ASPE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

ISSUE BRIEF

August 2, 2023

THE ECONOMIC VALUE OF UNPAID CARE PROVIDED TO OLDER ADULTS WHO NEED LONG-TERM SERVICES AND SUPPORTS

KEY POINTS

- We project that the average lifetime value of unpaid care after age 50 provided to individuals now turning 65 is $107,000. Among those who receive care, the average lifetime value of this care is $168,000.
- Nearly a quarter of care recipients receive unpaid care valued at $250,000 or more.
- Women, people who did not complete high school, married people, Hispanic people, Black people, and people with a surviving spouse or children receive more care than others.

BACKGROUND

Each year, older Americans who need long-term services and supports (LTSS) receive unpaid assistance with personal care from millions of helpers.[1] In 2011, 14.7 million caregivers helped older adults with daily functioning and personal activities.[2] Far more older people with care needs receive unpaid care than paid care.[3] Unpaid care reduces the need for expensive paid care and enables many older people with LTSS needs to stay at home instead of moving into residential care facilities.[4,5] However, policy debates on LTSS financing often overlook the value of unpaid care. And there is considerable evidence that many family caregivers experience physical, emotional, and financial strain.[6,7,8,9]

METHODS

This brief aims to project the amount and value of care received at older ages, based on family and demographic characteristics. Using estimates from the Health and Retirement Study (HRS) to describe current experiences[i] and projections from the Dynamic Simulation of Income Model (DYNASIM) to highlight experiences over time,[ii] and using a replacement cost approach,[10,11,12] we value an hour of unpaid care as the cost of receiving similar care from paid providers. We project the lifetime value of unpaid care received after age 50 by summing inflation-adjusted annual values from age 51 to death for people who survive until at least age 51. We report the value of unpaid care in two parts: care received when LTSS needs are significant, and care received for other LTSS needs.[iii] This distinction is important, because paid care financed by private long-term care insurance or Medicaid is usually reserved for those with more significant LTSS needs. This allows us to understand the proportion of care provided by families with less significant needs which would not be eligible to claim benefits from a private insurer or Medicaid, versus those that could be covered.

Our measure of significant need mirrors the “benefit triggers” for tax-advantaged long-term care insurance policies specified in the Health Insurance Portability and Accountability Act of 1966 (HIPAA). These HIPAA-based criteria focus on more severe disability, identifying people with chronic need for help with two or more activities of daily living (ADLs), including incontinence, and adding severe cognitive impairment as a separate

criterion. Besides establishing a benchmark for private insurance, the measure has become more common for approximating high need for long-term care services generally and eligibility for Medicaid services specifically, although considerable variation across state programs remains.[13]

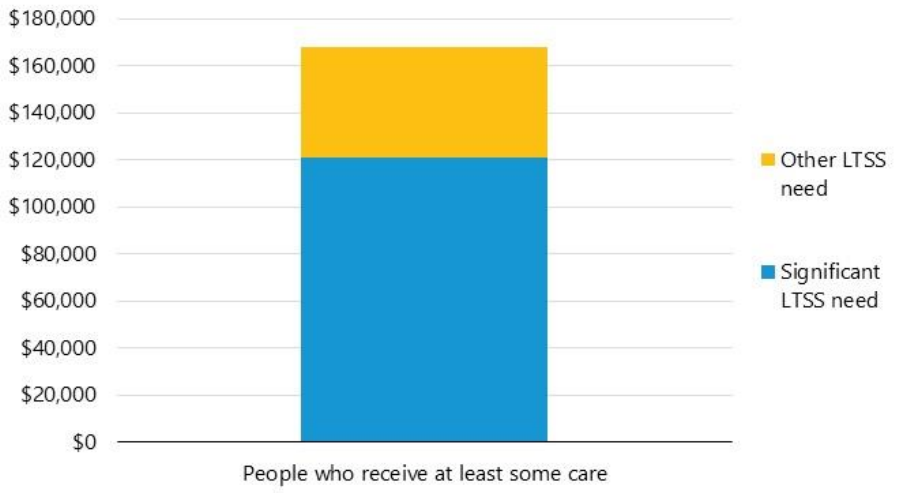
DYNASIM is a large-scale dynamic microsimulation model that starts with a nationally representative population and then endeavors to model directly all the underlying processes (disability, care needs, formal and informal care use, eligibility for and use of public programs, unmet need), including their evolving interactions. To dynamically age the population, we use algorithms that generate transition probabilities from year to year. The underlying data for the model includes the HRS (pooled waves 2016 and 2018), the National Health and Aging Trends Study (2015) and the National Health Interview Survey (2018).

OLDER ADULTS RECEIVE EXTENSIVE HELP

On average, we project the lifetime value of unpaid care after age 50 at $168,000 for people who receive unpaid care and are born between 1956 and 1960, the oldest of whom turn 65 this year (***Figure 1***). About 70% of this care is provided by unpaid family and friends when LTSS needs are significant, and 30% when needs are less significant. 68% of all people born between 1956 and 1960 receive unpaid care after age 50. If we include the 32% of people who never receive unpaid care in calculating value, the average value of unpaid care drops to $107,000.

Figure 1. Value of Unpaid Family Care for People Born between 1956 and 1960 Who Receive Some Care, by Significance of LTSS Needs

Inflation-adjusted 2021 dollars



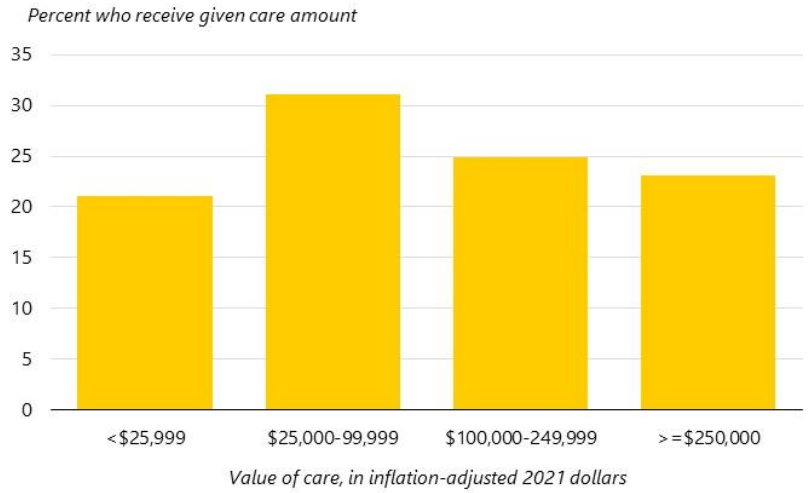
SOURCE: Urban Institute projections from DYNASIM.
NOTES: Sample includes people who survive until at least age 51 and receive unpaid care. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. People are classified as having less significant LTSS need if they report difficulty with at least 1 ADL or instrumental ADL, or if they have mild cognitive impairment.

Distribution of the Value of Care Received

The average amount of care received masks the wide variation in LTSS needs and care in the population. Some people receive care for only a short time, whereas others receive assistance for many years. Nearly a quarter of people who receive care from family receive the paid equivalent of more than $250,000 in unpaid care over their lifetime (***Figure 2***).

Figure 2. Distribution of the Value of Unpaid Family Care for People Born between 1956 and 1960 Who Receive Care (Inflation-Adjusted 2021 Dollars)

Nearly a quarter of older adults will receive care worth more than $250,000 over their lifetime

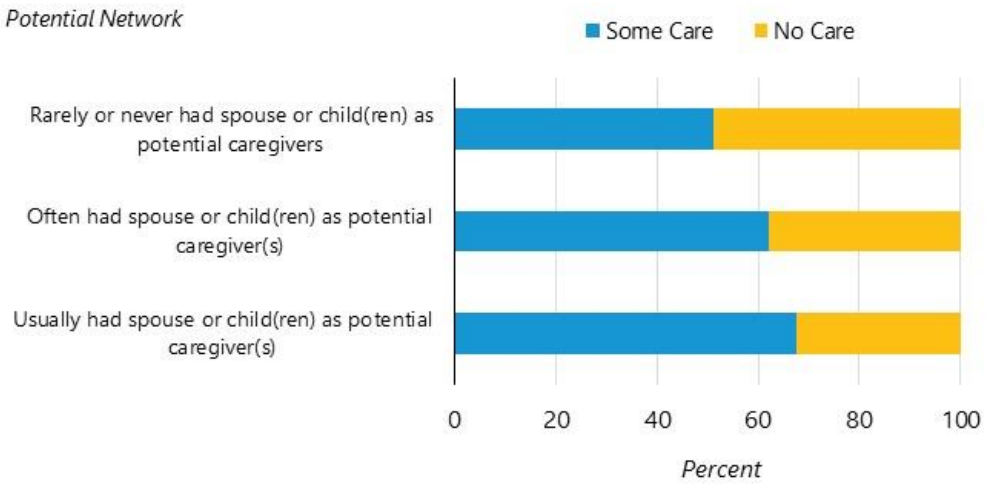


SOURCE: Urban Institute projections from DYNASIM.
NOTES: Sample includes people who survive until at least age 51. Values include care provide to people with significant LTSS needs as well as those with other LTSS needs.

The receipt of unpaid care is closely related to the composition of the potential care network (***Figure 3***). People with a surviving spouse or child are more likely to receive family care than other people. About two-thirds of those who have at least one surviving spouse or child for most of their old age are projected to receive some unpaid care, compared with only about half of those with no close surviving family members or those with a close surviving family member for only a small portion of their old age. Those with close family in their potential care network for much of their later life also tend to receive substantial amounts of care (***Figure 4***). Among those ever receiving care, about a quarter of people who have at least one living spouse or child for at least 75% of the time they are alive after age 50 (termed as "usually" having a potential care network) received at least a quarter of a million dollars in unpaid care. Only 12% of those without a spouse or child for most of later life received care of at least that value.

Figure 3. Presence of Unpaid Family Care by the Percentage of Time with and without Family Caregivers in Their Potential Care Network, People Born between 1956 and 1960

People who have more close caregivers in their potential care network for more time are more likely to receive care

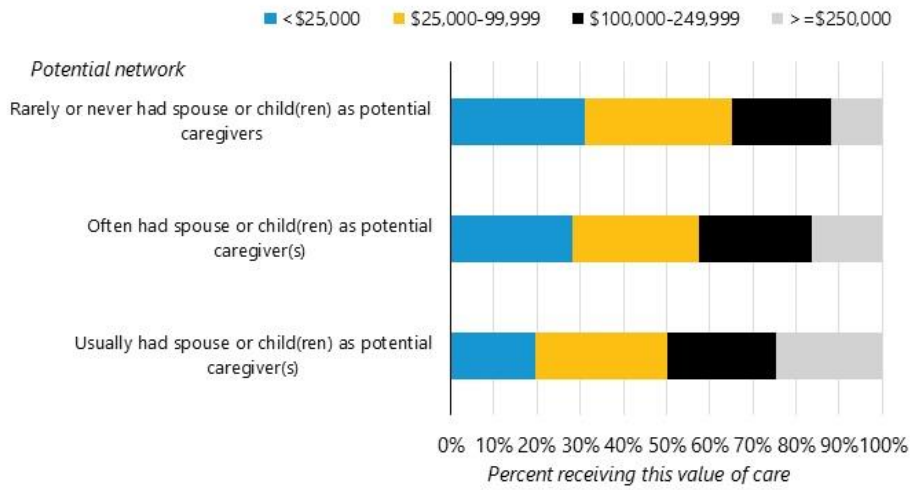


SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample includes people who survive until at least age 51. People in the "rarely or never" category do not have a living spouse or child for at least 25% of the time they are alive after age 50. People in the "often" category have at least 1 living spouse or child for 25-74.9% of the time they are alive after age 50. People in the "usually" category have at least 1 living spouse or child for at least 75% of the time they are alive after age 50. The term "spouse" includes legal spouses and unmarried co-residents who identify as partners.

Figure 4. Distribution of the Value of Unpaid Family Care by the Percentage of Time with and without Surviving Spouses and Children for People Born between 1956 and 1960 (Inflation-Adjusted 2021 Dollars)

Older adult care recipients with dense networks are most likely to receive substantial amounts of care



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample includes people who survive until at least age 51. People in the "rarely or never" category do not have a living spouse or child for more than 25% of the time they are alive after age 50. People in the "mostly" category have at least 1 living spouse or child for 25-74.9% of the time they are alive after age 50. People in the "usually" category have at least 1 living spouse or child for at least 75% of the time they are alive after age 50. The term "spouse" includes legal spouses and unmarried co-residents who identify as partners.

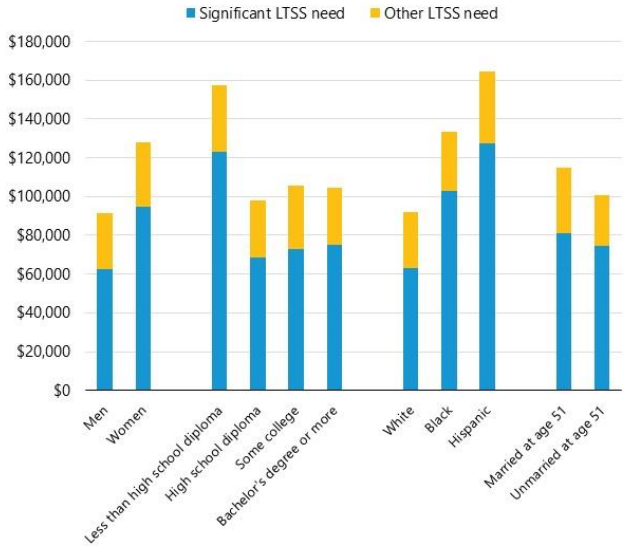
The amount of unpaid care received also varies by education and race and ethnicity of the care recipient (***Figure 5***). Those without a high school diploma can expect to receive roughly 50% more unpaid family care than those with at least a four-year college degree. Hispanic people and Black people can expect to use significantly more unpaid care than White people. These differences arise in part because people with limited education and Black and Hispanic people are more likely than others to develop disabilities at older ages.[14,15]

Women receive about 30% more unpaid care than men, partly because of their longer average lifespan. People who are married in midlife (at age 51) receive about 10% more unpaid family care than people who are not married.

One of the most significant determinants of the amount of unpaid family care received is the care recipient's length of life. Those who live into their early nineties can expect to receive about 3.0 times as much unpaid family care as those who die in their seventies (not shown). Those surviving until at least age 95 can expect to receive 3.3 times as much family care than those who die in their seventies. These marked differences underscore the challenges of preparing for future LTSS needs given uncertainty about one's life span.

Figure 5. Value of Unpaid Family Care for People Born from 1956 to 1960 by Demographic Characteristics and Level of LTSS Need (Inflation-Adjusted 2021 Dollars)

Women, Black and Hispanic people, people with limited education, and those married at age 51 use more family care on average than others



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample includes people who survive until at least age 51, regardless of whether they ever receive unpaid care. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. People are classified as having less significant LTSS need if they report difficulty with at least 1 ADL or instrumental ADL, or if they have mild cognitive impairment. The White and Black categories exclude people of Hispanic origin.

People who receive the most paid care often also receive the most unpaid care over their lifetimes. People with prolonged significant LTSS needs receive more unpaid care than people whose disabilities do not last as long, even if they never transition to a formal care setting like residential care or a nursing home. Again, this finding underscores the fact that a small but significant share of the population needs LTSS from both family and paid helpers in supportive settings; extensive family care does not always obviate the need for nursing home care.

DISCUSSION

Family caregivers provide essential services to older adults with significant LTSS needs. These networks are instrumental to older people's ability to remain in the community.[13] If informal care is not available, persons with disabilities may receive paid LTSS or not have their needs met. Health insurance does not cover LTSS costs, and Medicare, the major public insurance program for older Americans, does not cover most LTSS expenses. Medicaid provides LTSS, but it is only available for individuals who meet income and other eligibility requirements.[16] Research suggests that need for care can vary by race and ethnicity, with Blacks and Hispanics having higher rates of disability requiring assistance than Whites. Further, privately paid care at home is likely to be unsustainable, particularly for unmarried people and those with lower incomes.[13] When valued using replacement cost, the average care recipient approaching retirement age in 2021 can expect to receive $168,000 in unpaid family care after age 50. Yet this value reflects current costs of care, which rely on direct care workers that generally receive low pay, which also may be an unsustainable model.[17] Differences by education, race-ethnicity, gender, marital status, density of the late-life potential care network, and longevity are important. About one in five people who receive care can expect to receive support valued at nearly a quarter million dollars. People who are married or have children are more likely to receive substantial amounts of unpaid care. Substantial unpaid care does not preclude the receipt of significant paid care.

In companion briefs, we discuss other aspects of the diversity in the unpaid care that family and friends provide by race and Hispanic origin,[15] how care use changes over the course of a disability,[18] and how care needs and networks are likely to change in coming decades.[19]

ADDITIONAL METHODOLOGICAL INFORMATION

Our estimates are based on projections from the Urban Institute's Dynamic Simulation of Income Model (DYNASIM).[20] The model simulates unpaid family care using equations estimated on data from the Health and Retirement Study (HRS).[iv] We calibrate the projections to an updated baseline from Social Security's Office of the Chief Actuary that uses early data to try to determine the long-term effects of the COVID-19 pandemic on key demographic and economic outcomes.[21]

Our replacement cost approach to valuing unpaid care is based on the cost of receiving similar care from paid providers. We consider both the wages paid to direct care workers and rates that care agencies charge for in-home care. For the wage rate direct care workers receive, we use the state-specific mean hourly wage for home health and personal care aides reported by the Bureau of Labor Statistics (https://www.bls.gov/oes/current/oes311120.htm#st). For the rate charged by home care agencies, we use state-specific data from Genworth on the median hourly cost for homemaker care.[22] The analysis sets the value of an hour of unpaid care equal to the average of these two estimates. An alternative approach to valuing unpaid care is based on family caregivers' opportunity costs and values each hour of care at the wage the caregiver could receive if otherwise employed.[23] Each of these approaches has strengths and limitations given the broader conceptual challenges.[24] Both of these approaches could potentially understate the true value of unpaid care, because they ignore any non-financial benefits.[25]

We project the lifetime value of unpaid care by summing annual values from age 51 to death. Alternatively, we could have computed the present value at a particular age of the future care stream, which is the lump sum needed to finance those future LTSS costs. Unlike a simple summation of future values, the present value accounts for the interest that could be earned on the funds set aside until they are needed for care.

ENDNOTES

i. The HRS is a longitudinal study of adults ages 51 and older. It oversamples Black and Hispanic people as well as Florida residents.
ii. For information about DYNASIM, see our methods appendix.
iii. Our measure of significant LTSS needs is based on the definition of disability used to determine whether a long-term care insurance policy qualifies for tax benefits, as described in the Health Insurance Portability and Accountability Act of 1996: a need for assistance with at least two activities of daily living (ADLs; among eating, toileting, transferring, bathing, dressing, and continence) that one is unable to perform due to a condition that is expected to last at least 90 days, or a need for substantial supervision for health and safety threats due to severe cognitive impairment (SCI). Other LTSS needs are those that fall below this level, when people report limits with at least one ADL or instrument ADL or moderate cognitive impairment.
iv. Our projections are sensitive to how we treat people who report very intensive caregiving. Some HRS respondents, for example, report that they provide care all the time. Whether we count this as 24 hours per day, 7 days per week or topcode this value affects the projections. Another measurement challenge is care duration. The HRS asks about care in the past month. Data on care over the entire year are more limited.

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ABOUT THE AUTHORS
Melissa M. Favreault, Ph.D., and Richard W. Johnson, Ph.D., work at the Urban Institute.

Judith Dey, Ph.D., William Marton, Ph.D., Helen Lamont, Ph.D., and Lauren Anderson work in the Office of Behavioral Health, Disability, and Aging Policy in the Office of the Assistant Secretary for Planning and Evaluation.

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