Family Caregiving

In the United States, the vast majority of care that allows older people to live in their own homes is provided by family members who do not receive pay for their services. As the older share of the population increases and people live longer with chronic disabling conditions, particularly dementia, meeting the care needs of older Americans will become more challenging for families.

This report highlights recent National Institute on Aging-supported research on the impact of caregiving on family members, the dynamics of caregiving within extended families, and the future need and availability of family care. As policies deemphasize nursing home care in favor of community-based long-term support services, a better understanding of the family’s central role in caregiving is needed. This perspective can help policymakers, health care providers, and planners identify and implement strategies that better meet the care needs of older Americans and improve the lives of the family members who care for them.

Caregiver Availability and Constraints

A variety of trends have contributed to a widening gap between older Americans’ need for care and the availability of family members to provide that care, raising the potential for growing unmet needs, a heavier burden on individual caregivers, and increased demand for paid care. The combined effects of delayed childbearing and longer life expectancy mean more adults in later-middle age may be “sandwiched” between the competing demands of their children and those of their aging parents and parents-in-law. Women—who have traditionally served as parent care providers—are more likely to be employed than in previous generations, limiting their availability, and increasing their time constraints.

Highlights

- Almost half of U.S. adults ages 65 and older report they either need help or are currently receiving help with routine daily activities, such as shopping, transportation, bathing, meal preparation, or managing medication.
- Family members provide more than 95 percent of the informal care for older adults who do not live in nursing homes.
- The number of U.S. 75-year-olds without the types of family members who are the most common family care providers (a living spouse or a child living nearby) is projected to increase substantially between 2010 and 2030: The number without a living spouse is expected to more than double from roughly 875,000 to 1.8 million, and those without an adult child within 10 miles could increase by a multiple of six—from about 100,000 to more than 600,000.
- Nearly two out of three caregivers rated their caregiving experience as largely positive, pointing to benefits such as feeling closer to the care recipient and assured that the recipient is receiving high-quality care. However, one in 10 caregivers found caregiving a negative experience overall, citing financial difficulties, physical problems, or stress.
- The estimated dollar value of the informal care that family and friends provide for older Americans totals $522 billion a year—more than Medicaid spending in 2014.
- On average, dementia is the most costly and time-intensive health condition for family caregivers.
- For older adults leaving full-time employment, those with new caregiving responsibilities are less likely to be able to work part time if they want or need to do so.
- Disabled older adults in cohabiting relationships were considerably less likely to receive care from their live-in partners than older married people with disabilities.

This publication summarizes research related to the objectives of the National Institute on Aging (NIA), with emphasis on work conducted at the NIA Centers on the Demography and Economics of Aging. Our objective is to provide decisionmakers in government, business, and nongovernmental organizations with up-to-date scientific evidence relevant to policy debates and program design. These newsletters can be accessed at www.prb.org/About/Projects/Aging/ TodaysResearchAging.aspx
Using the nationally representative Panel Survey of Income Dynamics (PSID), Wiemers and Bianchi (2015) showed a 20 percent increase between 1988 and 2007 in the share of women ages 45 to 64 who had both children and living parents or parents-in-law. One in 10 women in this age group provided significant parental care and either financial assistance or housing (within their homes for one year or more) to both an adult child (age 25 or older) and a parent during the period. Supporting multiple generations “may affect well-being in retirement if women decrease labor supply to care for parents or if money transfers to children are made at the expense of retirement savings,” the researchers argue.

Adults in their 50s, 60s, and 70s are more likely than those in previous generations to have divorced, increasing their likelihood of reaching old age without a spouse to assume the role of caregiver. Divorce also has implications for whether older adults will receive care from their children. In particular, divorce and remarriage may weaken adult children’s sense of obligation to provide elder care, particularly for fathers with whom they did not reside and for stepparents (Silverstein and Giarrusso 2010).

Taking a variety of trends into account including divorce, low fertility, and rising life expectancy, Ryan and colleagues (2012) created a model of the baby boom population to examine the future availability of family support. The model, based on census data and findings from the nationally representative Health and Retirement Study (HRS), allowed researchers to estimate how many baby boomers would have the types of family members who are the most common care providers—a living spouse or an adult child within 10 miles. The projections show that the share of 75-year-olds without the most common care providers will increase substantially between 2010 and 2030. Given the size of the baby boom population, the number of 75-year-olds without a spouse could more than double from roughly 875,000 in 2010 to 1.8 million in 2030, and those without an adult child nearby could increase by a multiple of six during that time—from about 100,000 to more than 600,000. The researchers suggest that baby boomers may need to rely on paid care providers or nontraditional caregivers such as siblings or stepchildren. Unmarried women with few economic resources are likely to be particularly disadvantaged by not having a spouse to provide care. To address this widening care gap, researchers argue for expanding long-term care insurance, designing aging-friendly neighborhoods, and planning for an increased demand for paid care services.

Another way to meet older adults’ care needs is to better involve grown children who live at a distance from their parents, proposes Piette and colleagues (2010). Their analysis of HRS data showed that one in three chronically ill older adults had no children nearby but did have adult children living elsewhere. And three in four grown children were in frequent contact with their aging parents despite distance, through phone calls or visits (especially those who lived within a one-hour drive). More than half of the older adults said they could rely on their children if they had a serious problem and that their relationships were amicable. Involving out-of-town adult children in parents’ medical care and medication management is one way to better meet the needs of this group of chronically ill older people, the authors suggest.

Satariano, Scharlach, and Lindeman (2014) identify a wide range of new technologies that can support older adults and their caregivers, such as electronic medication reminders and ingestible devices to improve medication compliance, and wearable sensors that immediately report abrupt movements related to fall or injury. They recommend that research on the safety and effectiveness of these devices include input from caregivers and give special attention to economic barriers to their use.

Understanding the Impact of Caregiving on Family Members

Providing uncompensated care for a spouse or parent living with physical limitations can be both rewarding and stressful, and new research has helped identify how—and under what circumstances—providing care to an older relative is beneficial or harmful to the care provider’s well-being.

Roth, Fredman, and Haley (2015) examined five studies that followed groups of people over time and found that those who became caregivers tended to live longer and had lower mortality rates than similar noncaregivers.
The researchers noted that “most caregivers also report benefits from caregiving, and many report little or no caregiving-related strain.” In one of those studies, Brown and colleagues (2009) tracked more than 3,300 married people ages 50 and older for eight years using HRS data. They found that those who spent 14 or more hours weekly caring for a spouse had a lower risk of death than otherwise comparable non-caregivers.

But other evidence indicates that prolonged caregiving for a spouse can negatively affect physical and mental health. Two recent studies based on eight years of HRS data tracked older married people who did not have high blood pressure or cardiovascular disease (CVD) at the beginning of the study (Capistrant, Moon, and Glymour 2012; and Capistrant et al. 2012). Caregiving for 14 hours or more weekly for two or more years doubled the risk of CVD onset.

Box 1
A Profile of Care Needs and Informal Caregiving

Almost half of U.S. adults ages 65 and older—about 18 million people—report they either need help (20 percent) or are currently receiving help (29 percent) with routine daily activities, such as shopping, transportation, bathing, walking, meals, or managing medication (see Figure 1, page 4) (Freedman and Spillman 2014). These findings are based on data from the 2011 National Health and Aging Trends Study (NHATS), which used in-depth, in-person interviews with a nationally representative sample of more than 8,000 Medicare beneficiaries; and the National Study of Caregiving, which surveyed the NHATS interviewees’ entire network of care providers (Spillman et al. 2014).

Among the older adults receiving help, three-quarters lived in houses or apartments in the community and 70 percent received informal unpaid help. About one-quarter of older people who needed assistance lived in either a nursing home (10 percent) or supportive care setting (15 percent), such as an assisted living residence that did not offer full-time nursing care.

Family members represented nearly 90 percent of informal caregivers (see Figure 2, page 4). One in five caregivers (21 percent) were spouses who provided 31 percent of total hours of care. While adult children together provided almost half of all care hours, daughters’ share of caregiving (31 percent) was almost twice that of sons (16 percent).

The average informal caregiver reported providing 75 hours of care per month. Spouses and other live-in caregivers clocked the highest number of care hours, 110 or more monthly. A majority of older adults receiving help named at least three people they could turn to for care, although most relied on one or two main caregivers. However, 5 percent of older adults had no friends or family members who could provide care.

Older adults who received help reported receiving about 144 hours of care a month from multiple informal caregivers—an average of about five hours per day. Among the subset of older adults living in supportive care settings, many still received unpaid care each month but at a much lower level (just under 50 hours) and 15 percent paid for assistance from outside the facility. Older people and their families may be choosing supportive care settings, which tend to cost less than nursing homes, to make caregiving “more sustainable” as the older person’s need for assistance and supervision rises, suggest Freedman and Spillman (2014).

The NHATS-based study uncovered sizable unmet needs, particularly among those with low-incomes or who were minorities, never-married, or widowed. Among those who had difficulty with routine activities or received help, about one in three (32 percent) had an “adverse consequence” in the previous month when a need was not met. The most common negative events were soiling or wetting clothes, being unable to move about inside or go outside, and making medication errors. Unmet needs also can lead to falls, hospitalizations, and emergency room visits.

Older adults with high needs and their caregivers are of special interest because eligibility for public programs is often tied to need. Caregivers assisting those who needed help with at least three self-care or mobility activities made up less than one-third of all caregivers but provided more than half of the total hours of care. About 40 percent of total care hours were devoted to people who likely had dementia (referred to in some studies as probable dementia) (see Box 2, page 6).

Analysis of the NHATS data identified a particularly vulnerable, high-needs group of older adults not living in nursing homes—those who received help with both medical visits and managing their medications (Wolff and Spillman 2014). Most of these older adults had probable dementia, rated their health as fair or poor, and also received help with self-care and mobility. This group received twice as many hours of informal care per week (more than 60) than their peers who did not need help with both medical visits and managing medication. Caring for older people who need help with both medical visits and managing medicine is time intensive, putting their informal caregivers at risk for high levels of stress. To improve the care of this group of older people, the researchers suggest that health care providers take a patient-family partnership approach and identify at-risk older caregivers who might be particularly burdened by caregiving and need support services.

References

### Figure 1
**Help With Shopping and Transportation Are the Most Common Types of Assistance Provided to Older Adults Living Outside Nursing Homes.**

#### Percent of Caregivers Providing Various Types of Assistance, 2011

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Percent of Caregivers Providing Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping</td>
<td>90</td>
</tr>
<tr>
<td>Transportation</td>
<td>86</td>
</tr>
<tr>
<td>Laundry, housework, and meal preparation</td>
<td>79</td>
</tr>
<tr>
<td>Mobility (help moving within the home)</td>
<td>72</td>
</tr>
<tr>
<td>Making medical appointments*</td>
<td>61</td>
</tr>
<tr>
<td>Helping with bills, managing money</td>
<td>58</td>
</tr>
<tr>
<td>Speaking to a doctor*</td>
<td>55</td>
</tr>
<tr>
<td>Self-care (including bathing, dressing, and eating)</td>
<td>49</td>
</tr>
<tr>
<td>Keeping track of medicine</td>
<td>49</td>
</tr>
<tr>
<td>Ordering medicine</td>
<td>48</td>
</tr>
<tr>
<td>Medical insurance issues*</td>
<td>34</td>
</tr>
<tr>
<td>Helping with diet</td>
<td>27</td>
</tr>
<tr>
<td>Foot care</td>
<td>27</td>
</tr>
</tbody>
</table>

**Note:** The reference period is “in the last year” for activities marked with an asterisk (*). The reference period for other more frequent activities is the past month. “Medical insurance issues” does not include adding or changing insurance.

**Source:** Brenda Spillman et al., “Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving,” Report to the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (January, 2014).

### Figure 2
**More Than Half of Informal Care Is Provided by Daughters and Spouses.**

#### Percent of All Caregivers

- Daughter: 29%
- Spouse: 21%
- Other Relative*: 22%
- Son: 18%
- Nonrelative: 9%

#### Share of Total Hours of Care Provided

- Daughter: 31%
- Spouse: 31%
- Other Relative*: 18%
- Son: 16%
- Nonrelative: 4%

*Notes:
- Sons-in-law, daughters-in-law, and grandchildren represented 50 percent of other relatives who provide care.
- **Source:** Brenda Spillman et al., “Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving,” Report to the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (January, 2014).
and significantly increased the risk of developing high blood pressure compared to other similar adults who were not caregivers. Becoming a caregiver for a spouse (14 hours per week or more) also significantly increased an older adult’s risk of depression, according to another study of married HRS participants (Capistrant, Berkman, and Glymour 2014). But long-term caregiving (for two or more years) did not elevate the risks further, suggesting that grief related to experiencing a spouse’s functional decline rather than the long-term “wear and tear” of caregiving may be at the root of depression.

New findings from the nationally representative 2011 National Study of Caregiving offer a window into how caregivers experience their roles and which caregivers might be at risk of debilitating stress. This study collected information on the entire network of caregivers of each adult age 65 or older with activity limitations identified as part of the 2011 National Health and Aging Trends Study (NHATS), making it more comprehensive than previous large studies. Nine out of 10 informal caregivers are family members, mainly spouses or adult children (Spillman et al. 2014) (see Box 1, page 3).

In interviews, nearly two out of three caregivers rated their caregiving experience as largely positive, pointing to benefits such as feeling closer to the care recipient and assured that the recipient was receiving high-quality care (Spillman et al. 2014). But one in 10 caregivers found caregiving a negative experience overall. Additionally, one in four caregivers surveyed said caregiving took an emotional toll and about one in seven cited either financial difficulties or physical problems related to their caregiving responsibilities. About one in six caregivers told researchers that they had more than they can handle, were exhausted at the end of the day, or had little personal time.

Those who experienced caregiving as negative and stressful tended to care for recipients with greater limitations or with dementia symptoms, provided more hours of care, or had health problems of their own. Specifically, caregivers with symptoms of depression and anxiety as well as those with their own physical limitations were much more likely to experience caregiving as negative and stressful.

Researchers are gaining a better understanding of how the stress and time demands of intensive caregiving may weaken the immune system and increase the risk of accelerated aging by examining telomeres—structures found on the ends of chromosomes that protect against DNA damage. Over the past decade, a growing body of research has identified links between shorter telomeres and increased risks for depression and for a number of chronic diseases, including CVD, some cancers, and diabetes. Researchers have documented that caregivers experiencing the greatest stress have shorter telomeres than other caregivers, adding to evidence that chronic stress affects caregivers’ bodies at the genetic and molecular level (Litzelman et al. 2014). Another study that examined differences in telomeres suggests that the chronic stress spouses and adult children experience while caring for Alzheimer’s disease patients may shorten the caregivers’ lives by as much as four to eight years (Damjanovic et al. 2007) (see Box 2, page 6).

Caregiving Patterns Within Families

For an older married person living with a disability, the spouse is usually at the forefront of care activities. And traditionally, parents have tended to rely on daughters (and daughters-in-law) for more care than sons. Recent studies examining the dynamics of elder care within families show how gender and proximity continue to influence who makes up an older person’s network of caregivers (see Box 3, page 7).

Wives tended to be the sole care providers for their husbands no matter how much personal care the men needed, according to analysis of the HRS-related Asset and Health Dynamics Among the Oldest Old (AHEAD) study, which examined more than 7,000 adults ages 70 and older not living in nursing homes in the early 1990s (Feld et al. 2010). But the more functional limitations a wife had, the less likely her husband was her only caregiver and the more likely others helped provide her care, particularly daughters.

This difference in who provides care for married men and women may reflect the fact that many wives are younger than their husbands and are often less disabled. Hands-on
Box 2
Family Care for Older Adults With Dementia

Alzheimer’s disease and other related dementias are a group of chronic diseases of aging characterized by progressive cognitive decline that interferes with independent functioning. Older people who are classified as likely having dementia receive a disproportionate share of informal care, according to the 2011 National Survey of Caregivers. Although older adults with probable dementia represent only about 10 percent of people ages 65 and older, they receive 40 percent of all care hours and their informal caregivers make up one-third of all caregivers (Kasper et al. 2015). People with dementia also account for a substantial share of older adults with severe disability: They make up 50 percent of those who receive help with mobility or three or more self-care activities, such as bathing, dressing, and eating.

Only about 10 percent of people ages 65 and older have dementia, but they receive 40 percent of all informal care hours.

Caring for people with dementia not living in nursing homes is the most time-intensive type of elder care, according to Kasper, Freedman, and Spillman using data from the 2011 National Health and Aging Trends Study (2014). Among adults age 65 and older who received help, those with probable dementia received more than twice as many hours of care, 221 hours in the last month versus 105 for those without dementia. Analysis of Health and Retirement Study (HRS) data, which uses a somewhat different definition of care, showed similar wide differences. Among adults ages 70 and older, those with probable dementia received more than twice as many hours of monthly care on average than adults without dementia, 171 hours versus 66 hours (Friedman 2015).

A recent estimate of the monetary cost of dementia in the United States ranges from $159 billion to $215 billion annually. The main costs associated with dementia are related to institutional and home-based long-term care rather than medical services. However, one-third to one-half of the total cost of dementia represents the estimated value of informal care (Hurd et al. 2013). The researchers predict that the costs of dementia could more than double by 2040 as the baby boom generation reaches advanced ages.

Care for people with dementia is more costly than other conditions and puts a disproportionate burden on families, according to another analysis based on HRS data (Kelley et al. 2015). Researchers found that health care for Medicare beneficiaries in the last five years of life was far more costly and involved significantly higher uncovered out-of-pocket costs for those with dementia than for those with heart disease, cancer, or other medical conditions. Out-of-pocket costs averaged $62,000 for people with dementia, more than 80 percent higher than the out-of-pocket costs for someone with heart disease or cancer. Families of older people with dementia also spent a larger share of family assets for end-of-life care than families of those with other conditions. African Americans, people with less than a high school education, and unmarried or widowed women faced the greatest economic burdens.

Kelley and colleagues (2015) point out that what people with dementia need most is supervision and help with personal care—services not covered by Medicare—while the drugs or surgeries commonly used to treat heart disease and cancer are covered. The burden of providing informal care and the costs of hiring home care services or long-term nursing home care are “largely borne by individuals and families, particularly among vulnerable subgroups,” they write.

Caring for a spouse with dementia at the end of life is more likely to take a lasting toll on the health and cognitive functioning of caregivers than caring for a spouse with other conditions, researchers found using HRS data (Dassel and Carr, 2014; and Dassel, Carr, and Vitaliano, 2015). They examined caregivers’ overall physical and mental health using a frailty index that tracked chronic disease, mobility, physical functioning, symptoms of depression, and self-reported health; they also measured cognitive functioning. Those caring for a spouse who probably had dementia were much more likely to become increasingly more frail over time (even after the spouse’s death) and experience accelerated cognitive decline compared with similar caregivers whose spouses did not have dementia. The researchers suggest that respite services for caregivers may help lessen the toll that caring for a spouse with dementia takes and “enhance the opportunities of dementia caregivers to remain healthy and independent longer.”

Another study compared informal caregivers of older adults with dementia to those caring for older adults with CIND (Cognitive Impairment, Not Dementia), a milder condition that may progress to dementia (Fischer et al. 2011). HRS data showed that 44 percent of dementia caregivers had symptoms of depression compared with 27 percent of CIND caregivers. Both groups were more likely to report emotional strain if they cared for a recipient with behavioral problems. The researchers point out that CIND caregivers “may be struggling with many challenges that are well known as problems for dementia caregivers.” They argue that CIND caregivers should be able to receive access to the same services and support available to dementia caregivers.

References
caring is frequently central to a woman’s identity and may cause her to resist seeking or accepting help, suggest Feld and colleagues (2010). Another study, based on HRS data, showed that adult children tend to be involved in their mothers’ care no matter what their fathers’ health level, but are much more likely to provide care for their fathers after their mothers’ death (Noël-Miller 2010).

If a couple has both sons and daughters, the daughters are much more likely to become their mother’s primary caregivers, underscoring the “primacy of the mother-daughter tie,” report Leopold, Raab, and Engelhart (2014). Their analysis of HRS data tracked 2,400 previously independent adults and their grown children over a decade. Geography was the main factor determining which adult child provided care when a parent began needing assistance; caregivers’ work and family constraints had somewhat less influence. Other factors influencing caregiver selection included parent expectations, frequency of contact before the caregiving need arose, and whether the parent had provided financial assistance to the adult child or made the child a beneficiary of a will.

Among siblings, daughters and grown children living in close proximity to parents were more likely to be continuous care providers, according to another HRS-based study that tracked changes in primary caregivers over a two-year period (Szinovacz and Davey 2013). Parents were more likely to experience a switch in caregivers if they lived alone, had more sons than daughters, or had a higher number of children (and thus more alternative caregivers). The researchers found that the choice of a primary caregiver had more to do with expected gender norms and availability than adult children’s competing obligations such as work or family. The researchers point out that society has traditionally expected daughters to care for their parents and argue that it might be “psychologically more costly for women to decrease their care commitments,” despite the burden or conflicts they may experience.

Economics of Caregiving

The dollar value of the informal care that family and friends provide for older Americans totals an estimated $522 billion a year—more than total Medicaid spending ($449 billion in 2014), according to Chari and colleagues (2015). The researchers used new data from the 2011 and 2012 American Time Use Survey—which uses a relatively broad definition of elder care—to calculate the monetary value of the time uncompensated caregivers gave up in order to provide care. Replacing that care with unskilled paid care at minimum wage would cost $221 billion, while replacing it with skilled nursing care would cost $642 billion annually. Because most caregivers are employed, “the bulk of the economic burden of elderly care is shouldered by working adults,” the researchers argue.

Box 3
Cohabiting Couples and Caregiving

Older adults represent a small share of all U.S. cohabiting couples but their numbers have experienced rapid growth. The number of cohabiting couples over age 50 more than doubled between 2000 and 2010, totaling 2.75 million (Brown et al. 2012). Because cohabitation may reflect a lower level of commitment than marriage, researchers speculate that some older couples who want intimacy without caregiving responsibilities are choosing to cohabit rather than marry.

Using Health and Retirement Study (HRS) data, Noël-Miller (2011) found that individuals with a disability were considerably less likely to receive care from their cohabiting partners than similar married people. She argues that some older adults in cohabiting relationships may risk having their care needs unmet if they are unable to rely on paid care or nursing homes. But she found that when cohabiting partners did provide care, they provided as many hours of care as spouses. “Once nonmarital partners enter the caregiving role, they are as dedicated to providing personal care to their partners as spouses,” she writes.

In another study using HRS data, Vespa (2013) tracked about 1,100 older cohabiting couples over eight years and examined which couples stayed together, married, or split up. Men in poor health were more likely to marry their cohabiting partners if the men were extremely wealthy, while women with the lowest incomes were more likely to marry if the women were in excellent health. He suggests that low-income older women may marry and exchange caregiving for economic security. The study also found that women who had pension income or large social networks were less likely to marry. “Cohabitation could be an alternative that older women choose [in order] to avoid the obligatory caregiving roles of marriage and lead more independent lives,” he writes.

References


Caregiving responsibilities appear to influence labor force participation, according to a study based on HRS data (Van Houtven, Coe, and Skira 2013). Providing personal care assistance to a parent slightly reduced men's likelihood of working and may lead employed women to work fewer hours. The researchers suggest that women may seek lower-paying jobs with more flexibility to accommodate caregiving. Among older workers who left a full-time position, taking on new caregiving responsibilities appeared to act as a barrier to working part time, according to Carr and Kail’s analysis of HRS data (2012). The more caregiving responsibilities the individuals had, the less likely they were to work part-time. “Providing support to new caregivers as they leave full-time work may help them remain engaged in the workforce longer,” the authors suggest.

Women who leave work to provide parental care lose substantial current and future earnings.

To estimate the impact of parent care on adult daughters’ current and future labor force participation and earnings, Skira (2015) created a model that accounts for declining parental health, the impact of a leave on daughters’ work history and experience, and the availability of job offers afterward. Incorporating data from HRS, she found that after taking an employment leave or cutting hours to provide parental care, the chances are low that adult daughters will return to work or increase their work hours. “Women who leave work forgo experience and the associated wage returns and also face a lower expected wage if they return to work,” she writes. The model suggests that the overall median cost to a woman in her mid-50s who leaves work is about $165,000 over two years, about equal to the cost of two years of nursing home care. This estimate is many times higher than estimates that only take into account the cost of lost wages.

Policy Implications

Family caregivers provide the majority of support that allows older adults with disabilities to live independently and avoid costly nursing home care. The estimated dollar value of uncompensated family care overshadows many large federal programs. As the disproportionately large baby boom generation ages, the gap between elder care needs and available caregivers will widen dramatically. In 2010, there were seven potential caregivers ages 45 to 64 (the age group of the average family caregiver) for every person age 80 and older (the age group most likely to have a disability) (Redfoot, Feinberg, and Houser 2013). That ratio is projected to drop to 4 to 1 by 2030 and bottom out at 3 to 1 in 2050 when the entire baby boom generation passes the age 80 milestone. The shrinking pool of potential caregivers reflects the combined impact of lower fertility and longer life expectancy; the former reduces the number of adult children and grandchildren that an older person can turn to for care and the latter increases the length of time individuals may need care. This demographic shift is occurring alongside other trends that also limit the availability of potential caregivers, including an increased share of employed women and caregiving expectations weakened by divorce.

To meet the growing care needs of older people, researchers underscore the importance of anticipating a growing demand for paid care services and designing neighborhoods that allow older people with disabilities to age in place more easily. Policies that enable employed caregivers to manage their competing roles are key to keeping families from seeking nursing home care for the older adults with functional limitations. Researchers also point to innovative approaches, such as designing ways to involve adult children living at a distance in managing their elderly parents’ health care.

Policies that improve long-term care services and supports, and reduce unmet needs, could benefit both older adults and their caregivers.

New surveys document high levels of unmet care needs, particularly among older people with low incomes. New data on caregivers identify those who face particularly high caregiving burdens, such as those caring for older people with dementia or more mild cognitive impairment. These new data can guide policymakers and planners as they target home-based support services and caregiver assistance programs. Indeed, policies that improve long-term care services and supports, and reduce unmet needs, could benefit both older adults and their caregivers, now and in the future.
References


The NIA Centers on the Demography and Economics of Aging

The National Institute on Aging of the National Institutes of Health supports research centers on the demography and economics of aging, based at the University of California at Berkeley; Duke University; Harvard University; the University of Michigan; the National Bureau of Economic Research; the University of Pennsylvania; the RAND Corporation; the University of Southern California and the University of California at Los Angeles; Stanford University; the University of Washington; and the University of Wisconsin.

This newsletter was produced by the Population Reference Bureau (PRB) with funding from the University of Michigan Center on the Demography of Aging. This center coordinates the dissemination of findings from the NIA demography and economics centers listed above. This issue was written by Paola Scommegna, senior writer at PRB.