

## Trends in Disability, Community Living, and Caregiving: Analysis of Data from the National Long-Term Care Survey

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 persons age 65 or older 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 federal and state Medicaid spending on nursing homes would have been \$24 billion higher.

The ways in which community-dwelling older people with disabilities managed their conditions also changed significantly between 1984 and 2004. Many more persons with less severe disabilities managed with assistive devices. Among those receiving human assistance, the vast majority were helped by family caregivers, who are increasingly taking full responsibility for providing care. Since 1994, the proportion of family care supplemented by formal (paid) care declined from 39% to 28%, and since 1999, the hours of paid care decreased significantly.

The detailed analyses of the NLTCS data in two new research reports provide insight into the factors driving these changes.

This In Brief summarizes two new AARP Public Policy Institute research reports, *More Older People with Disabilities Living in the Community: Trends from the National Long-Term Care Survey, 1984–2004* and *Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey*.

These companion pieces draw on data from the most recent 2004 wave of the National Long-Term Care Survey, as well as comparable data from previous waves to elucidate important trends in

disability, institutional use, community living, family caregiving, and paid home care.

### More Older People with Disabilities Living in the Community

The major findings of this report 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 overall rate of chronic disabilities, including instrumental activities of daily living (IADL) disabilities and activity of daily living (ADL) disabilities, 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.

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

The age-adjusted rate of institutional use among older persons declined by 37 percent between 1984 and 2004. 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. Declines in institutional use among older persons translated into estimated savings in nursing home costs to Medicaid of roughly \$24 billion in 2004.

**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 nearly 1.2 million people, between 1984 and 2004.

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

The age-adjusted disability rate declined twice as rapidly among older men (by 24 percent) as among older women (by only 12 percent) between 1984 and 2004.

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

However, 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**

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.

**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.

## **Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community**

Building on the research in the companion piece, this report focuses on the growing number of older people with disabilities in the community and their care arrangements, summarized by seven trends that organize the report.

### **Trend #1: The number of older people managing disabilities exclusively with assistive devices has increased dramatically**

The number of community residents age 65+ with disabilities who relied on assistive equipment instead of human help with personal care or independent living activities increased by 155 percent, and now exceeds the number of older people living in institutional settings. Persons with lower levels of disability are far more likely to rely on assistive equipment.

### **Trend #2: The number of older people with disabilities living in the community who received care from family, friends, or paid caregivers has changed little over time, despite substantial growth in the older population**

The number of community residents age 65+ with disabilities receiving assistance from other individuals (family care, paid formal care, or both) remained almost the same in 1984 and 2004.

### **Trend #3: A small but growing number of community residents age 65+ with disabilities is receiving only formal services, but the vast majority continues to receive family care**

In all years, at least 90 percent of older people receiving care in the community received family care, either alone or in combination with formal care.

### **Trend #4: Among older community residents with disabilities who received family care, the number receiving supplemental formal care increased from 1984 to 1994 but has since declined back to 1984 levels**

The proportion of people receiving family care who also received formal care increased from 28 percent in 1984 to 39 percent in 1994, before declining back to 28 percent by 2004.

### **Trend #5: Spouses and children continue to be the primary family caregivers; gender disparities persist**

Eighty-five percent of older family care recipients received care from their spouses or children in 2004, up from 80 percent in 1994. Wives represented 57 percent of all caregiving spouses in 2004, as they did in 1994, while daughters represented almost two-thirds of all caregiving children in both years.

### **Trend #6: Private resources have been the primary payment source for services in the community**

The most common source of payment for home care was out-of-pocket payments by the care recipients themselves. Only 11 percent of all community residents with disabilities received any publicly funded home and community-based care in 2004,

### **Trend #7: The total hours of formal “skilled care” have declined, while the hours of family care have held steady**

The steepest drops in formal care occurred at higher levels of disability and in hours of nursing services provided at home by someone such as a visiting nurse, home health aide, or nurse's aide (skilled care). Older people with disabilities who paid out-of-pocket for formal services received more hours of formal care and more hours of skilled care than those who did not.

## Conclusions

The NLTC 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.

Despite the increase in both the number and level of need of older people with disabilities living in the community, the share receiving formal home care services remains very low, and in fact has declined significantly since 1994. Moreover, out-of-pocket payments by older people remain the primary funding source for such services, despite the low

incomes of those needing the services; those not paying for services out of pocket have seen the greatest declines in the amount of care received. Family caregivers, themselves older and caring for people with more severe disabilities, continue to be the primary providers of LTSS, and since 1994, are more likely to carry the burden of caregiving alone, without supplemental formal care. This trend toward more community living for older persons with disabilities is likely to accelerate in the coming decades when the boomers reach advanced old age. Moving much more rapidly to expand the network of services and supports for people with disabilities and their family caregivers should be a national priority today so that tomorrow's much larger cohorts of older people can look forward to aging with dignity and independence.

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This In Brief is a synopsis of two AARP Public Policy Institute Research Reports:

*More Older People with Disabilities Living in the Community: Trends from the National Long-Term Care Survey, 1984–2004*, #2010-08, by Donald L. Redfoot and Ari Houser, and

*Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey*, #2010-09, by Ari Houser, Mary Jo Gibson, and Donald L. Redfoot.

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