of disability, less than half (43.0 percent) of older persons now live in institutional settings.

Age-specific rates of institutional use were essentially unchanged between 1984 and 1994. Since that time, rates of institutional use have declined dramatically among all 65+ age groups.

Age group	1984	1989	1994	1999	2004	Change 1994–2004
65–74	1.7%	2.4%	1.7%	1.4%	1.1%	-35%
75–84	6.8%	6.8%	6.7%	4.6%	4.2%	-38%
85–94	23.1%	23.3%	24.4%	18.2%	14.9%	-35%
95+	49.4%	47.0%	47.2%	41.5%	33.4%	-32%

Source: AARP Public Policy Institute analysis of NLTC data, 2010.

Medicaid Expenditures for Nursing Home Care Would Have Been \$24 billion Higher in 2004 if 1984 Disability and Utilization Rates Had Remained Unchanged.

Much of the public policy interest in disability trends is related to concerns about a potential explosion of health and long-term care expenditures for older persons. Data presented in the sections above dispel concerns that growing numbers of older persons automatically translate into similar growth in the numbers of persons with disabilities and those using institutional services. But how do these numbers translate into spending for institutional services? This question has specific urgency for policymakers at the state and federal levels who have been concerned about the potential for major increases in the Medicaid program due to the aging of the population, because the program is the largest payer of nursing home costs.

Because of the decline in institutional utilization rates documented above, nursing home expenditures have been among the slowest growing of all health-related expenditures (Hartman et al. 2009). Tracking the findings reported above, nursing home expenditures rose at roughly the same pace as overall health-related spending between 1984 and 1994 (see table A7 in the appendix). But in the succeeding decade, the relative increase in nursing home expenditures was less than half the rate of increase of the 1984–1994 decade, and Medicaid expenditures increased at a much lower rate than overall nursing home expenditures.

According to the Congressional Budget Office (CBO), even these increases in Medicaid expenditures were not due to the growth in the older population. Growth in the number of older Medicaid beneficiaries contributed only 0.6 percent to the total growth in Medicaid spending between 1975 and 2002. However, growth in the per-person costs of older Medicaid beneficiaries contributed 22.7 percent to the total cost increase during this period. In other words, the growth in the older population and its use of Medicaid services was a negligible factor in the growth in Medicaid spending, but the rising cost of services for older persons (mostly in nursing homes) was a major factor (Marron 2006). These costs grew even more for individuals paying privately than they did for public programs.

To demonstrate the importance of declining institutional use for the Medicaid program, we estimated the costs that would have been incurred had institutional utilization rates remained constant at 1984 levels. *Under that scenario,¹ Medicaid's 2004 nursing home expenditures would have been \$24 billion higher than they were.* Of that reduction, \$4 billion could be attributed to the decline in disability rates. Five times as much (\$20 billion) was due to the decline in institutional utilization at all levels of disability, as described above. These estimates should be taken as rough approximations, but they give a reasonable picture of the magnitude of the costs that would have been incurred if institutional utilization had remained unchanged.

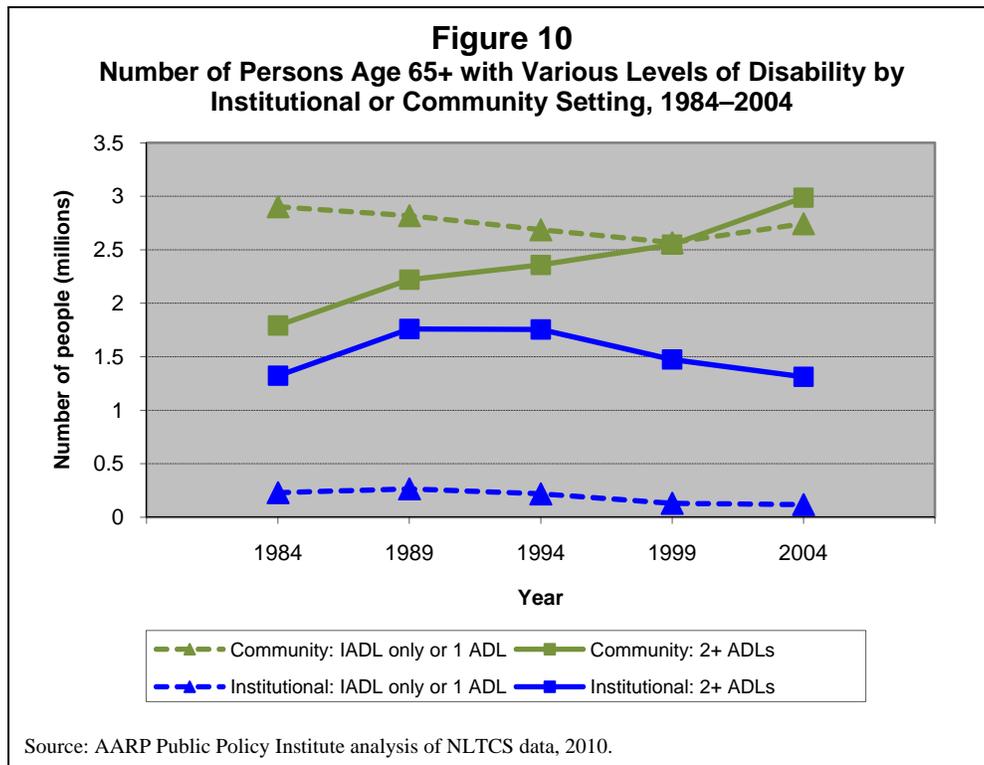
Total Medicaid spending on HCBS was \$33 billion in 2004, of which an estimated \$9.3 billion was spent on people age 65+ living in home and community settings.² How much of the estimated reduction in nursing home costs can be attributed to increased HCBS expenditures is a matter for conjecture, but the reduction in nursing home costs from the expected level is likely much greater than Medicaid expenditures for alternative HCBS options for older persons.

¹ Our estimate of the reduction in Medicaid nursing home expenditures was based on what would have been the case if age- and gender-specific disability and institutional rates had remained constant at 1984 rates. If only institutional rates are held at 1984 levels, using actual declining disability rates, the savings would be about \$20 billion. Our analysis assumes that (a) the reduction in institutional use was constant between Medicaid beneficiaries and non-beneficiaries, within age and sex; and (b) the mix of expected additional residents would be cost-equivalent of existing residents. The first assumption is grounded in the fact that the percentage of older nursing home residents with Medicaid as a primary payer has not changed dramatically over time. The second assumption may be less reliable since regions with different institutional costs have markedly different institutional use trends. In addition, levels of disability have increased among the nursing home population, but the durations of stays have decreased. These estimates apply only to the decline from the expected rate among the population age 65+.

² Our estimate of the amount spent on HCBS for older persons relies on data from Burwell, Sredl, and Eiken (2009) on the total amount spent on HCBS for 2004 along with an estimate from the Kaiser Family Foundation (2002) of the percentage of such funding that went to older beneficiaries.

TREND #3: OLDER PERSONS WITH DISABILITIES ARE INCREASINGLY LIVING IN THE COMMUNITY—EVEN AT THE HIGHEST LEVELS OF DISABILITY

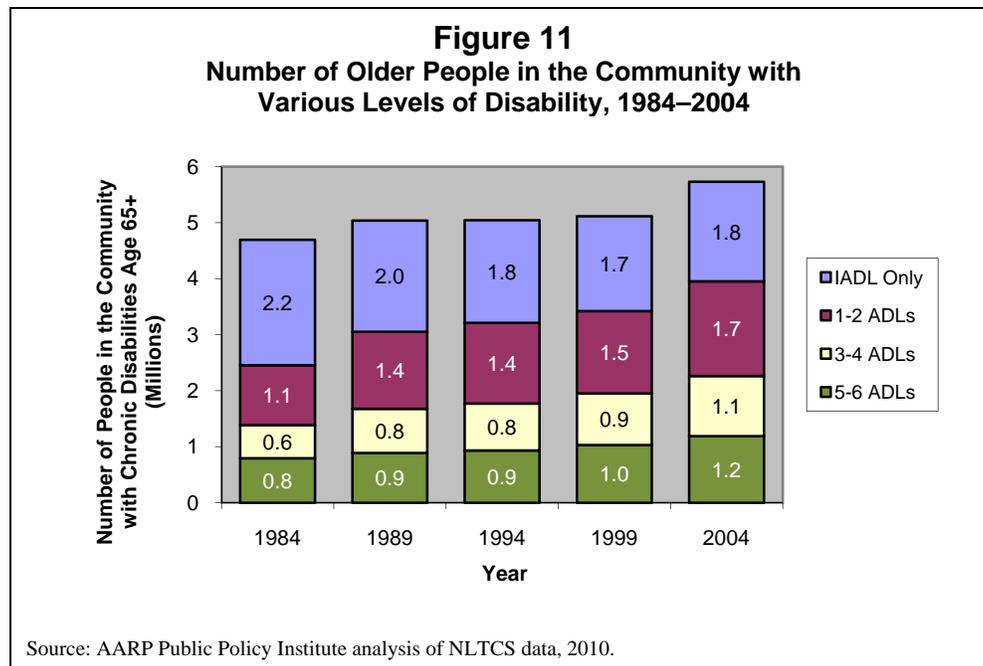
The number of older persons with two or more ADL disabilities in the community increased by two-thirds, or by nearly 1.2 million people, between 1984 and 2004.



DATA HIGHLIGHTS

- *The percentage of older persons with two or more ADL disabilities living in the community increased from 57.5 percent in 1984 to 69.5 percent in 2004.* Among all older persons with any level of disability, the percentage living in the community increased from 75 percent in 1984 to 80 percent in 2004.
- Reflecting the decline in those reporting only IADL disabilities, 52.1 percent of the older population with disabilities in the community reported two or more ADL disabilities in 2004—up from 38.2 percent in 1984.
- In 1984, 1.4 older persons with two or more ADL disabilities were in the community for every person in an institution at that level of disability; by 2004, that ratio had increased to 2.3.

Because fewer older people with high levels of disabilities are in institutional settings, the older population in the community has higher levels of ADL disabilities.



While the number older persons with a disability living in institutions decreased between 1984 and 2004, the total number of community-dwelling older persons with a disability increased dramatically. Among all older persons with a disability—

- the number living in institutions declined by 7.8 percent (see table A2 in the appendix); and
- the number living in the community increased by more than 1 million—from 4.7 million to 5.7 million—a relative increase of 22 percent.

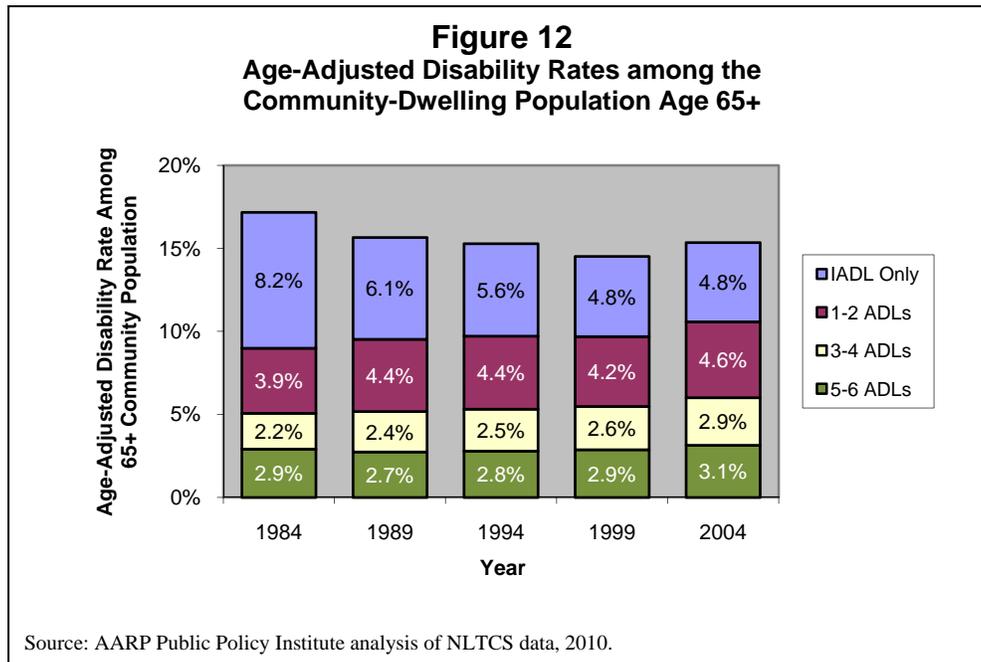
Focusing on the older population with two or more ADL disabilities between 1984 and 2004 (see table A10 in the appendix)—

- the number in institutions remained essentially unchanged; and
- the number in the community increased by two-thirds, from 1.8 million to 3.0 million.
- The divergence is particularly notable beginning in 1994 (see figure 10 above), as the community population continued to increase while the institutional population, which had also been increasing, began to decline.

The number of older persons in the community reporting ADL disabilities increased dramatically at all levels of disability between 1984 and 2004— by 58 percent for one to two ADL disabilities, 82 percent for three to four ADL disabilities, and 50 percent for five to six ADLs. This finding is consistent with the finding in Trend 2 that institutional rates declined for all levels of disability, especially three to four ADL disabilities. The

number of older persons in the community reporting IADL-only disabilities declined by 21 percent over the twenty years of the NLTCs.

Rates of all levels of ADL disabilities have increased gradually in the older community population, as illustrated in figure 12. In part because of the sharp decline in IADL-only disability, 52.1 percent of all older persons with disabilities in the community reported two or more ADL disabilities in 2004—up from 38.2 percent in 1984.



Both the absolute number and (except for transferring) the percentage of older persons living in the community increased for each of the six specific ADL disabilities between 1999 and 2004 (see table 2). The number of older persons in the community with any ADL disability increased by 15 percent, with the largest increases related to toileting, bathing, and getting around in the house.

ADL	1999		2004		% Change 1999–2004
	Number with ADL disability	Percentage of 65+ population	Number with ADL disability	Percentage of 65+ population	
Bathing	3,313,455	10.3%	3,950,369	11.7%	+19%
Getting Around Inside	2,904,813	9.0%	3,420,998	10.1%	+18%
Toileting	2,116,308	6.6%	2,623,508	7.8%	+24%
Transferring	2,275,558	7.1%	2,396,391	7.1%	+5%
Dressing	1,396,692	4.3%	1,613,480	4.8%	+16%
Eating	817,816	2.5%	939,749	2.8%	+15%
Any ADL	3,423,651	10.7%	3,953,162	11.7%	+15%

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

Growth in the older population living in the community with disabilities was especially strong among the oldest age groups.

Increases in the numbers of older persons with disabilities living in the community have not been evenly distributed among all segments of the older population. As table 3 indicates, growth in the population with two or more ADL disabilities was particularly strong among—

- the oldest age categories;
- older women;
- those who were widowed or otherwise unmarried; and
- those living alone.

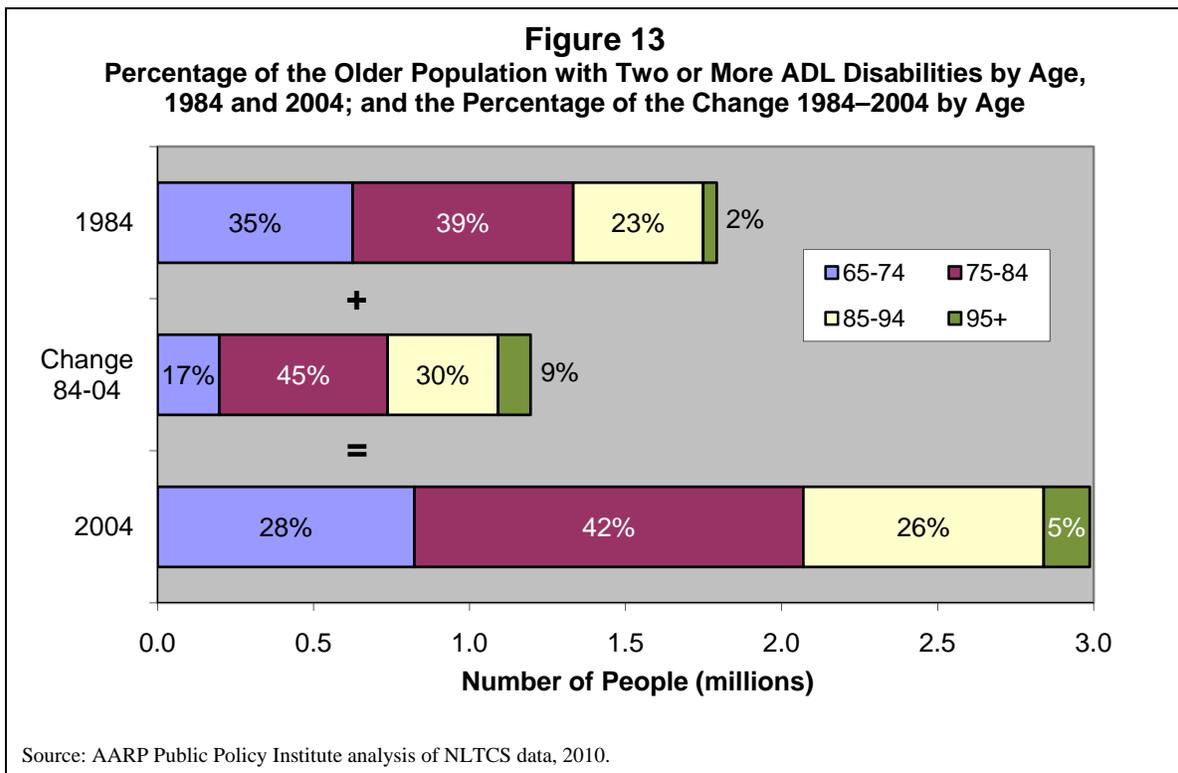
Table 3			
Number and Percentage Increase of Older Population with Two or More ADL Disabilities Living in the Community by Social Characteristics, 1984, 2004, and 1984–2004			
	1984	2004	Increase 1984–2004
Community two or more ADLs	1,791,927	2,987,361	+67%
Age			
65–74	625,088	823,154	+32%
75–84	706,859	1,246,042	+76%
85–94	416,657	770,818	+85%
95+	43,323	147,347	+240%
Gender			
Male	638,191	926,621	+45%
Female	1,153,737	2,060,740	+79%
Marital status			
Married	813,692	1,131,132	+39%
Widowed	824,563	1,494,743	+81%
Unmarried	153,672	361,487	+135%
Living Alone	437,054	1,057,385	+142%
With Others	1,354,874	1,929,976	+42%
Source: AARP Public Policy Institute analysis of NLTC data, 2010.			

To give a full picture of how these trends differ for different subgroups of the older population, the following sections present trend data in three different ways in table 3 and in figures 13, 18, 23, and 24 below. The analyses focus on the population with two or more ADL disabilities, both because this level is often used to determine eligibility for various public and private benefits and because declining numbers of respondents reporting only IADL disabilities tend to obscure important trends in ADL disability. The role of age in figure 13 illustrates the three types of trend analyses.

1. *The percentage growth between 1984 and 2004 in the older population with two or more ADL disabilities living in the community with a given set of characteristics.* The population age 95+ grew by 240 percent (albeit from a very small base), the 85–94

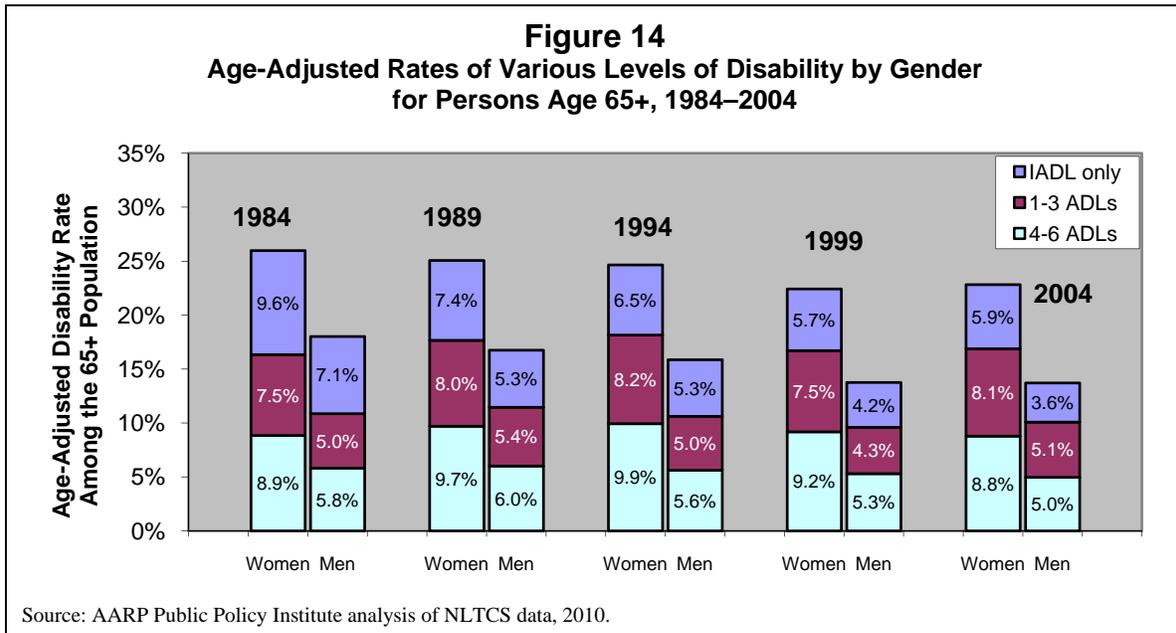
age group grew by 85 percent; the 75–84 age group grew by 76 percent; and the 65–74 age group grew by a comparatively small 32 percent (see table 3).

2. *The distribution of characteristics in the older population with two or more ADL disabilities living in the community in 1984 and 2004.* The 85+ age group rose from 25 percent to 31 percent; the 65–74 age group declined from 35 percent to 28 percent (see figure 13, comparing the top and bottom bars).
3. *The percentage of the growth in the older population with two or more ADL disabilities living in the community that can be attributed to a given characteristic.* Forty-five percent of the growth was among the 75–84 age group, and 39 percent was among the 85+ age group (see figure 13, middle bar).



TREND #4: THE GENDER GAP IN DISABILITIES IS GROWING

Rates of disability and institutional use both remained higher among older women in 2004 than they had been among older men twenty years earlier, but growth in the number older persons living in the community with disabilities has been heavily concentrated among women.



DATA HIGHLIGHTS

- Older women were 1.75 times as likely to have a disability and 2.2 times as likely to be in an institution as older men in 2004.
- *The age-adjusted disability rate declined twice as rapidly among older men (by 24 percent) as among older women (by 12 percent).*
- IADL-only disabilities declined substantially among both men and women, but ADL disabilities declined slightly only among men while increasing slightly among older women.
- Age-adjusted rates of institutional usage declined by 38 percent among men and by 33 percent among women.
- Of the total growth in the older population living in the community with two or more ADL disabilities, 76 percent was due to the increase among women.

Disability rates have been lower and have declined more among older men than among older women.

Disability rates have always been lower for older men, and they declined more among men than among women between 1984 and 2004. When age-adjusted to the 1984 population, the percentage of men reporting any disability declined from 18.0 percent in 1984 to 13.7 percent in 2004, a relative decline of 24 percent. Among women, the age-adjusted rate declined from 26.0 percent to 22.8 percent, a relative decline of 12 percent.

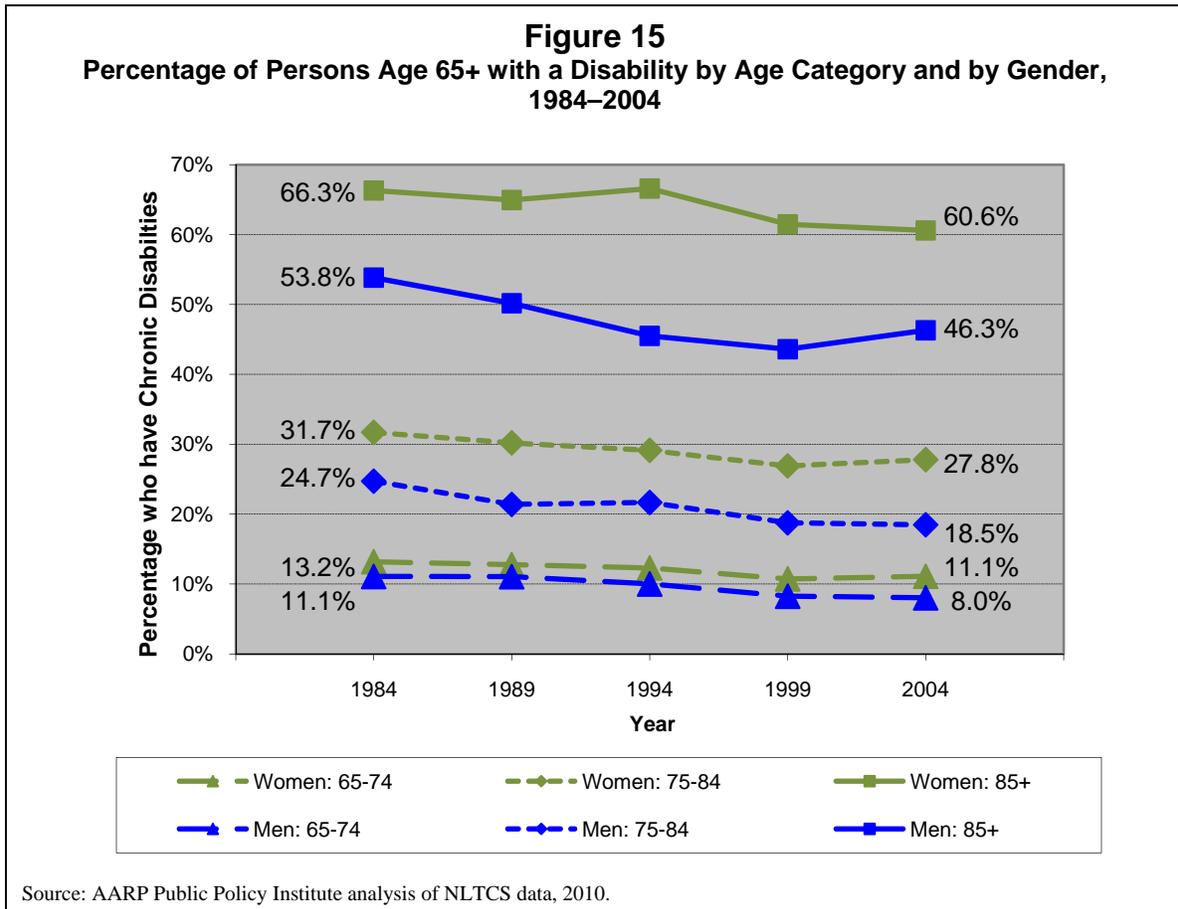
Table 4						
Age-Adjusted Rates of Having Any Disability and of Being in an Institution among Respondents Age 65+ with a Disability by Gender, 1984–2004						
	1984	1989	1994	1999	2004	Change 1984–2004
Men						
Disability rate	18.0%	16.8%	15.9%	13.8%	13.7%	-24%
% of disabled in institutions	19.6%	24.5%	24.5%	20.2%	15.9%	-19%
Total institutional	3.5%	4.1%	3.9%	2.8%	2.2%	-38%
Women						
Disability rate	26.0%	25.1%	24.7%	22.4%	22.8%	-12%
% of disabled in institutions	27.2%	29.6%	29.0%	24.5%	20.7%	-24%
Total institutional	7.1%	7.4%	7.2%	5.5%	4.7%	-33%

Source: AARP Public Policy Institute analysis of NLTC data, 2010.

As shown in figure 14, IADL-only disabilities declined substantially for both genders between 1984 and 2004—by 38 percent among older women (from 9.6 percent to 5.9 percent) and by 49 percent among older men (from 7.1 percent to 3.6 percent). However, ADL disabilities declined only among men.

- Among women, the age-adjusted percentage reporting one to three ADL disabilities actually increased from 7.5 percent to 8.1 percent (and to 8.6 percent in unadjusted terms); the age-adjusted percentage reporting four to six ADL disabilities returned to the 1984 level (8.9 percent) in 2004 (8.8 percent) after increasing in the intervening years.
- Among men, the age-adjusted percentage reporting one to three ADLs rose slightly from 5.0 percent to 5.1 percent (and to 5.5 percent in unadjusted terms). The age-adjusted percentage reporting four to six ADL disabilities declined from 5.8 percent to 5.0 percent.
- The number of older men with two or more ADL disabilities rose by 30 percent during the twenty years of the NLTC, and the number of older women with two or more ADL disabilities rose by 41 percent.

The gender gap in disability rates widens with advancing age.

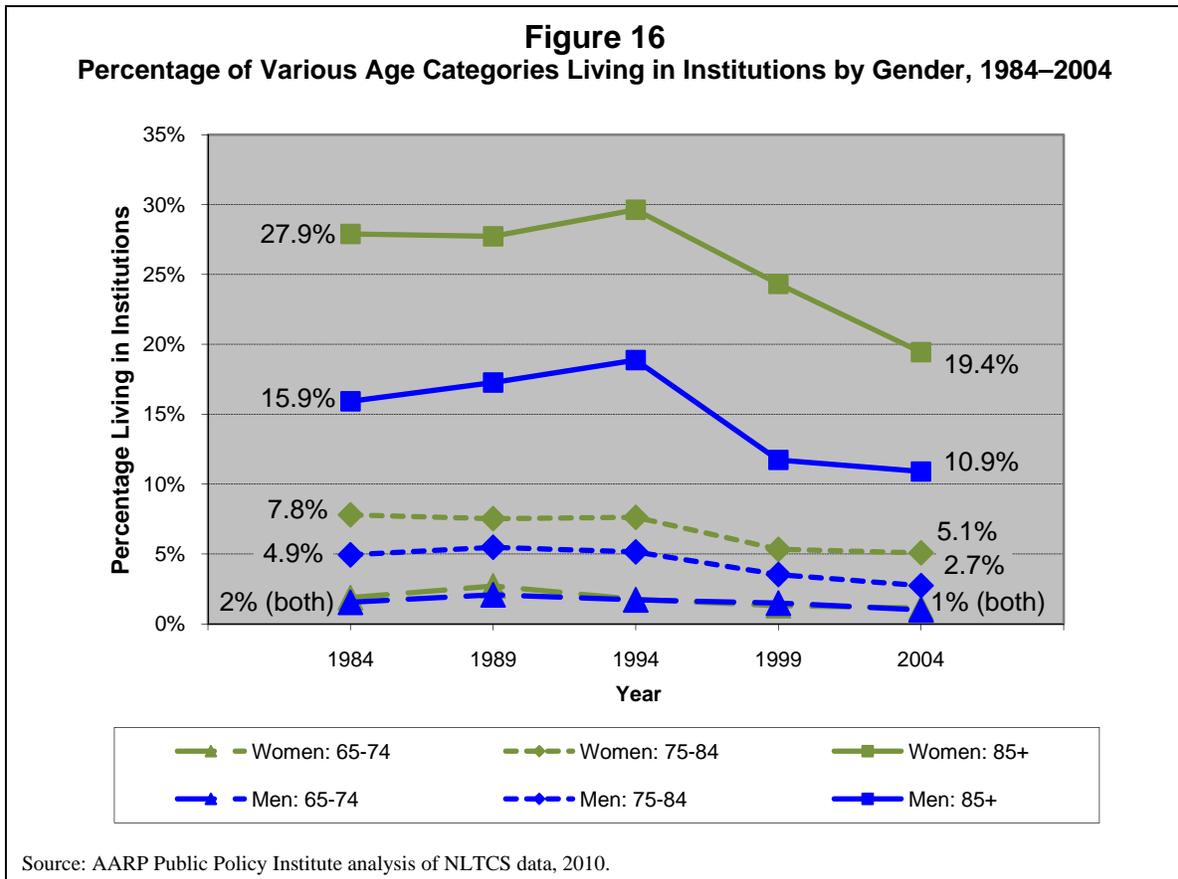


The disability trend lines at different ages in figure 15 show how the percentage gap between men and women grows larger at older ages. Moreover, the gap has grown wider in each age group over the twenty years of the NLTCS.

- Among respondents age 65–74, the gap between men and women grew from 2.1 percent in 1984 to 3.1 percent in 2004.
- Among those aged 75–84, the gender gap grew from 7.0 percent in 1984 to 9.3 percent in 2004.
- Among those aged 85+, the gender gap grew from 12.5 percent in 1984 to 14.3 percent in 2004.

Even though overall rates decreased among men and women in each of the age categories, disability rates for women age 65–74 in 2004 had only come down to where they were in 1984 for men. For women age 75+, disability rates remained higher in 2004 than they had been for men of the same ages twenty years earlier.

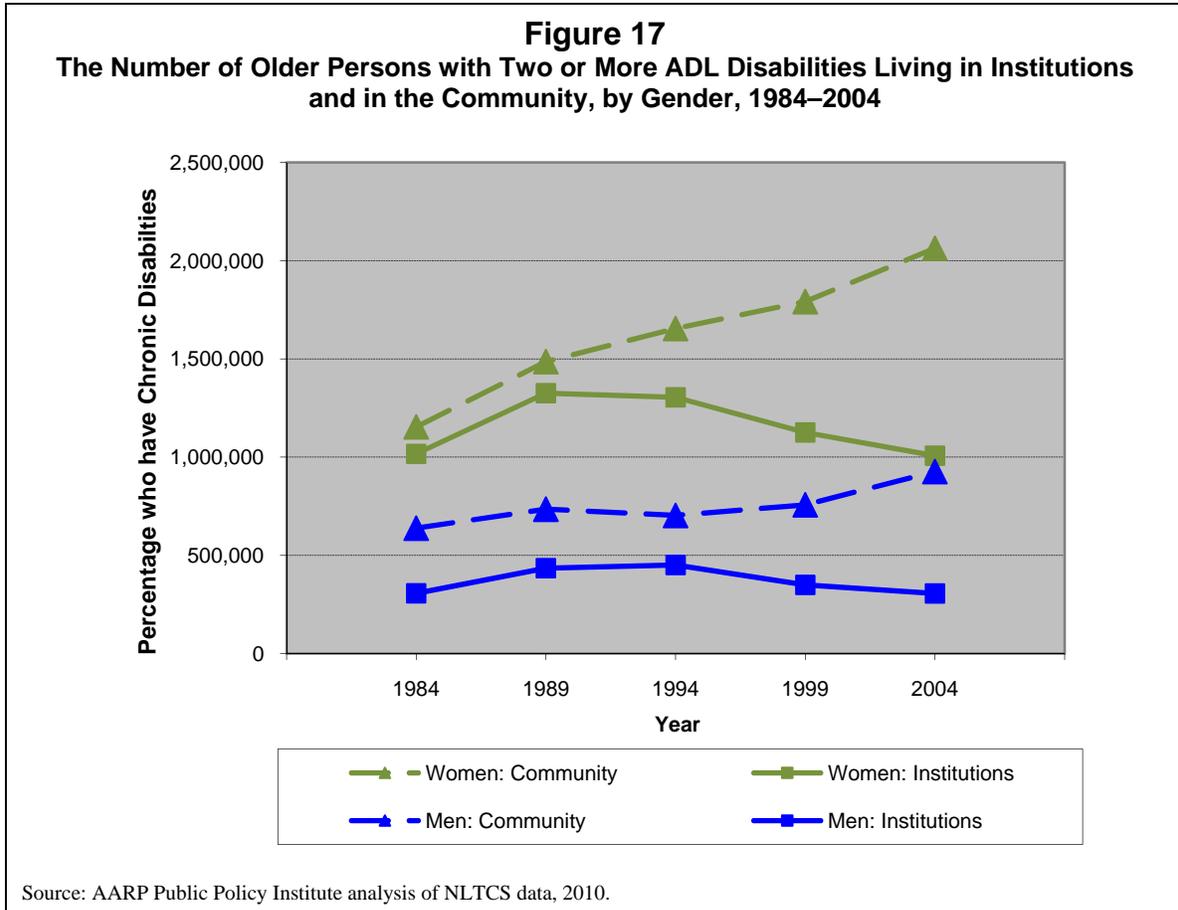
Institutional use has declined at all ages among both men and women, though it has remained consistently higher among women than men at ages 75+.



As figure 16 shows, declines in institutional use have been particularly dramatic since 1994 among men and women age 85+. The number of institutional residents declined among both men and women between 1984 and 2004 despite substantial increases in the older population among both genders. The population of older men increased by 36 percent between 1984 and 2004, but the number of older men in institutions decreased by 8 percent during that time. Similarly, the number of older women increased by 24 percent, but the number in institutions decreased by 8 percent. Age-adjusted rates of institutional usage declined by one-third or more for both men (-38 percent) and women (-33 percent).

Among older men with a disability, the rate of institutional use was 19.6 percent in 1984 and 16.3 percent in 2004. Among older women with a disability, the rates of institutional use were 27.2 percent in 1984 and 21.5 percent in 2004. Once again, despite substantial declines in the use of institutions among both older women and men with disabilities, the rate still remained higher in 2004 among older women with disabilities than it was for men twenty years earlier (see table 5 below).

The trend from institutional to community settings among the older population with disabilities has been most pronounced among older women—three-fourths of the growth among those living in the community with two or more ADL disabilities was among women.

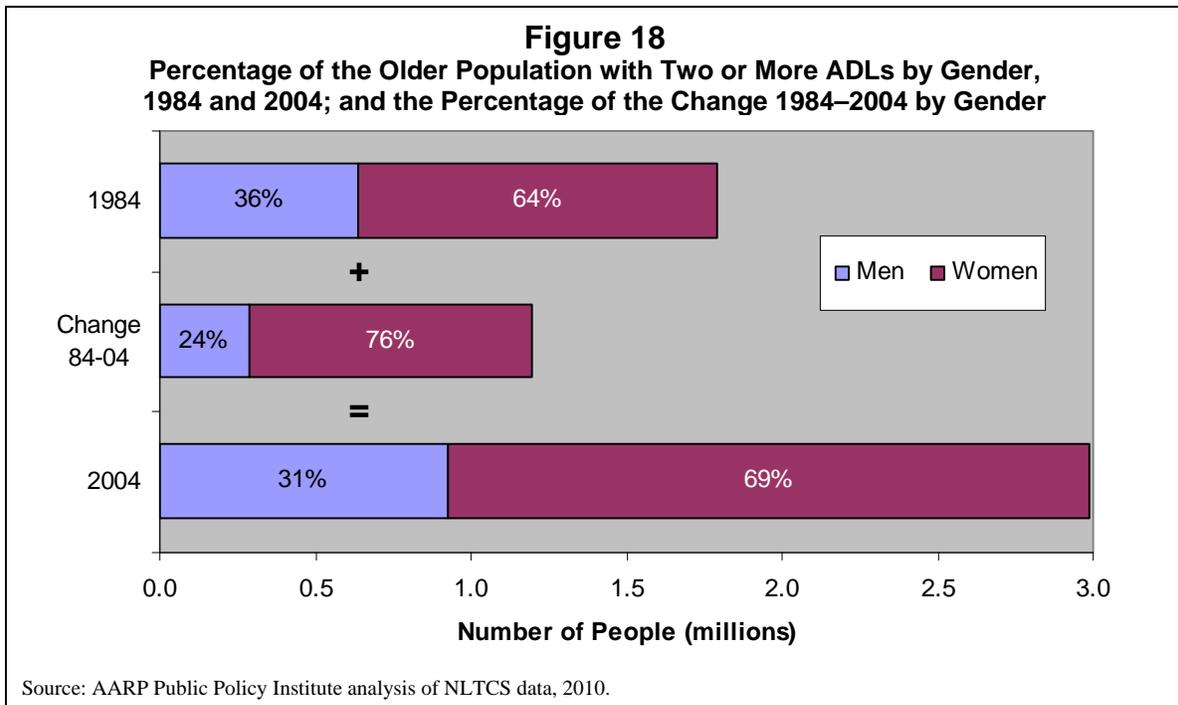


The trend from institutions to the community among older persons with disabilities has overwhelmingly been among women. Although the basic trends have been similar among men and women, both the sheer numbers and the intensity of the trend have been more dramatic among women. Between 1984 and 2004, the number of older women with two or more ADL disabilities in the community increased by 79 percent for women compared to 45 percent for men (see table A10 in the appendix). The number of people in institutions has followed a similar pattern for both older men and women with two or more ADL disabilities, rising from 1984 to a peak in 1989–1994 and then returning to 1984 levels in 2004. For the full 1984–2004 period, the institutional population declined by less than 1 percent for both men and women with two or more ADL disabilities.

Because of greater longevity and higher rates of disabilities, the number of older women in the community with disabilities has always exceeded the number of men, even though older women with disabilities have had a higher likelihood of being in an institution. The trend from institutional to community settings has increased the gender disparity in the

numbers of older people living in the community with two or more ADL disabilities. As figure 18 shows—

- The share of the older population with two or more ADL disabilities living in the community who were men decreased from 36 percent in 1984 to 31 percent in 2004 (compare the top and bottom bars).
- Of the total growth in the older population living in the community with two or more ADL disabilities, 76 percent was due to the increase among women (see the middle bar).



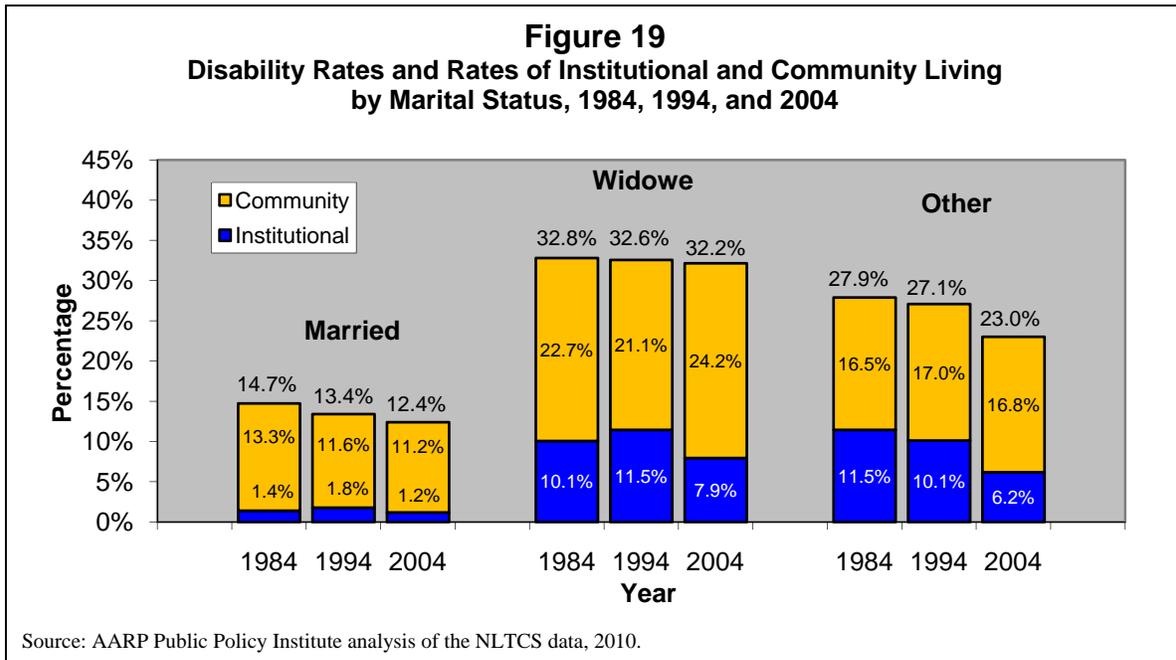
In contrast to the widening gender gap in disability rates, the gender gap has narrowed significantly with respect to the ability to remain in the community with a disability, from 14.4 percent in 1984 to 8.0 percent in 2004 (see table 5). In 1984, only 53.2 percent of older women with two or more ADL disabilities were able to live in the community. By 2004, that proportion had risen to 67.2 percent.

% in Community	1984	1989	1994	1999	2004	% Change 1984–2004
Men	67.5%	62.8%	61.0%	68.4%	75.2%	+11%
Women	53.2%	52.9%	55.9%	61.4%	67.2%	+26%
Gender Gap	14.4%	10.0%	5.0%	7.0%	8.0%	-44%

Source: AARP Public Policy Institute analysis of NLTCS data, 2010 (data are not age-adjusted).

TREND #5: MARRIED PERSONS ARE LESS LIKELY TO HAVE A DISABILITY OR LIVE IN INSTITUTIONS

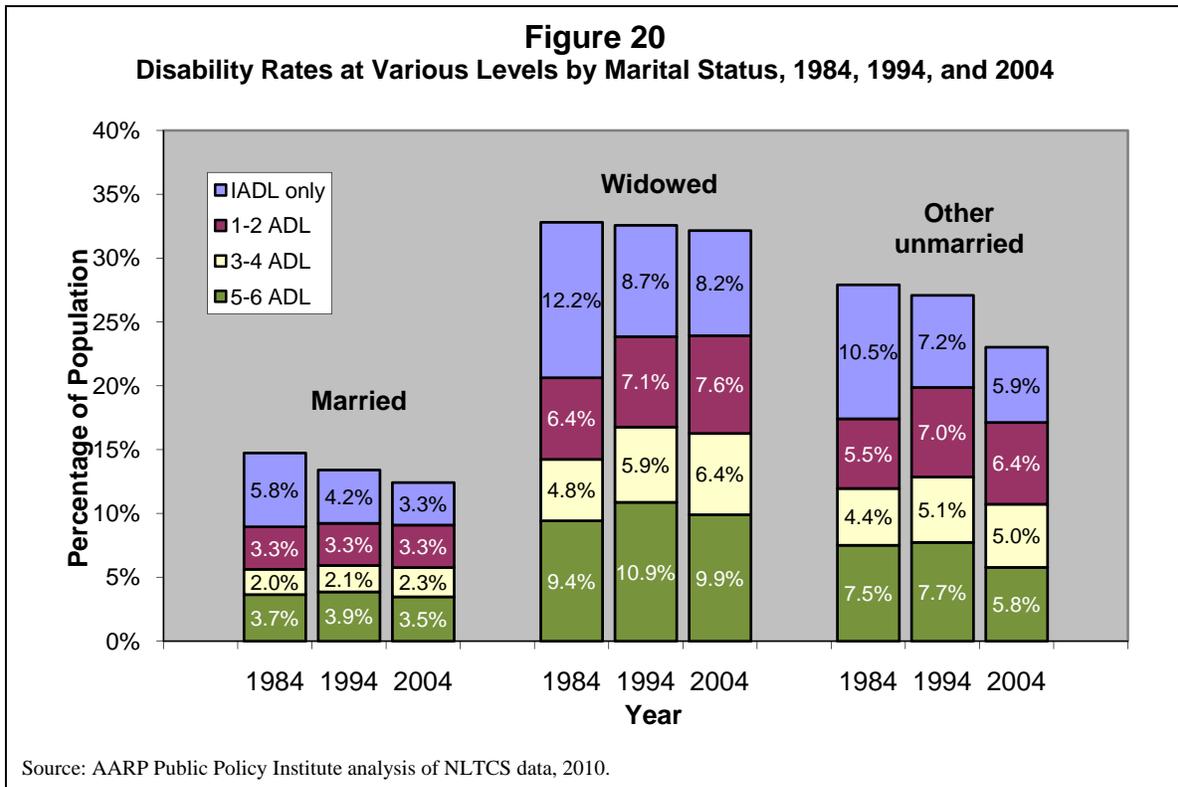
But institutional use is declining more rapidly among those who are widowed or otherwise unmarried.



DATA HIGHLIGHTS

- Disability rates were much lower for married persons than for those who were widowed or otherwise unmarried (divorced, never married) in all NLTC waves.
- IADL-only disabilities declined for all marital statuses. ADL disability rates stayed about the same for married persons, increased among widowed persons, and were mixed among persons who were otherwise unmarried.
- Among respondents who reported two or more ADL disabilities, between 1984 and 2004 the rate of institutional use declined—
 - From 18.5 percent to 15.3 percent among those who were married,
 - From 52.0 percent to 36.8 percent among those who were widowed, and
 - From 61.4 percent to 40.7 percent among those who were otherwise unmarried.
- *More than half (56 percent) of the total increase in the number of older persons in the community with two or more ADL disabilities was among those who were widowed.*

Disability rates were consistently much lower among older persons who were married than among those who were widowed or otherwise unmarried.

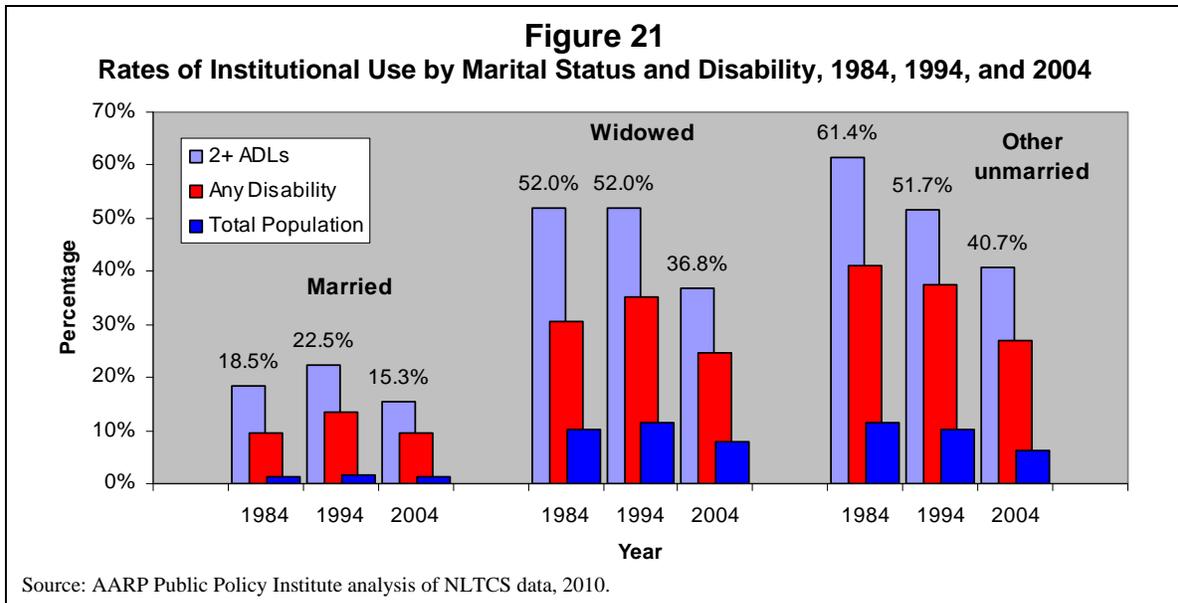


Despite the skewing of the growth in the older population toward the oldest age groups, the percentage of NLTCS respondents who were widowed decreased somewhat, from 37.3 percent in 1984 to 34.0 percent in 2004, while the percentage who were married rose slightly, from 52.4 percent to 53.9 percent. Disability rates were much lower for married respondents than for widowed or other unmarried respondents (including those who were divorced or never married), a pattern that held across the twenty-year period.

Between 1984 and 2004, IADL-only disabilities declined in all three marital statuses, but there were significant differences in ADL disabilities (see figure 20; see also table A8 in the appendix for more detailed numbers). The rates of two or more ADL disabilities changed little among married respondents (about 7 percent in both 1984 and 2004) and unmarried respondents (about 14 percent in both 1984 and 2004), while the rate increased from 16.8 to 19.8 percent among widowed people.

In part, the increases in ADL disability rates among widows are likely due to the fact that widowhood is occurring at older ages. According to census data, rates of widowhood declined among both men and women and among all age groups between 1984 and 2004. Women age 65–74 saw a particularly large decline, from 39.1 percent to 28.8 percent, while rates among women age 75+ decreased from 66.9 percent to 58.8 percent. Rates of widowhood were much lower and declined less among older men (U.S. Census Bureau 2010).

Despite the fact that ADL disabilities were generally flat or even increased, rates of institutional use declined among each marital status—especially among those widowed or not married.

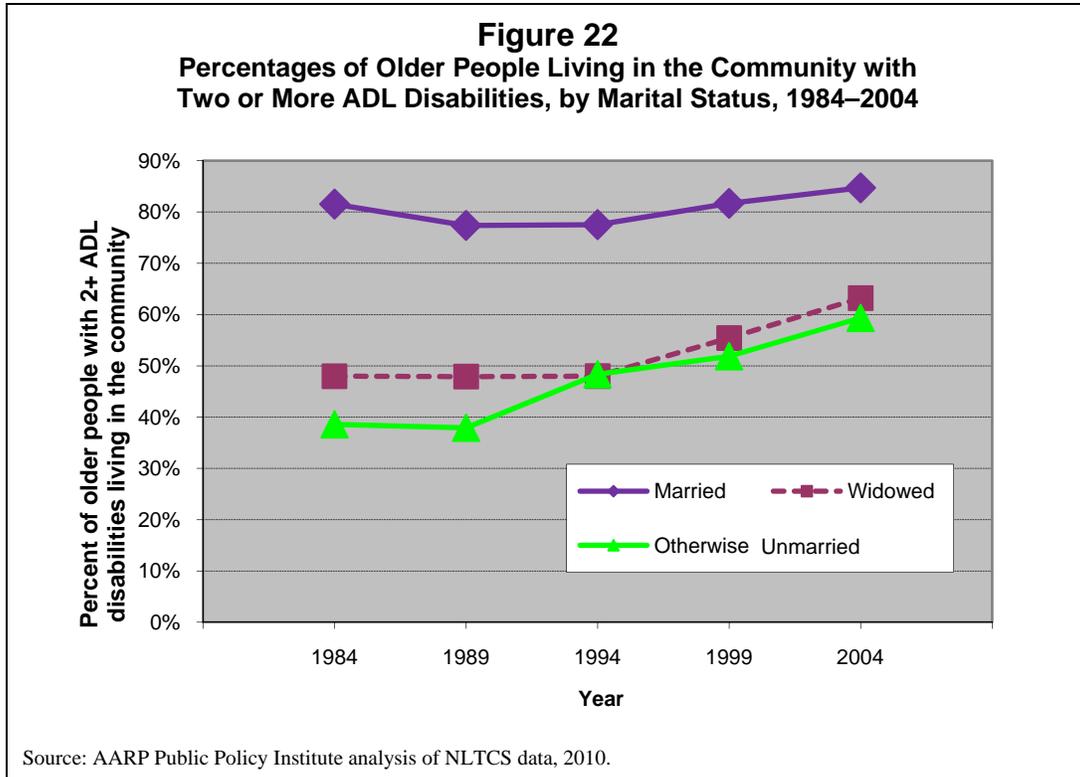


Institutional use declined slightly because of the declining rate of widowhood, but a bigger factor was the declining use of institutions among those who were widowed or otherwise unmarried (see table A9 in the appendix). The decline in institutional use was most striking among respondents who were not married; the rate of institutional use in this group was nearly cut nearly in half between 1984 and 2004 (-46 percent).

Among respondents who reported two or more ADL disabilities, between 1984 and 2004 the rate of institutional use declined—

- From 18.5 percent to 15.3 percent among those who were married,
- From 52.0 percent to 36.8 percent among those who were widowed, and
- From 61.4 percent to 40.7 percent among those who were otherwise unmarried.

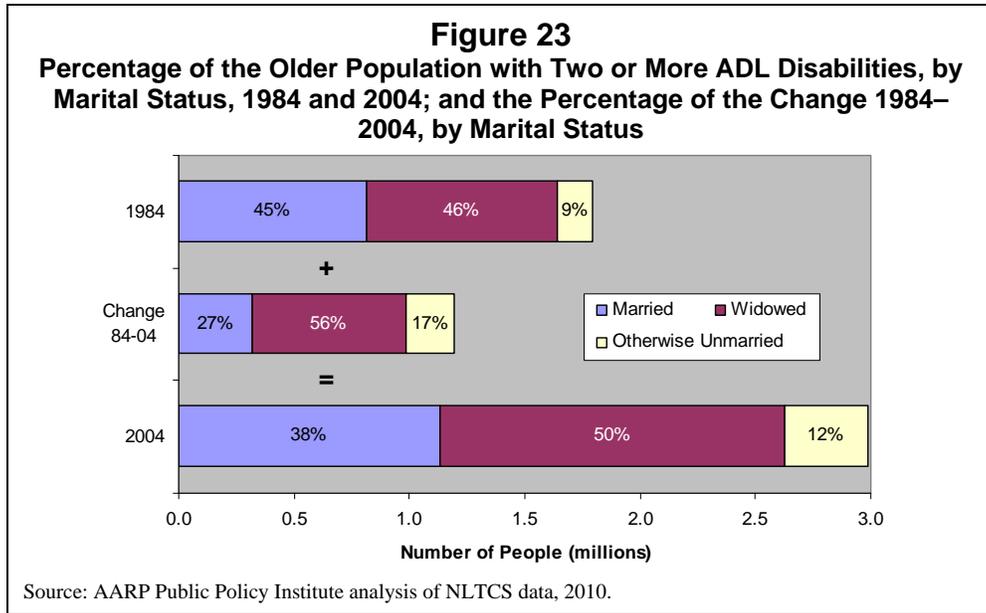
The increase in older persons with disabilities living in the community was particularly dramatic among the widowed and those otherwise unmarried, leading to an increasing share of older persons with disabilities living alone.



Much higher percentages of married persons were able to live in the community with two or more ADL disabilities in 2004 (84.7 percent) throughout the entire twenty-year period. But increasingly, those who were widowed or otherwise unmarried were also able to live in the community at a level of acuity often identified as eligible for institutional care. The number of persons with two or more ADL disabilities age 65+ in institutions remained fairly constant between 1984 and 2004 for all marital statuses. In contrast, the number residing in the community increased dramatically, especially among respondents who were widowed (+81 percent) or otherwise unmarried (+135 percent). The number of older married persons with two or more ADL disabilities increased by a relatively modest 39 percent (see table A11 in the appendix for more detailed numbers).

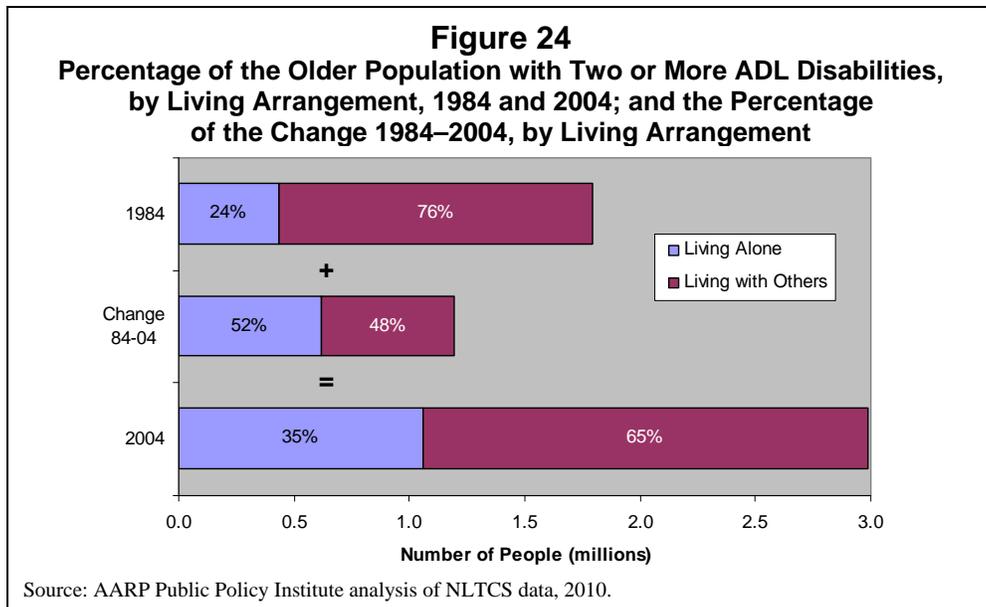
In 1984, the number of the older married people living in the community with two or more ADL disabilities was roughly the same as the number who were widowed. The trends since then have resulted in a community-dwelling population with disabilities that was much more likely to be widowed or otherwise unmarried in 2004 (see figure 23):

- The percentage who were married declined from 45 to 38 percent, while those who were widowed increased from 45 to 50 percent and those who were otherwise unmarried increased from 9 to 12 percent (compare the top and bottom bars).
- More than half (56 percent) of the total increase was among those who were widowed (see the middle bar).



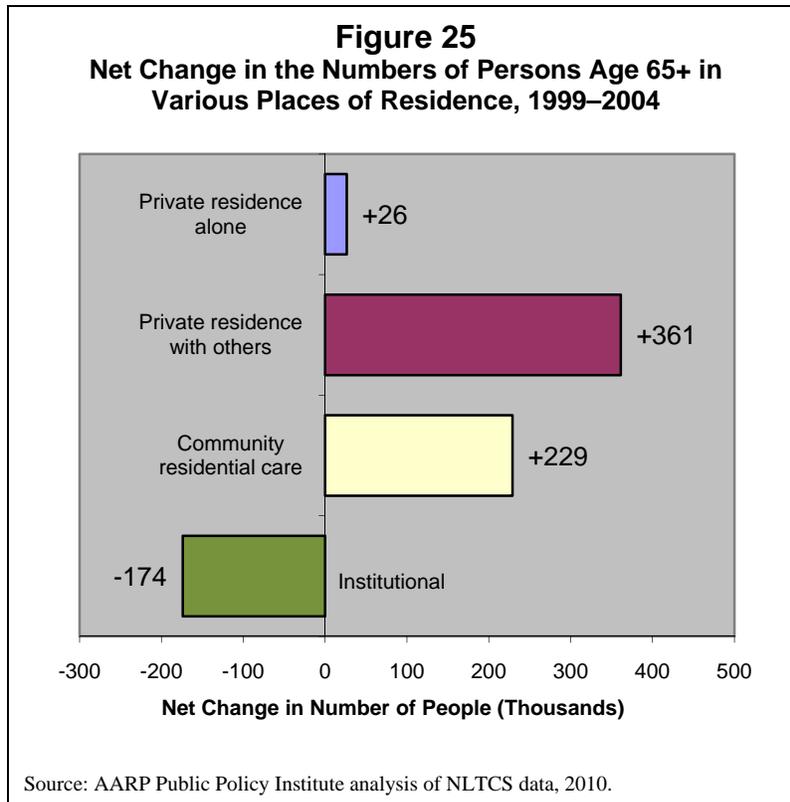
With respect to trends in living arrangements among the community-dwelling older population with two or more ADL disabilities between 1984 and 2004—

- The number living alone increased by 142 percent, compared to an increase of 42 percent among those living with others (see table 3 above).
- The percentage living alone increased from 24 to 35 percent (see figure 24; compare the top and bottom bars).
- Most of the increase in the community-dwelling population with disabilities (52 percent) was among those living alone (see figure 24, middle bar).



TREND #6: THE GROWTH IN ASSISTED LIVING HAS BEEN A SIGNIFICANT FACTOR IN THE SHIFT FROM INSTITUTIONAL TO COMMUNITY SETTINGS

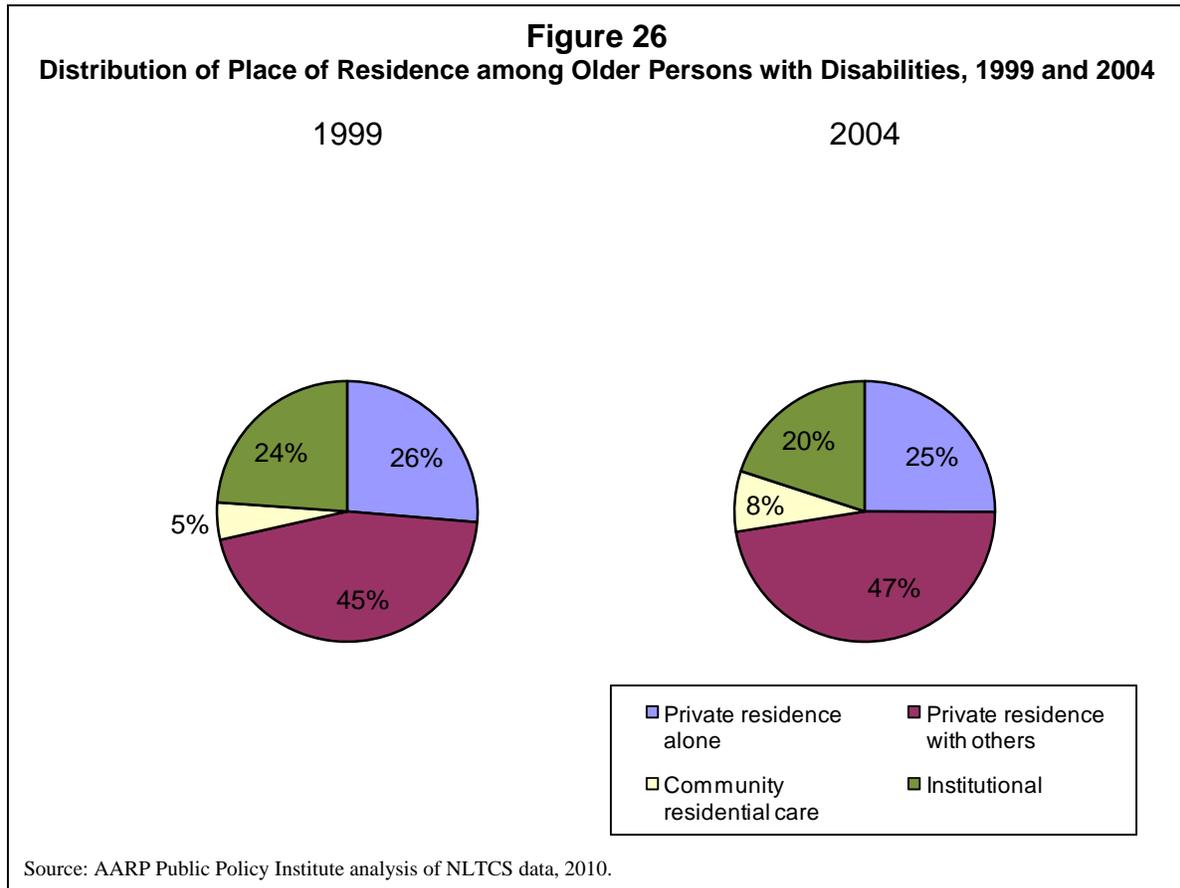
The decline in the number of older persons with disabilities in institutions is exceeded by the growth in the number of persons with disabilities in community residential care facilities such as assisted living.



DATA HIGHLIGHTS

- The number of older persons in the institutions declined by 174,000 (11 percent) between 1999 and 2004, even though this number includes some assisted living residents who received nursing services.
- In contrast, the number of older persons with disabilities in community residential care facilities increased from 310,000 to 539,000 (74 percent) during the same period.
- The number of older persons with disabilities living in a private residence with others increased by 361,000 (12 percent), which may be partly due to declining rates of widowhood.

Where do older persons with disabilities live?



Figures 25 and 26 summarize recent shifts in where older people with disabilities live (see also table A12 for more detailed numbers). The increase in the number of older people with disabilities living in community residential care facilities offset the decline in the institutional population between 1999 and 2004—an indication that assisted living may be replacing nursing home care for a segment of the older population with disabilities in recent years.

The growth in residential care such as assisted living is also documented by the changes in the numbers of older people in various settings. The number of older people with a chronic disability increased by 6.6 percent between 1999 and 2004, while the number with disabilities in community residential care increased by 74 percent. The number of older persons with chronic disabilities in various living arrangements changed by the following percentages (see table A12 for more detailed data):

- Private residence alone: increased by 1.5 percent
- Private residence with others: increased by 12 percent
- Community residential care setting: increased by 74 percent
- Institutional: decreased by 11 percent

The Definition of “Assisted Living” Reflects the Blurring of The Distinction Between “Institutional” and “Community” Settings of Care

As noted above, the NLTCs used two different survey questionnaires for residents in assisted living; those receiving “substantial nursing of any kind” were assigned to an institutional interview, and those who did not receive such assistance were assigned to a community interview. Roughly a quarter (23 percent) of assisted living residents were characterized as living in institutions in 1999 using this definition, representing 11 percent of the NLTCs institutional population. Those who received the community survey are characterized as living in “community residential care” settings, along with persons in other group settings such as personal care homes where there is no health care professional on duty daily. As one further complication, more than a third of the residents in “community residential care” facilities reported no disabilities in both 1999 and 2004. In this report, we looked only at the population that reported disabilities.

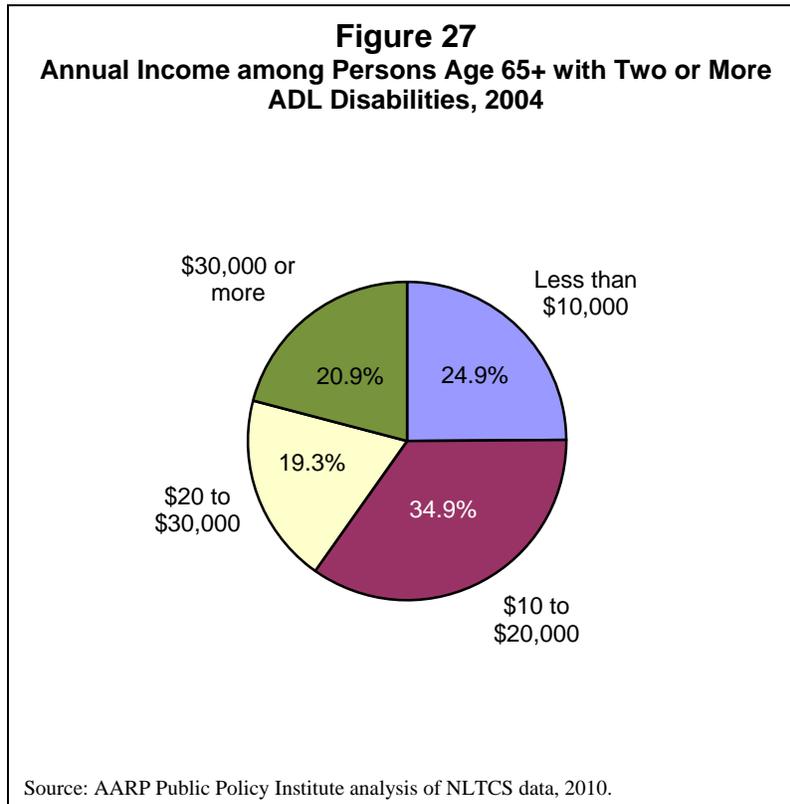
Besides these definitional and measurement issues in the NLTCs, the increasing diversity of service options defies easy categorization into traditional service types. No one standard definition exists for “assisted living,” a service option that, unlike nursing homes, is regulated and thus defined only at the state level. But the whole array of long-term services and supports (LTSS) is undergoing major changes. For example, an industry survey with a narrower definition of “assisted living” than the NLTCs found that almost 85 percent of such settings had a licensed nurse (registered nurse or licensed professional nurse) available on site for more than eight hours a day, and 27 percent had a licensed nurse available 24 hours a day (AAHSA et al. 2009). Given the growth in assisted living and the increasing availability of nursing services in such settings, it is likely that a growing segment of the institutional population as defined by the NLTCs is made up of assisted living residents.

Partly in response to the competition from assisted living, a growing number of nursing homes are changing their cultures of care to be more consumer-centered and their physical settings to be more residential. Even though they are licensed as nursing homes, Green Houses® with private rooms in small cottages whose dominant architectural features are a hearth at one end and a country kitchen at the other may be less “institutional” in feel than a large assisted living facility with shared rooms and substantial nursing services. At the other end of the spectrum, unlicensed housing settings serving older populations are increasingly making health-related and other supportive services available on site.

In short, assisted living not only stands at the intersection of institutional and community services, but the increasingly diverse array of housing and service options available to older persons with disabilities is beginning to challenge traditional ways of distinguishing between institutional and community settings. These changes in the marketplace of services present research challenges, as noted in the difficulties of characterizing assisted living in the NLTCs. More important, they present some of the most significant public policy challenges related to the future of the regulation of and reimbursement for LTSS.

TREND #7: GROWING NUMBERS OF OLDER PERSONS LIVING IN THE COMMUNITY WITH DISABILITIES HAVE LOW INCOMES

Three out of five older persons living in the community with two or more ADL disabilities reported annual incomes of less than \$20,000, roughly the individual income eligibility standard for Medicaid assistance in most states in 2004.

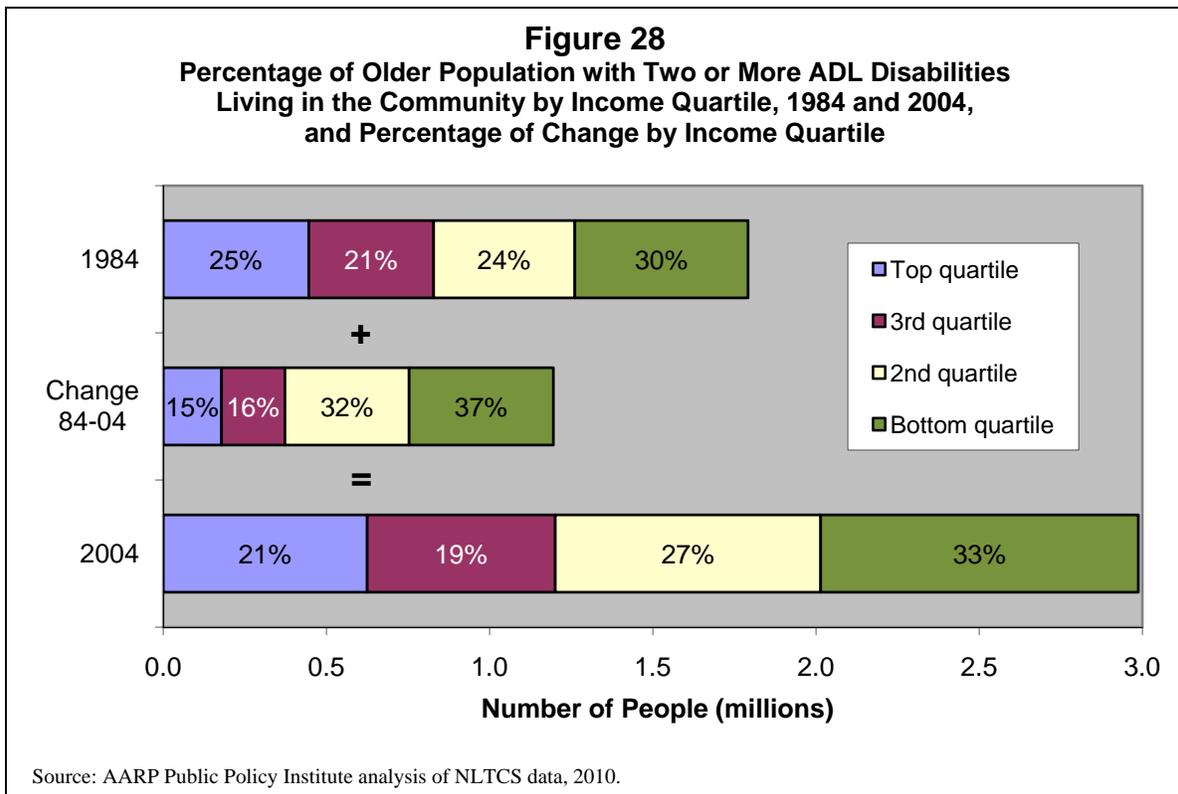


DATA HIGHLIGHTS

- Thirty-seven percent of the growth in the number of older persons living in the community with two or more ADL disabilities was among those in the lowest income quartile.
- In 2004, 25 percent older persons with two or more ADL disabilities living in the community reported annual incomes of less than \$10,000; only 21 percent reported an income of more than \$30,000.
- By way of comparison, the 2004 income eligibility standard in most states for LTSS paid for under the Medicaid home and community-based services waiver program was \$20,304 for individuals and \$30,456 for couples.

Growth in the older community-dwelling population with disabilities was heavily weighted toward the bottom half of the income quartile rankings.

Because eligibility for public assistance for LTSS under the Medicaid program is determined by income as well as disability, trends related to the income levels of older persons with disabilities are of particular interest to policymakers. As figure 28 indicates, 69 percent of the growth in the older population living in the community with two or more ADL disabilities was among those in the bottom two income quartiles—37 percent was due to increases in the lowest income quartile (see table A13 in the appendix for more detailed numbers).



Data on specific income levels of respondents living in the community with disabilities in 2004 (see figure 27 above; see also table A14 in the Appendix for more detailed numbers) confirm the heavy concentration at the lowest income levels. One in every four (24.9 percent) older persons with two or more ADL disabilities living in the community reported annual incomes of less than \$10,000, whereas only 20.9 percent reported incomes in excess of \$30,000 per year. To put those income levels into context, the 2004 income eligibility standard in most states for LTSS under the Medicaid waiver program (300 percent of the Supplemental Security Income payment standard) was \$20,304 in for individuals and \$30,456 for couples. While stringent asset limits also apply to Medicaid eligibility, clearly the great majority of older persons with two or more ADL disabilities would be eligible in terms of income and disability and are at risk of spending down their financial assets to qualify for needed services.

CONCLUSION

The National Long-Term Care Survey provides an important look at changes in disabilities and the use of institutional care over an important twenty-year period of time that saw major changes in the delivery of services as well as public policies related to long-term services and supports. Data from the NLTCs provide insight on the degree to which these changes have altered the experiences of older persons with disabilities. The data show that, even at the highest levels of disability, increasing majorities of older persons with chronic disabilities now receive services in community settings rather than institutions. The substantial declines in institutional use documented by these data indicates some success in efforts to provide alternatives to older people, who almost uniformly desire to stay in their communities and receive services rather than relocating to an institutional environment. Moreover, declining institutional use has undoubtedly resulted in substantial savings to the Medicaid program, which funds nursing home care for most residents.

While the NLTCs shows dramatic declines in the number and percentage of older people reporting only IADL disabilities, declines in ADL disabilities have been very modest and limited to the highest levels of disability. Indeed, our analysis indicates that the bulk of the decline in institutional use cannot be explained by declining disability rates. Rather, institutional use has declined because fewer older people with disabilities—at all ages and at all levels of disabilities—are living in institutional settings. The resulting large increases in the number of people in the community with very substantial disabilities and needs for supportive services, especially among women and those with lower incomes, highlight the need for more policy focus on providing services in those environments. Providing more support to family caregivers who are the backbone of the support system for those living in the community will be especially critical, as documented in the companion to this report on caregiving issues (Houser, Gibson, and Redfoot 2010).

The NLTCs data demonstrate that increasing numbers of older persons do not automatically mean similar increases in numbers of people with disabilities or those using institutional services. But continuing the trends toward more community living for older persons with disabilities in the coming decades when the boomers reach advanced old age will require laying the foundation of support for home and community-based services and family caregivers today.

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More Older People with Disabilities Living in the Community:
Trends from the National Long-Term Care Survey, 1984–2004

Table A1					
Age Distribution and Growth by Age in Medicare Beneficiaries, 1984–2004; and Census Projections for the 65+ Population, 2005–2025					
Age group	1984	1994	2004	Change 1984–2004	Projections 2005–2025
65–74	15,742,629	18,484,300	18,550,967	+18%	+95%
75–84	8,851,153	10,516,968	12,374,713	+40%	+56%
85–94	2,574,314	3,179,515	3,734,699	+45%	+37%
95+	176,378	369,984	475,487	+170%	+94%
Total 65+	27,344,473	32,550,767	35,135,866	+28%	+74%

Sources: Medicare beneficiary estimates from the NLTCs; U.S. Census projections.

Table A2						
Predicted and Actual Use of Institutions by Persons Age 65+, 1984–2004						
	1984	1989	1994	1999	2004	Change 1984–2004
Actual Number	1,552,437	2,024,492	1,973,104	1,604,790	1,430,849	-7.8%
Expected at 1984 Rates	1,552,437	1,908,162	1,903,260	2,053,210	2,177,824	+40%
Actual vs. Expected	0	+116,330	+69,844	-448,420	-746,975	

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

Table A3						
Nursing Home Utilization Rates for the Population 65+, NLTCs, 1984–2004						
Age group	1984	1989	1994	1999	2004	Change 1984–2004
65–74	1.7%	2.4%	1.7%	1.4%	1.1%	-35%
75–84	6.8%	6.8%	6.7%	4.6%	4.2%	-38%
85–94	23.1%	23.3%	24.4%	18.2%	14.9%	-35%
95+	49.4%	47.0%	47.2%	41.5%	33.4%	-32%
Total 65+ Unadjusted	5.7%	6.7%	6.1%	4.8%	4.1%	-28%
65+ Age-Adjusted	5.7%	6.1%	5.7%	4.3%	3.6%	-37%
Population Number	1,552,437	2,024,492	1,973,104	1,604,790	1,430,849	-7.8%

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

Table A4					
Nursing Home Utilization Rates for the Population 65+, National Nursing Home Survey, 1985–2004					
Age group	1985	1995	1999	2004	Change 1985–2004
65–74	1.2%	1.0%	1.1%	0.9%	-25%
75–84	5.8%	4.6%	4.3%	3.6%	-38%
85+	22.0%	20.1%	18.2%	13.9%	-37%
Total 65+ Unadjusted	4.6%	4.3%	4.3%	3.6%	-22%
65+, Age-Adjusted	5.4%	4.6%	4.3%	3.5%	-35%
Population Number	1,318,300	1,422,900	1,469,500	1,317,300	-0.1%

Source: National Center for Health Statistics (NCHS); numbers were age-adjusted by the NCHS to the 2000 population.

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	1984	1989	1994	1999	2004
Expected at 1984 Age/Gender-specific Rates of Disability and Institutional Use	1,552,437	1,908,162	1,903,260	2,053,210	2,177,824
Expected at 1984 Age/Gender/Disability-specific Rates of Institutional Use	1,552,437	1,965,488	1,981,610	1,968,782	2,050,926
Actual Number	1,552,437	2,024,492	1,973,104	1,604,790	1,430,849
Actual vs. Expected	0	+116,330	+69,844	-448,420	-746,975
Due to Changes in Disability Rates		+57,326	+78,351	-84,428	-126,898
Due to Changes in Institutional Rates		+59,004	-8,506	-363,992	-620,076

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

	1984	1989	1994	1999	2004	Change 1994–2004
IADL Disabilities Only	5.5%	6.4%	7.5%	5.1%	4.3%	-43%
1–2 ADL Disabilities	16.6%	16.9%	11.9%	6.2%	6.8%	-43%
3–4 ADL Disabilities	34.3%	31.9%	31.1%	27.2%	23.6%	-24%
5–6 ADL Disabilities	53.1%	58.2%	57.3%	51.0%	43.0%	-25%
Any Disability	24.8%	28.7%	28.1%	23.9%	20.0%	-29%
2+ ADL Disabilities	42.5%	44.2%	42.7%	36.7%	30.5%	-28%

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

	1984–1994	1994–2004	1984–2004
Total National Health Expenditures	+140%	+93%	+362%
Total Nursing Home Expenditures	+142%	+70%	+310%
Total Medicaid Nursing Home Expenditures	+131%	+55%	+258%
State Medicaid Nursing Home Expenditures	+118%	+52%	+231%

Source: AARP Public Policy Institute analysis of National Health Expenditure data, 2010.

	Married			Widowed			Other, Not Married		
	1984	1994	2004	1984	1994	2004	1984	1994	2004
Any Dis.	14.7%	13.4%	12.4%	32.8%	32.6%	32.2%	27.9%	27.1%	23.0%
IADLs	5.8%	4.2%	3.3%	12.2%	8.7%	8.2%	10.5%	7.2%	5.9%
1–2 ADL	3.3%	3.3%	3.3%	6.4%	7.1%	7.6%	5.4%	7.0%	6.4%
3–4 ADL	2.0%	2.1%	2.3%	4.8%	5.9%	6.4%	4.4%	5.1%	5.0%
5–6 ADL	3.7%	3.9%	3.5%	9.4%	10.9%	9.9%	7.5%	7.7%	5.8%
2+ ADLs	7.0%	7.3%	7.0%	16.8%	19.9%	19.8%	14.3%	15.9%	14.1%

Source: AARP Public Policy Institute analysis of NLTCs data, 2010.

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Table A9									
Rates of Institutional Use by Marital Status and Disability, 1984–2004									
	Married			Widowed			Other, Not Married		
	1984	1994	2004	1984	1994	2004	1984	1994	2004
Any Dis.	9.6%	13.4%	9.5%	30.7%	35.2%	24.7%	41.0%	37.4%	26.9%
2+ ADLs	18.5%	22.5%	15.3%	52.0%	52.0%	36.8%	61.4%	51.7%	40.7%
Total	1.4%	1.8%	1.2%	10.1%	11.5%	7.9%	11.5%	10.1%	6.2%

Source: AARP Public Policy Institute analysis of NLTCS data, 2010.

Table A10				
The Number of Older Persons with Two or More ADL Disabilities in Community and Institutional Settings and the Percentage Change by Gender, 1984–2004				
	1984	1994	2004	% Change 1984–2004
Men				
Community	638,191	703,385	926,621	+45%
Institution	306,625	450,372	305,591	-0.3%
Women				
Community	1,153,737	1,654,778	2,062,740	+79%
Institution	1,016,302	1,304,184	1,007,027	-0.9%
Total				
Community	1,791,928	2,358,163	2,985,361	+67%
Institution	1,322,927	1,754,556	1,007,027	-0.7%

Source: AARP Public Policy Institute analysis of NLTCS data, 2010.

Table A11				
Numbers of Older Persons with Two or More ADL Disabilities Living in the Community and in Institutions by Marital Status, 1984, 1994, and 2004				
	1984	1994	2004	% Change 1984–2004
Married				
Community	813,692	1,003,953	1,131,132	+39%
Institution	184,324	291,004	204,245	+11%
% in Community	81.5%	77.5%	84.7%	+3.9%
Widowed				
Community	824,563	1,087,384	1,494,743	+81%
Institution	893,891	1,178,435	870,123	-0.9%
% in Community	48.0%	48.0%	63.2%	+32%
Not Married				
Community	153,672	266,827	361,487	+135%
Institution	244,713	285,117	238,250	-2.6%
% in Community	38.6%	48.3%	61.7%	+60%

Source: AARP Public Policy Institute analysis of NLTCS data, 2010.

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Table A12				
Numbers of Older Persons with Two or More ADL Disabilities by Living Arrangement, 1999 and 2004				
	1999	2004	Population Change 1999-2004	Percentage Change 1999-2004
Private Residence Alone	1,768,185	1,794,515	+26,330	+1.5%
Private Residence with Others	3,035,998	3,397,162	+361,169	+12%
Community Residential Care	310,423	539,347	+228,924	+74%
Institutional	1,604,790	1,430,849	-173,941	-11%
Total with Chronic Disability	6,719,386	7,161,874	+442,488	+6.6%

Source: AARP Public Policy Institute analysis of NLTC data, 2009.

Table A13					
Percentage of Older Population with Two or More ADL Disabilities Living in the Community, by Economic Characteristics, 1984, 1994, and 2004					
Income	1984	1994	2004	Population Increase 1984–2004	% Total Increase Due to This Factor
Bottom Quartile	29.6%	30.2%	32.6%	+83%	37.0%
2nd Quartile	24.1%	20.7%	27.2%	+88%	31.8%
3rd Quartile	21.3%	25.2%	19.3%	+51%	16.2%
Top Quartile	24.9%	23.8%	20.9%	+40%	14.9%

Source: AARP Public Policy Institute analysis of NLTC data, 2009.

Table A14		
Percentage of Older Persons Living in the Community with Disabilities by Level of Income, 2004		
Annual Income	Any Disability	Two or More ADL Disabilities
Less than \$10,000	23.0%	24.9%
\$10,000 to \$20,000	36.4%	34.9%
\$20,000 to \$30,000	20.0%	19.3%
\$30,000 to \$40,000	8.9%	9.7%
\$40,000 to \$50,000	4.7%	4.2%
\$50,000 or more	7.0%	7.0%

Source: AARP Public Policy Institute analysis of NLTC data, 2009.