

beyond 50.03

A Report to the Nation on
Independent Living and Disability



Many individuals contributed to this report, which was written by staff in the AARP Public Policy Institute (PPI).

Mary Jo Gibson of PPI's Independent Living/Long-Term Care Team is the lead author of the report. Other authors are:

Marc Freiman	Sheel Pandya
Steven Gregory	Don Redfoot
Enid Kassner	Audrey Straight
Andrew Kochera	Bernadette Wright
Faith Mullen	

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For additional information about this report, please contact the AARP Public Policy Institute, Independent Living/Long-Term Care Team, at 601 E Street, N.W., Washington, D.C. 20049 or call (202) 434-3860. www.aarp.org.

Beyond 50 2003:

A Report to the Nation on Independent Living and Disability

This *Beyond 50.03* report is the third in a series of special reports to the nation on the status of its midlife and older population. Economic security (2001) and health security (2002) were spotlighted in the two prior reports. This year, the focus is on the range of services that enhance the long-term independence of persons 50 and older with disabilities. **The desire for independence and being “in charge” of our own lives spans all generations and all boundaries, whether demographic, geographic, or bureaucratic. This story is not just about persons with disabilities. It is about all of us—our communities, our families, ourselves.**

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Executive Summary

The desire for independence is important to people of all ages. Toddlers struggle to walk unaided, teenagers rebel against parental restraints, adults decide where they will live or work—all of us want control over what we do, when and where, and with whom. We want to be in charge of our lives.

What happens, then, when disabilities early or late in life threaten our independence and require us to rely on others for help with the ordinary routines of life?

This year's report in AARP's *Beyond Fifty* series takes an in-depth look at the roles of supportive services, family and community, and our social and physical environments in helping individuals 50 and older live with dignity and independence as they age.

The vast majority of persons 50 and older do not require long-term assistance at any given time. However, most people will require assistance at some point in their lives, and most families will face these issues with their older members. In the struggle to live with independence and dignity as we age, everyone has a story, and each story is unique and deeply personal. While most of this report focuses on “numbers” rather than narrative, the realities of living with disabilities are its backdrop:

- Long-term supportive services often needed by persons with disabilities are personal and intimate.
- The ability to be independent and “in charge” helps to define one's quality of life.
- Family life and community, our social and physical environments,

and long-term supportive services play key roles in influencing quality of life for persons with disabilities.

Scope of the Report

This report:

- Presents the perspective of persons with disabilities about what would make their lives better garnered from the first national survey of persons 50 and older devoted to this topic;
- Presents newly available estimates of levels of disability and the use of supportive services among persons 50 and older from the most reliable national data sources;
- Portrays new options for independent living available to persons with disabilities, challenging outdated stereotypes of long-term care as synonymous with nursing home care; and
- Discusses the roles of housing, communities, and transportation in creating a livable and accessible environment that supports the independence of persons with disabilities.

What Do We Mean by Disability?

Disability has multiple meanings that cannot be captured in one definition. There are huge differences in the causes of disabilities, the age of onset and pace of progression, and the degree of activity limitations that may result. Disabilities may occur at birth, suddenly, as a result of an accident, or slowly, as a chronic condition progresses. They may be sensory, cognitive, physical, or emotional. They may be visible or hidden.

Researchers find varying rates of disability based on the definition of

disability they use as well as other factors. But despite the complexity of defining and measuring the number of people with various types of disabilities, some points are universal. Disability usually involves difficulty conducting daily activities, such as bathing, cooking, or shopping, or getting around our communities. And almost all of us need some help with these activities at some point in our adult lives, especially as we grow older.

Does This Report Include Long-Term Care?

Yes, although the term “long-term care” is used only occasionally. Long-term care has been defined by gerontologists Rosalie Kane and Robert Kane as “personal care and assistance that an individual might receive on a long-term basis because of a disability or chronic illness that limits his or her ability to function.”¹ It includes not only nursing homes, but also the services received while living in many other settings, including private homes and apartments.

“Long-term supportive services” is the preferred term among many people with disabilities because the term “care” may imply dependence and convey paternalism.

Independent Living: The Framework for the Report

Expectations about living with disability have changed dramatically in the past few decades, in large part due to the influence of the independent living and disability rights movements, which seek to integrate persons with disabilities into the everyday life of their communities rather than isolating them in medically oriented facilities.

The independent living philosophy sees disability not as an individual characteristic or “problem” but as a relationship between the individual and the entire environment in which he or she lives. The environment includes everything from physical surroundings to family networks to quality of health and long-term supportive services and

In the struggle to live with independence and dignity as we age, everyone has a story, and each story is unique and deeply personal.

the federal and state policies that address these issues. **This report emphasizes these environmental factors in increasing independence and reducing levels of disability.**

The independent living movement also seeks to change social attitudes

What do we mean by “activities of daily living”? Surveys typically distinguish between two types of disabilities: limitations in activities of daily living (ADLs) and limitations in instrumental activities of daily living (IADLs). **ADLs refer to basic personal activities required for daily life** and typically include bathing, dressing, getting in or out of bed or a chair, using the toilet, eating, and getting around inside the home. **IADLs refer to activities related to being able to manage one’s affairs independently** and typically include grocery shopping, housework, preparing meals, managing money, using the telephone, taking medications, and getting around outside the home.

to recognize that persons with disabilities want to remain in control of their lives and should receive the services they need to remain independent. As Judith E. Heumann (co-founder, World Institute on Disability) has put it, “Independent living is not doing things by yourself, it is being in control of how things are done.”

Highlights of Findings

People’s lives are changed in unpredictable ways when they or family members need long-term assistance with everyday activities. Individuals with disabilities are

“Independent living is not doing things by yourself, it is being in control of how things are done.”

–Judith E. Heumann

often surprised to learn that they are largely on their own in finding, arranging, and paying for such services, which are rarely considered to be “medically necessary” by health insurers.

While long-term care has had a stereotypically negative image in the past, the reality is changing. New technologies, new living environments, and new ways of “staying in charge” are helping people with disabilities to maintain their independence. And we as a society are recognizing that environmental factors play critical roles in either facilitating or undermining the ability to remain independent.

Our examination of historical

patterns and new data presents an apparent paradox—recent trends and innovations, along with the growth of the disability rights movements, are helping many more persons with disabilities to live independently. But persons 50 and older with disabilities do not view their quality of life as improving—no aspect of life for which we have data has shown a positive trend over the last four years. In addition, it appears that the already large gap in life satisfaction between older persons without disabilities and those with disabilities may be growing.

Persons with Disabilities 50 and Older Speak for Themselves

To learn directly from those affected by policy decisions at the federal, state, and local levels, AARP commissioned Harris Interactive to seek the views of a nationally representative sample of persons 50 and older with disabilities on issues related to their disability, quality of life, and experiences in their communities.

The 1,102 respondents were a heterogeneous population in the types of disabilities they have experienced, the age of onset of these disabilities, and their life experiences. For example, a sizable majority (68%) have a long-lasting condition that limits their physical mobility, while 21 percent have a vision or hearing impairment, and 19 percent have a cognitive or emotional condition. Nearly three-quarters of persons age 50 to 64 (73%) report that their disability is “very/somewhat severe,” compared with 45 percent of those 65 and older. For a majority of persons 50 and older, the onset of disability

occurred between the ages of 40 and 64, a factor that was associated with greater severity of disability. On average, the income of persons 50 and older with disabilities was substantially lower than for persons 50 and older without disabilities, although their other demographic characteristics were similar, e.g., gender, race/ethnicity, and geographic region.

The quantitative findings from the survey are summarized below, along with other report findings.

But the numbers do not fully convey the respondents' individuality and resiliency and the centrality of independence and dignity in their lives. **When we asked open-ended questions about hopes and concerns, their number one fear was loss of independence.** Control over decision making also emerged as a major theme.

Here is a sampling of verbatim responses by the 53 percent of respondents who answered "yes" to the question, "Have there been times in the past month when you could not do something you really needed or wanted to do because of your disability or health condition?"

"I would like to just go for a ride."

"Walk on the beach."

"Pay my bills, nothing else."

"Make a minor car repair, walk to the corner, get something off a high shelf, tie shoes."

"Just get out of bed."

"Just getting back and forth to the store.
I have to wait for friends or family members."

"I can hardly go to visit relatives because of the stairs."

"Be able to afford food and getting here and there."

"I could not play my violin."

"Going fishing and being in the boat."

"Go to the park with my grandchildren."

These responses reflect the daily challenges faced by people with disabilities in doing simple things that people without disabilities take for granted.

Key Findings and Policy Implications

Summarized below are key findings from the entire report, including new analyses of the federally sponsored National Long-Term Care Surveys and the Medical Expenditure Panel Survey, and the new AARP survey conducted by Harris Interactive. We also draw out the implications of these findings for federal and state policy makers who wish to remove barriers to independence. (Note: Please see page 176 for a detailed list of findings that support these recommendations.)

1. Persons 50 and older with disabilities, particularly those age 50 to 64, strongly prefer independent living in their own homes to other alternatives. They also want more direct control over what long-term supportive services they receive and when they receive them.

Loss of independence and loss of mobility are what people with disabilities 50 and older say they fear the most as they look to the future. They also say having more control over decisions about the services and help they receive would cause a major improvement in their current lives. For example, a large majority of people with disabilities would prefer to manage any publicly funded in-home services themselves, rather than have an agency do so. In addition, a majority would prefer cash payments for such home care services over services provided directly by agencies.

Policy Implication: Encourage “consumer-directed” long-term supportive services in publicly funded programs such as Medicaid. Such services would help people “stay in charge” and would respect their varying life experiences and preferences. Although the Medicaid program is administered at the state level, federal policy could promote more consumer choice in the types of services offered and the settings in which they are offered.

2. Disability rates have declined steeply for less severe levels of disability. This decline is good news, because it suggests that early interventions to avert declines in functional status can work. In addition, the proportion of persons 65 and older with disabilities in the community who use assistive technology but do not require human assistance, including people age 85 and older, has increased dramatically since the mid-1980s.

The proportion of persons 65 and older reporting only limitations in “instrumental activities of daily living” (IADLs), such as the ability to pay bills or go shopping, declined nearly 40 percent between 1984 and 1999. However, the proportion of persons 65 and older with two or more limitations in activities of daily living (ADLs), such as bathing and eating, remained almost unchanged.

Interventions that do not require ongoing human help—such as use of equipment—are increasingly important in helping individuals

maintain independence. The share of persons 65 and older living in the community with at least one limitation in any ADL who used special equipment unaided by others has more than doubled since the mid-1980s (from 9% to 20%). In addition, almost one-quarter of persons 50 and older with disabilities who do not use any special equipment say that equipment such as a hearing aid, wheelchair, cane, or walker would make their lives easier.

Policy Implication: Encourage the use of independence-enhancing technologies. Assistive technologies should be more widely available and affordable. These technologies should be as readily available as other forms of support, and funding for them should be integrated into programs providing long-term supportive services. At the very least, “low-technology” devices, such as canes and wheelchairs, should be available to persons 50 and older with disabilities who need them. Because a high proportion of persons with disabilities use computers, new ways of using computers to help older persons with everyday activities, including online shopping for information and services, should be pursued.

3. Many persons with disabilities, especially those with severe disabilities, have unmet needs for long-term supportive services and assistive equipment in their homes and communities. Some of these needs would be relatively simple to meet; others, such

as providing more personal assistance services, would require significant resources and our collective will.

Only about half of persons 50 and older with disabilities report receiving any regular help with daily activities from one or more people. The vast majority of such help is the unpaid assistance of family or other informal caregivers. In addition, only one out of three uses any community-based service. Because there is no organized “system” for delivering services, many individuals do not know about sources of support or how to find them, or if they are eligible for any publicly funded services.

Our data indicate there are high levels of unmet need among persons 50 and older with disabilities:

- Almost one-quarter report needing more help than they receive now with basic daily activities, such as bathing, cooking, or shopping.
- One-half said they were not able to do something they needed or wanted to do in the past month because of their disability. These needs were very basic, such as doing household chores, getting some exercise, or getting out of the house.
- More than one-third of homeowners would like to make home modifications that would make their lives easier, such as installing grab bars in the bathroom, but have not done so, largely because of cost.

Policy Implication: Reorient public funding to enable persons with disabilities to

live independently in their communities. Medicaid is the major public benefit program funding long-term supportive services for older persons with disabilities. Federal and state funding for home and community-based services should be expanded through Medicaid, and the shift in current funding from institutional to community-based care in many states should continue. More emphasis also needs to be placed on recognizing the rights of older persons with disabilities to live in their communities and obtain services in the least restrictive environment possible.

Policy Implication: Develop navigation tools and a single point of entry in localities and states to enable consumers to learn more easily about the range and location of service options and to get assistance in determining their eligibility for public programs.

4. On average, people with disabilities 50 and older give their community a grade of B-/C+ as a place to live for people with disabilities. While some community features receive good marks, others are rated poorly by persons with disabilities, particularly public transportation. In addition, many older residents of federally subsidized housing are at risk of needing more supportive housing environments with services.

Barely one-third of respondents currently give their communities a “B” or higher rating for having dependable and accessible public

transportation. Getting safely to places they want to go is the second most important concern persons with disabilities have about their communities. Among persons 65 and older with disabilities, the perception that crime is a serious problem in their neighborhoods nearly doubled, from 4.5 percent to 8.2 percent between 1984 and 1999.

Residents in federally subsidized housing for older persons share many of the characteristics of those at high risk of needing long-term supportive services. Subsidized housing residents are overwhelmingly female, report more disabilities than older persons who do not live in subsidized housing, and are less likely to have someone to whom they can turn if they become sick or disabled.

Policy Implication: Provide more supportive physical environments and livable communities. To be more “livable,” communities must include the physical features and readily accessible services that enable older residents to remain independent. Better transportation is the top priority; making communities safe from crime is also important. While much of the funding is federal and state, housing and transportation programs are often administered locally. Local housing and transportation authorities should take the initiative to find ways to serve older persons with disabilities. Local planning boards should be aware of the needs of persons with disabilities when making decisions regarding the location of services and commercial establishments.

Policy Implication: Reduce barriers to “aging in place” for persons with disabilities. Funding for home modification programs could have an immediate impact on the ability of persons with disabilities to remain independent. Incentives to builders to incorporate universal design into homes would improve access for persons with disabilities as well as for families with young children.

In addition, target more funding for services to residents in federally subsidized housing. The high concentration of residents needing supportive services calls for a special focus on these settings, e.g., by including service coordinators on the staff of subsidized housing properties to help bring services to people so they do not have to move to obtain them.

5. Family support remains strong, but the impact of such trends as greater longevity, more women in the labor force, and greater geographic dispersion is now hitting home. Either in person or “at a distance,” families are finding themselves with new roles as caregivers to aging parents, spouses or siblings, aging children with developmental disabilities, and other relatives and friends. Caregivers age 50 and older often experience considerable stress as a result of their caregiving roles.

Strong social support from families and friends can protect against functional decline and help individuals cope with functional decline if it occurs. While contact between

persons 65 and older with disabilities and their families and friends remains strong, it has declined since the mid-1980s.

Larger social trends are affecting the composition of families and their roles as caregivers, including the growing number of women in the workforce who must juggle work and caregiving responsibilities. Among 50- to 64-year-old caregivers, 60 percent are working full- or part-time. In addition, significant economic sacrifices during peak earning years are common among caregivers 50 and older who have been in the workforce.

Parents caring for aging children with cognitive and developmental disabilities represent a growing group in the older caregiver population. This trend reflects the emergence of two-generation families in which parents are caring for children who are in their 50s and 60s.

A preference for family assistance for help with everyday tasks is even stronger among persons 50 and older with disabilities than among persons 50 and older in the general population. This preference declines somewhat when 24-hour care is needed.

Policy Implication: Strengthen supports for family and other informal caregivers. As we have seen, families and other informal caregivers provide the overwhelming share of long-term supportive services for persons with disabilities. Their unpaid efforts consume substantial human resources and may result in serious stresses in the caregivers’ own lives. Providing respite care, adult day care, and tax credits makes sense for

both ethical and economic reasons. In addition, caregivers in the workplace need support, such as adequate family and medical leave.

6. Inadequate health insurance is at the top of the list of problems experienced by persons with disabilities 50 and older, including those with Medicare coverage. In addition to gaps in coverage, such as the lack of coverage for prescription drugs, problems range from inappropriate care for chronic conditions to lack of coordination between medical care and long-term supportive services for persons with disabilities.

People with disabilities say better medical insurance is the number one change that would be a major improvement in their lives. In addition, one out of three persons with disabilities reports specific needs, such as for particular therapies or equipment, not covered by health insurance. Problems include delivery as well as coverage issues: The overlap between chronic conditions and disabilities increases with advancing age, but little coordination exists between medical care and long-term supportive services. Finally, the trends concerning access to and satisfaction with health care among people 50 and older with disabilities over the last four years are in a negative direction. Concerns about recent trends extend to programs that have historically played a positive role in the health care of people with disabilities. Persons age 50 to

64 with disabilities rely much more heavily on Medicaid than do those without disabilities, but Medicaid budgets are being cut in many states due to budget crises.

Policy Implication: Focus on functioning and health-related quality of life, not just acute and curative care, in our health care system. In addition to filling gaps in Medicare's benefit structure, such as prescription drugs, we need to provide services to help persons with disabilities maintain or restore function and quality of life. Medicare policies should support delivery of health care that meets the needs of persons with chronic illness and disabling conditions for ongoing, rather than episodic, health care. In addition, coverage for the equipment and therapies often needed by persons with disabilities should be expanded in both private and public insurance programs. Finally, essential Medicaid services, such as prescription drug assistance, need to be protected during tough fiscal times.

7. Despite some improvements, the quality of long-term supportive services is a persistent problem in all settings. A focus on consumers' quality of life is rare. In addition, there is an unprecedented shortage of the frontline workers needed to provide long-term supportive services to persons with disabilities, such as personal care attendants and nursing assistants.

While the quality of care in nursing homes has generally improved with

the passage of the Nursing Home Reform Act in 1987, problems with quality of care and quality of life persist. Two-thirds of persons 50 and older with firsthand experience with nursing homes believe the government is not doing enough to enforce quality standards. Low staffing levels lead to poor care in nursing homes. According to a recent report sponsored by the Centers for Medicare and Medicaid Services, 91 percent of nursing homes do not provide the minimum number of hours of care by certified nurse assistants needed per resident per day to avoid serious quality-of-care problems.

Difficulty in recruiting and retaining direct service staff, such as nursing assistants and personal care attendants, is growing. According to some estimates, the need for these workers will double over the next decade. Unmet need for registered nurses is also increasing. Reports of quality problems also continue in assisted living facilities, despite efforts to support residents' privacy, choice, and independence. Efforts to promote quality in supportive housing other than assisted living have been sporadic at best.

Policy Implication: Improve the quality of long-term supportive services. One important element of improving quality would be tools that enable individuals to use information on quality in selecting service providers. A navigation system should include up-to-date reports on quality based on standardized measures of each provider's performance. In addition, states need to do a better job of overseeing providers of services

through better measures of performance, better systems of responding to consumer complaints, and much stronger enforcement action against those who fail to provide quality services. Providing funding to support strong, independent ombudsman programs would supplement those formal state efforts.

Policy Implication: Increase the supply of frontline workers. One way for states to improve the stability of the workforce is to provide reimbursements for long-term supportive services that are adequate to pay for sufficient numbers of suitably trained and reasonably compensated workers. Providers can play an important role by developing more responsive systems to improve morale and reduce turnover among workers providing long-term supportive services in all settings.

8. The costs of long-term supportive services, which individuals typically need at the time their income is most limited, are often unaffordable to individuals with disabilities and their families.

The need for long-term supportive services can be financially catastrophic to individuals with disabilities and their families, even those with substantial income and resources. A recent study estimated that only 27 percent of older persons have sufficient income and assets to be able to withstand a long-term care "shock" totalling \$150,000 over three years without impoverishing themselves. Lower- and middle-income Americans

with disabilities often find that their options are limited and out-of-pocket costs are burdensome. In the AARP/Harris Interactive survey, persons 50 and older with disabilities with incomes “in the middle” were the income group most likely to say that having a way to pay for long-term supportive services (such as help with bathing or shopping) and equipment would be a major improvement in their lives.

The high costs of a long-term disability remain largely uninsured. Public programs such as Medicaid pay only after individuals have spent down their income and exhausted their assets. Private health and long-term care insurance account for only 11 percent of total long-term care expenditures in the United States. Disability income insurance policies aimed at replacing lost wages usually end by age 65 or earlier.

Services in a nursing home average \$55,000 a year; hourly home care agency rates average \$37 for a licensed practical nurse (LPN) and \$18 for a home health aide.

Long-term care is the single largest component of direct health-related out-of-pocket spending by Medicare beneficiaries, followed by spending on prescription drugs. Moreover, the indirect costs of providing long-term supportive services in the home, borne by unpaid family members and friends of persons with disabilities, are immeasurable.

Policy Implication: Insure individuals against the high costs of long-term supportive services. Our nation’s current financing structure relies too heavily on individuals and families to bear the financial burden of long-term supportive services and other types of assistance for persons with disabilities. The financial burden can be so large that, for many individuals, including those with middle incomes, the only alternative is Medicaid, which requires impoverishment to receive benefits.

Finding ways as a society to share these unpredictable costs more widely must become a national priority. Expanding independent living options for individuals will depend on more societal responsibility for financing—specifically our ability to pool our resources and spread the risk broadly. A social insurance program for long-term supportive services based on functional criteria should be the core of the solution, complemented by private long-term care insurance options, with solid consumer protections, for those who can afford the premiums. In addition, we need a better Medicaid safety net, especially for home and community-based services. Medicaid’s safety net for lower-income individuals is particularly important to persons with disabilities at this time of economic uncertainty. Unfortunately, when state budgets face shortfalls, Medicaid home and community-based services and other “optional” services may be cut, since they are not mandatory. Finally, coordination of the disparate funding streams could lead to some economies and efficiencies.

Making Sense of It All

People age 50 and older with disabilities clearly are not satisfied with the current limited range of independent living options. The desire for more and better choices may be driven, in part, by higher educational levels and more diversity in today's older population as well as the growth of the independent living and disability rights movements. At the same time, innovative options for better service delivery and financing, being pioneered both in the United States and abroad, could make a dramatic difference in their lives.

While the vast majority of midlife and older persons with disabilities are managing to live independently, frequently with the help of family and friends, they often have unmet needs. What is striking is how modest many of their requests for assistance are—which should help to mitigate fears of runaway costs. It would not take much to help many individuals with disabilities and their families live with more dignity and independence. Relatively small changes, such as helping people make inexpensive home modifications and obtain assistive devices, can make a big difference. Other changes, such as finding ways as a society to pay for more long-term supportive services in homes and communities and funding better transportation options, will require more resources and more collective will.

Our nation needs to address the unmet needs of persons with disabilities. While trends show such positive changes as declining rates

of disability and more options for independent living, many of the most vulnerable individuals with disabilities are being left behind, including those with lower incomes and more severe disabilities.

Disparities by race/ethnicity, income, and gender persist in rates of disability, access to health care, family caregiving patterns, and use of long-term supportive services.

It is critical to lay the groundwork now for major reforms, which will require mobilizing public as well as private resources to invest in independence. The harsh realities faced today by some persons with disabilities, along with the demand for more and better choices for independent living that we can expect in the future, argue for putting reform of disability and long-term care policies firmly on the nation's agenda.

As this report goes to press, the economic downturn has led to crises in state budgets, and many states are proposing to cut back home and community-based services for older persons and persons with disabilities. While the first priority is to “do no harm” to such services, both federal and state policy makers can enhance dignity and independence among persons 50 and older with disabilities in many ways. Some of the recommendations made in this report can be implemented at relatively low cost; others will take substantial resources.

This story is not just about data and numbers. It is also about our nation's values and vision. It is about what we all want for ourselves—the ability to live independently and to be in control of our own lives. ■