



ASPE RESEARCH BRIEF

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF DISABILITY, AGING AND LONG-TERM CARE POLICY

WHAT IS THE LIFETIME RISK OF NEEDING AND RECEIVING LONG-TERM SERVICES AND SUPPORTS?

The prospect of becoming disabled and needing long-term services and supports (LTSS) is perhaps the most significant risk facing older Americans. Older adults with health problems tend to have less wealth than healthier older adults, and wealth tends to fall when people develop health problems (Johnson 2016a; Poterba, Venti, and Wise 2010, 2012). One study, for example, found that over a nine-year period median household wealth grew 20 percent for married people ages 70 and older who did not receive nursing home care, but fell 21 percent for their counterparts who received nursing home care; for single people who received nursing home care, median household wealth fell 74 percent (Johnson, Mermin, and Uccello 2006). Home equity does not decline much at older ages, except when homeowners become widowed or enter a nursing home (Venti and Wise 2004).

LTSS needs often lead to financial hardship because paid care is expensive, public programs like Medicare do not generally cover LTSS costs, and relatively few people have private insurance coverage that can help defray expenses (Cohen 2014; Johnson 2016b). Medicaid covers LTSS costs for people with limited income and assets, but many people incur substantial out-of-pocket costs until they deplete their financial resources and qualify for benefits (Wiener et al. 2013). Medicaid covers many nursing homes residents (Spillman and Waidmann 2015), but very few recipients of residential care or home care (National Center for Health Statistics 2016). Relatively few home care recipients receive Medicaid benefits because there are long waiting lists for Medicaid home and community-based services (HCBS), especially in such states as Texas, Florida, Ohio, and Louisiana (Ng et al. 2015; Peterson et al. 2014). Moreover, the Medicaid income allowances for HCBS enrollees are often too low to cover reasonable living expenses (Johnson and Lindner 2016). Inadequate reimbursement rates may also make residential care communities reluctant to admit Medicaid beneficiaries (O’Keeffe, O’Keeffe, and Bernard 2003).

Better information about the risk of receiving LTSS could inform efforts to formulate alternative financing options for these services and supports, an increasingly important policy objective as the population ages. Kemper, Komisar, and Alecxi (2005/2006) projected that 69 percent of adults turning 65 in 2005 would need LTSS before they died. They defined LTSS needs as limitations with two or more activities of daily living (ADLs), such as bathing, dressing, and getting up and down, limitations with four or more instrumental activities of daily living (IADLs), such as preparing meals, completing

household chores, and taking medication, or receipt of paid LTSS.¹ Kemper and colleagues also projected that 35 percent of adults turning 65 in 2005 would eventually enter a nursing home, 13 percent would spend at least some time in a residential care setting, and 42 percent would receive paid home care. These projections, however, are based on data mostly from the 1980s and 1990s, and the delivery of LTSS has changed significantly over the past two decades. Nursing home care has fallen dramatically, for example, and residential care options have proliferated (Bishop 1999; Freedman and Spillman 2014; National Center for Health Statistics 2016; Spillman and Black 2006).

More recent studies provide an updated but incomplete picture of the lifetime risk of receiving LTSS. Using longitudinal data through 2010, Hurd, Michaud, and Rohwedder (2014) estimate that 58 percent of adults receive nursing home care after age 50. However, the study includes short-term stays that generally involve rehabilitative care following an acute episode, such as a broken hip, and thus overstates the lifetime risk of receiving long-term nursing home care. Moreover, we are not aware of any study that uses recent data to estimate the lifetime risk of receiving home care or residential care. An updated, comprehensive analysis of the lifetime risk of needing and receiving LTSS can help inform ongoing development of LTSS projection models (Favreault and Dey 2015).

This brief provides new evidence on the lifetime risk that older adults will need LTSS and receive paid services and supports. Using longitudinal household survey data from 1995 to 2014 from the Health and Retirement Study (HRS), we estimated the likelihood that adults ever develop disabilities after age 65 and receive paid care, including paid home care, residential care (such as assisted living), nursing home care, and Medicaid-financed nursing home care, and the duration of need and care spells. The study focused on severe LTSS needs, defined as: (1) having difficulty with two or more ADLs expected to last at least 90 days or severe cognitive impairment (SCI); and (2) receiving unpaid care from family or friends or paid LTSS. We considered only those nursing home stays that lasted at least 90 days, which we describe as long-term nursing home care, because shorter stays usually involve rehabilitative care following an acute episode, not long-term care. The analysis incorporated data from exit interviews of close family members of recently deceased HRS respondents, who provided information on LTSS needs and care in the final months of life, when LTSS is most common.

Estimates of the lifetime risk of needing and receiving LTSS after age 65 and the duration of LTSS spells were based on statistical techniques that accounted for the absence of lifetime data for surviving respondents. We also tracked a subset of older Americans from the onset of severe LTSS needs until death. This part of the analysis measured LTSS needs and care for HRS respondents ages 70-79 in 1993 who did not have severe LTSS needs at that time and who died by 2014 (when they were ages 91-100) with a completed HRS exit interview by a family member providing information on LTSS in the last months of life. This sample is not representative of all older adults, because it excludes people who developed disabilities in their 60s or at younger ages, died before ages 70-79, or who survived to very advanced ages. However, this sample allowed us to analyze lifetime LTSS experience without having to make assumptions about future LTSS use by respondents who survived beyond the 2014 survey interview. See the Technical Appendix for more information on our data and methods.

Our results show that 70 percent of adults who survive to age 65 develop severe LTSS needs before they die and 48 percent receive some paid care over their lifetime. Many older people with severe LTSS needs rely exclusively on family and unpaid caregivers, and most paid care episodes are relatively short. Only 24 percent of older adults receive more than two years of paid LTSS care, and only 15 percent spend more than two years in a nursing home. However, the lifetime risk of receiving paid care is not evenly distributed across the population. Lengthy spells of severe LTSS needs and paid care are much more common among older adults with few financial resources than their wealthier counterparts.

Severe LTSS Needs Varies by Demographic Group

- **In 2014, 16 percent of adults ages 65 and older had severe LTSS needs and 8 percent received paid LTSS (Table 1).** Five percent received paid home care, 1 percent received residential care, and 4 percent received at least 90 days of nursing home care, including 2 percent who received Medicaid-financed nursing home care.
- **Severe LTSS needs and receipt of paid LTSS increases with age and are relatively common among women, people of color, and older adults with limited education.**
- **In 2014, 40 percent of adults ages 85 and older had severe LTSS needs, compared with 8 percent of those ages 65-74.** Adults ages 85 and older were also much more likely than younger adults to receive all types of paid LTSS; 13 percent of the oldest-old received long-term nursing home care, compared with only 1 percent of those ages 65-74.
- **Older adults who did not complete high school were three times as likely as older adults with at least a bachelor's degree to have severe LTSS needs.**
- **Differences in the use of paid care across population groups may reflect differences in the availability of informal care by families and friends, as well as differences in the affordability of paid care.**
- **Among older adults with severe LTSS needs in 2014, 52 percent received some paid LTSS (Table 2).** Thirty percent received paid home care, 6 percent received residential care, and 24 percent received long-term nursing home care, including 10 percent who received Medicaid-financed long-term nursing home care. Between 2002 and 2014, the share of older adults with severe LTSS needs receiving paid home care and residential care increased, while the share receiving long-term nursing home care fell.

Lifetime Risk of Service LTSS Needs and Paid LTSS

- **The chances of ever developing severe LTSS needs and receiving paid LTSS after age 65 are much greater than the chances of having such needs and receiving such services in a single year.** We estimate that 70 percent of adults who survive to age 65 develop severe LTSS needs before they die and 48 percent receive some paid LTSS over their lifetime (Table 3). After age 65, 29 percent of adults develop severe LTSS needs and receive paid home care, 5 percent receive residential care, and 28 percent receive at least 90 days of nursing home care, including 13 percent who receive long-term Medicaid-financed nursing home care.
- **Lifetime risk depends on life expectancy and the chances of needing or using LTSS at every age.** For example, we estimate that 28 percent of older adults who did not graduate from high school had severe LTSS needs in 2014, compared with only 9 percent of those with at least a bachelor's degree. However, because better-educated adults tend to live longer and LTSS needs increase with age, differences in lifetime risk are much narrower. We estimate that 72 percent of older adults who did not graduate from high school have severe LTSS needs during their lifetime, compared with 66 percent of those with at least a bachelor's degree.
- **Those who survive to older ages are more likely to develop severe LTSS needs and receive paid LTSS over their lifetime than those who die at younger ages.** For example, 54 percent of people who survive to age 85 receive some paid LTSS and 34 percent will receive long-term nursing home care, whereas only 23 percent of those who die between ages 65 and 74 receive any paid LTSS and only 9 percent receive long-term nursing home care.
- **Women are more likely than men to develop severe LTSS needs after age 65 and receive paid LTSS.** We estimate that 75 percent of 65-year-old women develop severe LTSS needs before they die, compared with 64 percent of their male counterparts; 55 percent of women and 38 percent of men receive some paid LTSS over their lifetime. Women are also about two-thirds more likely than men to receive long-term nursing home care over their lifetime (34 percent versus 20 percent), and about twice as likely to receive long-term Medicaid-financed nursing home care (17 percent versus 8 percent).
- **Socioeconomic differences in the lifetime risk of developing severe LTSS and receiving paid LTSS are relatively small.** People of color are only 3 percentage points more likely than nonHispanic Whites to develop severe LTSS needs, and nonHispanic Blacks are only 1 point more likely than nonHispanic Whites to receive any paid LTSS. Older adults with a bachelor's degree are 6 percentage points less likely than those who did not complete high school to develop severe LTSS needs but only 1 point less likely to receive any paid LTSS.

Duration of Severe LTSS Needs and Paid LTSS

- **Most spells of severe LTSS needs are relatively short.** Forty percent of adults who develop severe LTSS needs experience such disability for no more than two years, and another 22 percent have severe LTSS needs for only 2-4 years (Table 4). Severe LTSS needs last more than four years for only 38 percent of older adults with severe LTSS needs and only 26 percent of all adults who survive to age 65. Nonetheless, a small portion of older adults are severely disabled for a long time; severe needs last more than ten years for 9 percent of older adults with severe needs and 6 percent of all older adults.
- **Paid LTSS does not generally last nearly as long as severe LTSS needs.** Only 28 percent of older adults who receive paid LTSS care, only 13 percent of all older adults, obtain these paid services and support for more than for four years. Only 5 percent of users and 2 percent of all older adults receive paid LTSS care for more than ten years. Nearly half (49 percent) of users receive paid LTSS for no more than two years. Nursing home care lasts somewhat longer than paid home care; 22 percent of paid home care recipients and 25 percent of nursing home care recipients obtain those services for more than four years. Fifty percent of nursing home residents receive no more than two years of nursing home care after age 65, and only 15 percent of all older adults receive more than two years of nursing home care. Similarly, 58 percent of paid home care recipients and receive no more than two years of paid home care and only 13 percent of all older adults receive more than two years of paid home care.
- **Relatively long disability and paid care spells are common among people of color, women, and people with limited income and wealth.** Fifty percent of older nonHispanic Blacks and 57 percent of older Hispanics who develop severe LTSS needs experience those needs for more than four years, compared with only 35 percent of nonHispanic Whites (Table 5). Severe LTSS needs last more than four years for 47 percent of older adults who had no more than \$5,000 in nonhousing wealth when they developed severe LTSS needs, but lasted that long for only 35 percent of those with more than \$200,000 in nonhousing wealth. Older adults with limited financial resources likely receive paid LTSS for a relatively long time (Table 6), because many qualify for Medicaid-financed care.

Incidence and Duration of LTSS after Ages 70-79

- **Seventy-two percent of adults with no more than one ADL limitation at ages 70-79 develop severe LTSS needs before they die (Table 7).** Thirty-seven percent have severe LTSS needs for more than two years, and 9 percent have severe needs for more than six years. On average, severe LTSS needs last 2.2 years overall and 3.0 years among those who develop LTSS needs.
- **Nearly half (48 percent) of adults in our sample receive some paid LTSS before they die and 21 percent receive paid LTSS for more than two years.**

Only 3 percent receive paid LTSS for more than six years. For this subset of older adults, paid LTSS lasts 1.2 years overall, on average, and 1.6 years among people with severe LTSS needs and 2.4 years among people who receive paid LTSS.

- **Nursing home care is slightly more common than paid home care and tends to last longer.** Thirty-two percent of adults with no more than one ADL limitation at ages 70-79 receive at least 90 days of nursing home care before they die, including 13 percent who receive Medicaid-financed long-term nursing home care, 28 percent receive paid home care, and 4 percent receive residential care. Among users, nursing home care lasts 2.3 years on average, paid home care lasts 1.8 years, and residential care lasts 2.5 years. Only 2 percent of our sample receive more than six years of nursing home care before they die, including only 8 percent of those who ever receive at least 90 days of nursing home care.
- **Women are more likely than men to develop severe LTSS needs after age 70, and women's severe LTSS needs generally last longer.** Among adults who report no more than one ADL limitation at ages 70-79, 78 percent of women develop severe LTSS needs before they die, compared with 65 percent of men (Table 8); 44 percent of women, but only 28 percent of men, have severe LTSS needs lasting more than two years. The incidence of severe LTSS needs varies with other personal characteristics, but the differences are relatively small.
- **The duration of LTSS needs differs significantly among groups, with people of color--especially nonHispanic Blacks--and people with limited financial resources before developing disabilities experiencing much longer spells of severe LTSS needs than other people.** For example, 43 percent of those without any financial wealth (or with negative wealth) have severe LTSS needs for more than two years, compared with 28 percent of those with more than \$100,000 of financial wealth; 15 percent of those without any financial wealth and only 4 percent of those with more than \$100,000 have severe LTSS needs for more than six years.
- **People with little income or wealth before developing LTSS needs are much more likely to receive some paid LTSS by age 85 and are more likely to receive paid LTSS for a long time than those with more financial resources.** Among adults who report no more than one ADL limitation at ages 70-79, 31 percent of those with no more than \$5,000 in nonhousing wealth receive some paid LTSS by age 85 and 23 percent receive paid LTSS for more than two years (Table 9). By contrast, only 19 percent of those with more than \$200,000 in nonhousing wealth receive some paid LTSS by age 85 and only 17 percent receive some paid LTSS for more than two years.
- **Paid LTSS is especially common among women and single adults.** NonHispanic Blacks are also more likely to receive more than two years of paid LTSS than nonHispanic Whites.

- **Fourteen percent of our sample receives more than two years of nursing home care and 15 percent receive at least 90 days of care by age 85 (Table 10).** Women are more likely to receive at least 90 days of nursing home care than men, and people who were single before they developed LTSS needs are more likely to receive nursing home care than people who were married. People with less income and wealth before they became disabled are more likely to spend more than two years in a nursing home than people with more income and wealth, and they tend to enter nursing homes earlier.
- **Thirteen percent of adults with no more than one ADL limitation at ages 70-79 receive at least 90 days of Medicaid-financed nursing home care before they die, and 5 percent receive more than two years of Medicaid-financed care.** Medicaid-financed nursing home care is relatively common among women, African Americans, and people who were unmarried and had little income and wealth before they developed LTSS needs. For example, 23 percent of adults with no more than \$5,000 in nonhousing wealth receive at least 90 days of Medicaid-financed nursing home care, compared with only 3 percent of people with more than \$200,000 in nonhousing wealth.
- **People who receive Medicaid-financed nursing home care tend to spend more time in nursing homes than those who self-finance their care or have private long-term care insurance (LTCI).** Among adults ages with no more than one ADL limitation at ages 70-79 who subsequently receive at least 90 days of nursing home care, the average amount of lifetime nursing home care is 3.2 years for people who obtain some Medicaid-financed care and 1.7 years for people whose stay is never covered by Medicaid (Table 11). Three in ten nursing home care recipients who receive some Medicaid-financed care spend more than four years in a nursing home, compared with only one in ten nursing home care recipients whose care is never covered by Medicaid.

Conclusions

Although only 16 percent of adults ages 65 and older had severe LTSS needs in 2014 and only 8 percent received paid LTSS care, the lifetime risk of ever needing and receiving LTSS is much higher. Seventy percent of adults who survive to age 65 develop severe LTSS needs before they die and 48 percent receive some paid LTSS over their lifetime. After age 65, nearly three out of ten adults develop severe LTSS needs and receive paid home care, and about the same number receive at least 90 days of nursing home care. However, only 13 percent of older adults receive long-term Medicaid-financed nursing home care.

Most spells of severe LTSS needs and paid care are relatively short. Four out of ten adults who develop severe LTSS needs experience such disability for no more than two years, and only about one in four of all 65-year-olds experience more than four years of severe LTSS needs before they die. Lengthy spells of paid LTSS care are even

less common. Only 24 percent of older adults receive more than two years of paid LTSS care, and only 15 percent spend more than two years in a nursing home.

The lifetime risk of receiving paid care is not evenly distributed across the population. People with limited education and relatively few financial resources are more likely to have severe LTSS needs and receive paid care in a year than people with more education and resources. Over a lifetime, however, socioeconomic differentials in LTSS risks narrow because well-educated, wealthy adults tend to live longer than other people. Nonetheless, older adults with limited education and little income and wealth tend to develop severe LTSS needs and receive paid care at much younger ages than their wealthier counterparts, and thus are more likely to experience long spells of severe LTSS needs and paid care than their wealthier counterparts.

Many older people with LTSS needs rely exclusively on unpaid care from family and friends, even when their disabilities are severe, perhaps because relatively few people can afford paid care and private and public LTSS insurance is limited (Johnson and Wang 2017). In 2014, only one-half of adults ages 65 and older with severe LTSS needs received any paid LTSS. Only about two-thirds of older adults who eventually develop severe LTSS needs receive any paid care over their lifetime, and severe LTSS needs last about twice as long as spells of paid care. This reliance on unpaid care substantially reduces spending on LTSS but often creates significant burdens for informal caregivers (Eden and Schulz 2016; Kasper et al. 2015; Wolff et al. 2016).

Technical Appendix

Our estimates are based on data from the HRS, a longitudinal survey of older Americans conducted by the Survey Research Center at the University of Michigan. It collects data on a wide range of topics, including health and disability status, receipt of LTSS, financial status, number of adult children, and basic demographics. The survey's sampling frame is complex. The HRS began interviewing a sample of 12,652 respondents in 1992, consisting of adults ages 51-61 and their spouses, with follow-up interviews in 1994 and 1996. In 1993, it began interviewing another sample of 8,222 respondents, consisting of adults ages 70 and older and their spouses, with a follow-up interview in 1995. The HRS merged the two samples in 1998 and added new samples of respondents ages 51-56 and ages 67-74, so that the 1998 sampling frame consisted of adults ages 51 and older. HRS respondents have been interviewed every other year since 1998, and the survey adds a new sample of respondents ages 51-56 every six years (most recently in 2016, although those data are not yet available). In 2014, HRS interviewed 18,748 respondents, including 18,172 who were older than age 50 and 10,386 who were ages 65 or older.

All HRS respondents live in the community, not in nursing homes, when first interviewed, but the HRS follows them into nursing homes as necessary. Proxy responses are solicited from spouses and other close relatives when respondents are living in nursing homes or otherwise unable to respond themselves. The HRS also collects information from next of kin after respondents die, providing information about disability and care received in the last months of life.

Our study used data from 1995 through 2014, the most recent year available, and included information about recently deceased respondents from the exit interviews.² We restricted our sample to respondents ages 65 and older. The analysis excluded data from the 1992, 1993, and 1994 HRS waves because many HRS questions about disability and LTSS in those years differed from questions in later years.

Disability

The HRS collects detailed information about disability status. Each wave, the HRS asks respondents if they have any difficulty because of a physical, mental, emotional, or memory problem with ADLs or IADLs that is expected to last at least three months. ADLs include getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. IADLs include using a map, preparing a hot meal, shopping for groceries, making a phone call, and taking medication. We classified respondents who reported that they did not engage in a particular IADL as having a limitation only if they said that they did not perform that activity because of a health problem. Exit interviews ask the next of kin if recently deceased respondents received any help with ADLs or IADLs over the last three months of their lives; it does not ask if they had any difficulty with these activities.

The survey assesses cognitive impairment by administering a cognitive test to self-respondents. The test measures episodic memory and mental status. Interviewers read a list of ten nouns and ask respondents to recall as many words as possible. After about five minutes of questions on other topics, interviewers again ask respondents to recall as many words as possible from the original list of ten nouns. The test measures mental status by asking respondents to subtract 7 from 100 five successive times; count backwards ten times; report the month, day, year, and day of the week when interviewed; name an object they “usually used to cut paper” and the “kind of prickly plant that grows in the desert;” and name the United States president and vice president. HRS uses these responses to create a cognitive score, assigning one point for each correct word recalled (for a maximum score of 20 points), one point for each successful subtraction of seven (for a maximum score of 5), two points for successfully counting backwards (one point if successful on the second try but not the first), and one point for correctly naming each object, the president, the vice president, and each element of the date (for a maximum score of 8). The total possible score, then, is 35 points. The HRS imputed missing cognition data for self-respondents, based on demographic, health, and economic variables, as well as cognitive variables from the current and prior waves (Fisher et al. 2015).³

Respondents who provide survey information through proxies are more likely than self-respondents to have cognitive impairments, yet the HRS cannot administer a cognitive test to them. Instead, the survey asks proxies about several behaviors that are often symptomatic of SCI--whether respondents ever get lost in a familiar environment, ever wander off and do not return by themselves, or ever see or hear things that are not really there. The HRS also asks proxies to rate respondents' memory, from excellent to poor. Exit interviews administered to deceased respondents' next of kin include these questions about memory and behaviors associated with cognitive impairment.

We classified respondents as having SCI if they scored 7 points or less on the cognitive test or if their proxy respondents (or next of kin) reported that they had poor memory or ever exhibited symptoms of SCI. The 7-point threshold is the average of the 8-point threshold used by Herzog and Wallace (1997) to define cognitive impairment and the 6-point threshold used by Langa, Kabeto, and Weir (2009).

The analysis measured the lifetime risk of developing severe LTSS needs and the lifetime risk that adults with severe LTSS needs receive paid LTSS. We classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had two or more ADL limitations or SCI, a disability threshold similar to that specified in the Health Insurance Portability and Accountability Act (HIPAA) for collecting tax-free benefits from private LTCI.⁴

LTSS Use

The HRS collects data on respondents' use of various types of LTSS. Respondents who report receiving help with ADLs or IADLs are asked how much assistance they received from each helper over the past month and whether each helper was paid. Exit interviews collect information about help received in a "typical month" over the last three months of a respondent's life. The HRS also asks respondents (and next of kin) about nursing home care, including the number of nights spent in a nursing home over the past two years or since the previous wave and whether Medicaid covered any of the costs. The analysis considered only nursing home care that lasted at least 90 days because people with shorter stays most likely entered a nursing home for rehabilitative care and may not need long-term care. We used hotdeck techniques to impute missing responses on length of nursing home stays.

We also identified respondents who received Medicaid-financed nursing home care, including both those who explicitly reported that Medicaid paid for at least some of their nursing home care and those receiving nursing home care who reported having Medicaid coverage. Because household surveys generally undercount Medicaid coverage (Call et al. 2008), we also assigned Medicaid to HRS respondents who reported receiving Supplemental Security Income (SSI) payments, which generally qualifies people for Medicaid.

Finally, the HRS collects data on residential care. The survey identifies respondents whose home is part of a retirement community, senior housing, or another type of housing that provides services for older adults and asks them about the various services offered. We classified respondents as receiving residential care if they lived in a senior housing complex that offered group meals, transportation services, nursing care or an on-site nurse, help with housekeeping chores, or help with bathing, dressing, or eating and if they used any of these services. Exit interviews do not collect information on deceased respondents' living situations, so we could not identify respondents who received residential care in the final months of their life. Although it is difficult to measure residential care and many alternative definitions are possible, our estimate of the overall prevalence of such care using this measure is similar to the

recent prevalence estimate published by the National Center for Health Statistics (2016).

Financial Status

We constructed measures of household income and wealth, reported in inflation-adjusted 2015 dollars (based on changes in the consumer price index) and adjusted for differences in household size. Annual household income included earnings (from both wage and salary employment and self-employment); pensions and annuities; SSI and Social Security benefits (including disability insurance benefits); business or farm income; rent; dividend and interest income; trust funds; royalties; unemployment and worker's compensation benefits; veteran's benefits; welfare; benefits from the supplemental nutrition assistance program (formerly known as food stamps); alimony; and lump sums from insurance, pensions, and inheritances received by a respondent or spouse. Our total household wealth measure consisted of housing wealth, financial wealth, and other household wealth. Housing wealth included the value of first and second homes, net of any housing debt (including outstanding mortgages, home loans, and home equity lines of credit).⁵ Financial wealth included the value of IRAs; Keoghs; stocks; mutual funds; investment trusts; bonds; bond funds; CDs; government savings bonds; treasury bills; checking, savings, and money market accounts; and other savings, net of nonhousing debt. Other household wealth included the net value of businesses, vehicles, and real estate (except for primary and secondary residences). We used imputed financial values when respondents did not report complete information.

Our analysis adjusted the measures of household wealth and income for differences in household size. For married adults, whose resources must cover two spouses, we divided household wealth by 1.41--the square root of 2. We did not simply divide income and wealth in half because married couples generally have lower living expenses than two single adults living alone (Citro and Michael 1995).

Methods

We began by computing the share of adults ages 65 and older with severe LTSS needs and the share who received paid LTSS, by type of service. We show how these shares varied by personal characteristics and how they changed between 2002 and 2014.

The study then estimated the likelihood that adults ever developed severe LTSS needs after age 65 and received paid LTSS, including paid home care, residential care (such as assisted living), nursing home care, and Medicaid-financed nursing home care. Through 2014, the latest available interview, the HRS was unable to follow some respondents until death because they were still surviving or they dropped out of the survey over time. Considering only observed LTSS needs and use for these respondents would lead us to understate their lifetime experience, and considering only cases observed from disability onset until death would bias our estimates, because the sample would overrepresent people who died at relatively young ages or who developed LTSS needs at relatively old ages. Instead, we accounted for censoring by

basing our estimates of lifetime LTSS on Kaplan-Meier survivor functions that started at age 65 and showed at every subsequent age the share of respondents who had not yet experienced each outcome.⁶ Respondents remained in the sample until they experienced the outcome or dropped out of the survey.⁷ To show how probabilities vary by personal characteristics, we also estimated separate functions for men and women and for various groups defined by race and ethnicity, educational attainment, and age at death. Our estimates of lifetime outcomes were based on the share that experienced the outcome by age 95; we excluded outcomes at older ages because our sample included too few respondents older than 95 to generate reliable estimates.⁸ The sample included 248,232 observations on 25,055 respondents.

To estimate the duration of severe LTSS needs and use of LTSS, we estimated hazard models of time to cessation of severe needs (through recovery or, more commonly, death) or paid care for those respondents with severe LTSS needs and those receiving LTSS. Our duration models were estimated on a sample of 9,787 respondents with severe LTSS, 5,792 respondents receiving any paid LTSS, 3,625 respondents receiving paid home care, 3,082 respondents receiving long-term nursing home care, and 1,510 respondents receiving Medicaid-financed nursing home care.

We also measured the incidence and duration of LTSS needs and care for a sample of 3,236 HRS respondents ages 70-79 in 1993 who did not have severe LTSS needs at that time and who died by 2014 (when they were ages 91 to 100) with a completed HRS exit interview, which provided information on LTSS in the last months of life. This sample is not representative of all older adults, because it excludes people who developed disabilities in their 60s or at younger ages, died before ages 70 to 79, or who survived to very advanced ages. However, this sample allowed us to analyze lifetime LTSS experience without having to make assumptions about future LTSS use by respondents who survived beyond the 2014 survey interview.

Endnotes

1. Stallard (2011) and Brown and Warshawsky (2013) also present estimates of lifetime disability and disability transitions, respectively, using somewhat different measures.
2. The 2014 data were preliminary when we completed the analysis. RAND has produced a cleaned version of a subset of the HRS data, which we used whenever possible. When we completed our analysis, the latest release of the RAND dataset, version O, included information through the 2012 interview (Chien et al. 2015). It does not include data from the exit interviews.
3. We did not impute missing cognitive scores in the 2014 wave, however. For more information about the cognitive measures in the HRS, see McArdle, Fisher, and Kadlec (2007) and Ofstedal et al. (2005).
4. HIPAA stipulates that an individual must be unable to perform two or more ADLs for at least 90 days without substantial assistance from someone else or must

require substantial supervision because of SCI. However, the HRS does not ask respondents if they need assistance with various ADLs; it only asks if they have any difficulty with ADLs. To create a threshold more consistent with HIPAA, we added the requirement that individuals must also receive some LTSS.

5. Information about the value of second homes is not available in the 1993, 1994, and 1995 waves, because of problems with the way the HRS collected the data in those years.
6. We subtract this estimate from one to report the share that experienced each outcome.
7. Respondents who died before they experienced the event remained in the sample indefinitely, because unlike respondents who dropped out of the survey they could never subsequently experience the event.
8. For more information on survival curves, see Kiefer (1988).

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Tables

TABLE 1. Prevalence of Severe LTSS Needs and Receipt of Paid LTSS, Adults Ages 65 and Older, 2014 (%) (by LTSS type and personal characteristics)						
	Severe LTSS Needs	Any Paid LTSS	Paid Home Care	Residential Care	Long-Term Nursing Home Care	
					Any	Medicaid- Financed
All	16	8	5	1	4	2
Age						
65-74	8	3	2	<1	1	<1
75-84	17	8	4	1	4	1
85 and older	40	26	14	4	13	6
Sex						
Men	14	6	3	1	2	1
Women	17	10	6	1	5	2
Race and Ethnicity						
NonHispanic White	14	8	4	1	4	1
NonHispanic Black	22	10	7	<1	4	2
Hispanic	23	11	9	1	2	2
Education						
Not high school graduate	28	13	8	1	6	3
High school graduate only or some college	15	8	4	1	4	2
Bachelor's degree or more	9	5	3	1	2	0
SOURCE: Author's estimates from the HRS. NOTES: Estimates were based on a sample of 11,469 respondents ages 65 and older. The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. ADLs included getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. The analysis counted only LTSS received by adults with severe LTSS needs and only those nursing home stays that lasted at least 90 days. Health problems and residential care were measured at the time of the survey interview, receipt of home care was measured over the 30 days preceding the interview, and nursing home care was measured over the 2 years preceding the interview. Consequently, some respondents were classified as receiving both home care and nursing home care.						

TABLE 2. Prevalence of Paid LTSS, Adults Ages 65 and Older with Severe LTSS Needs, 2002-2014 (by LTSS type and year)						
	Number of Observations	Any Paid LTSS (%)	Paid Home Care (%)	Residential Care (%)	Long-Term Nursing Home Care (%)	
					Any	Medicaid- Financed
2002	2,052	52	25	4	29	13
2006	2,061	51	26	5	27	12
2010	2,317	52	30	5	25	11
2014	2,172	52	30	6	24	10
SOURCE: Author's estimates from the HRS. NOTES: The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. ADLs included getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. The analysis counted only paid LTSS received by adults with severe LTSS needs and only those nursing home stays that lasted at least 90 days. Health problems and residential care were measured at the time of the survey interview, receipt of home care was measured over the 30 days preceding the interview, and nursing home care was measured over the 2 years preceding the interview. Consequently, the analysis classified some respondents as receiving both home care and nursing home care.						

TABLE 3. Probability that Adults Will Ever Develop Severe LTSS Needs and Receive Paid LTSS after Age 65 (%) (by LTSS type and personal characteristics)						
	Severe LTSS Needs	Any Paid LTSS	Paid Home Care	Residential Care	Long-Term Nursing Home Care	
					Any	Medicaid-Financed
All	70	48	29	5	28	13
Age at Death						
65-74	51	23	17	<1	9	5
75-84	63	36	24	1	19	9
85 and older	75	54	31	5	34	15
Sex						
Men	64	38	24	3	20	8
Women	75	55	33	6	34	17
Race and Ethnicity						
NonHispanic White	70	48	28	5	29	12
NonHispanic Black	73	49	32	2	26	18
Hispanic	73	47	39	2	17	13
Education						
Not high school graduate	72	49	30	3	29	17
High school graduate only or some college	70	48	28	6	29	12
Bachelor's degree or more	66	48	34	7	25	5
SOURCE: Author's estimates from the HRS.						
NOTES: Probabilities were derived from hazard functions estimated for each outcome. The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. ADLs included getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. The analysis counted only LTSS received by adults with severe LTSS needs and only those nursing home stays that lasted at least 90 days.						

TABLE 4. Distribution of Duration in Years of Severe LTSS Needs and Paid LTSS after Age 65 (%) (older adults with severe LTSS needs or receiving paid LTSS)								
	No More Than 2	2 to 4	4 to 6	6 to 8	8 to 10	More Than 10	All	More Than 4
Older Adults with Severe LTSS Needs or Receiving Paid LTSS								
Severe LTSS needs	40	22	14	9	5	9	100	38
Any paid LTSS	49	23	12	7	4	5	100	28
Paid home care	58	20	8	6	2	6	100	22
Long-term nursing home care								
All	50	25	13	7	3	2	100	25
Medicaid-financed	53	24	10	8	3	2	100	23
All Adults Surviving to Age 65								
Severe LTSS needs	28	15	10	6	4	6	70	26
Any paid LTSS	24	11	6	3	2	2	48	13
Paid home care	17	6	2	2	1	2	29	7
Long-term nursing home care								
All	14	7	4	2	1	1	28	8
Medicaid-financed	7	3	1	1	0	0	13	2
SOURCE: Author's estimates from the HRS.								
NOTES: Estimates were restricted to adults with derived from hazard functions of time to the end of severe LTSS needs (through permanent recovery or death) or receipt of services. The duration of LTSS needs estimates were restricted to adults with severe needs, and duration of paid LTSS estimates were restricted to users of those services and supports. The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. ADLs include getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. Paid LTSS included nursing home care that lasted at least 90 days, paid home care, and residential care. The analysis counted only LTSS received by adults with severe LTSS needs.								

TABLE 5. Distribution of Duration in Years of Severe LTSS Needs after Age 65, by Personal Characteristics (%)
(older adults with severe LTSS needs or receiving paid LTSS)

	No More Than 2	2 to 4	4 to 6	6 to 8	8 to 10	More Than 10	All	More Than 4
Sex								
Men	47	22	13	7	5	7	100	32
Women	35	21	16	10	6	11	100	43
Race and Ethnicity								
NonHispanic White	42	22	14	9	5	7	100	35
NonHispanic Black	33	19	16	10	8	16	100	50
Hispanic	28	15	11	12	6	28	100	57
Education								
Not high school graduate	36	22	15	10	6	11	100	42
High school graduate only or some college	43	20	14	9	5	9	100	37
Bachelor's degree or more	41	25	14	6	6	8	100	34
Financial Wealth								
Negative or zero	34	19	15	8	7	17	100	47
\$1-\$20,000	39	23	14	10	5	9	100	37
\$20,001-\$100,000	42	22	17	10	5	5	100	37
More than \$100,000	45	22	14	9	5	6	100	34
Nonhousing Wealth								
No more than \$5,000	34	19	15	10	7	15	100	47
\$5,001-\$50,000	38	23	14	9	5	10	100	38
\$50,001-\$200,000	43	21	15	10	4	7	100	36
More than \$200,000	43	22	14	9	5	7	100	35
Household Income								
No more than \$13,500	38	20	14	10	7	12	100	43
\$12,5001-\$20,000	38	22	17	9	5	10	100	41
\$20,001-\$40,000	41	24	14	9	5	7	100	35
More than \$40,000	45	20	12	9	5	8	100	34

SOURCE: Author's estimates from the HRS.

NOTES: Estimates were derived from hazard functions of time to the end of severe LTSS needs through permanent recovery or death. The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. ADLs include getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. Wealth and income were measured in constant 2014 dollars in the wave preceding the onset of severe LTSS needs. We also adjusted household wealth and income for family size by dividing those measures by 1.41 when respondents were married.

TABLE 6. Distribution of Duration in Years of Paid LTSS after Age 65 (%)
(by personal characteristics, older adults receiving paid LTSS)

	No More Than 2	2 to 4	4 to 6	6 to 8	8 to 10	More Than 10	All	More Than 4
Sex								
Men	59	22	9	5	2	3	100	19
Women	44	24	13	8	5	6	100	32
Race and Ethnicity								
NonHispanic White	51	23	12	7	4	4	100	27
NonHispanic Black	44	22	15	8	4	8	100	35
Hispanic	32	17	10	13	6	22	100	51
Education								
Not high school graduate	48	23	12	8	4	6	100	30
High school graduate only or some college	50	22	12	7	5	4	100	28
Bachelor's degree or more	47	25	13	5	3	7	100	28
Financial Wealth								
Negative or zero	44	22	10	7	6	10	100	33
\$1-\$20,000	48	22	13	8	3	7	100	31
\$20,001-\$100,000	52	24	12	6	3	2	100	23
More than \$100,000	50	24	11	7	5	3	100	26
Nonhousing Wealth								
No more than \$5,000	42	23	11	8	5	11	100	35
\$5,001-\$50,000	47	23	13	8	4	6	100	31
\$50,001-\$200,000	53	23	11	7	4	2	100	24
More than \$200,000	51	24	11	6	5	3	100	25
Household Income								
No more than \$13,500	46	22	11	8	5	8	100	32
\$12,5001-\$20,000	48	24	12	7	4	5	100	28
\$20,001-\$40,000	51	23	13	6	4	3	100	26
More than \$40,000	52	33	11	7	4	4	100	26

SOURCE: Author's estimates from the HRS.

NOTES: Paid LTSS included nursing home care that lasted at least 90 days, paid home care, and residential care. Estimates were derived from hazard functions of time to the end of paid LTSS (often because of death) for adults ages 65 and older receiving paid LTSS. The analysis counted only LTSS received by adults with severe LTSS needs (2 or more ADL limitations or SCI). ADLs included getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet. Wealth and income were measured in constant 2014 dollars in the wave preceding the onset of severe LTSS needs. We also adjusted household wealth and income for family size by dividing those measures by 1.41 when respondents were married.

TABLE 7. Incidence and Duration of Severe LTSS Needs and Paid LTSS by Type (%)
(adults ages 70-79 in 1993 who report no more than 1 ADL limitation in 1993)

	Any (%)	More Than 2 Years (%)	Mean Number of Years	Duration in Years (%)					
				None	Some, But No More Than 2	2 to 4	4 to 6	More Than 6	All
All Adults									
Severe LTSS needs	72	37	2.2	28	35	18	11	9	100
Any paid LTSS	48	21	1.2	52	27	12	6	3	100
Paid home care	28	8	0.5	72	20	5	2	1	100
Residential care	4	2	0.1	96	3	1	0	0	100
Long-term nursing home care	32	14	0.7	68	7	8	3	2	100
Long-term Medicaid-financed nursing home care	13	5	0.3	87	4	3	1	1	100
Adults with Severe LTSS Needs									
Severe LTSS needs	100	52	3.0	0	48	25	15	12	100
Any paid LTSS	66	28	1.6	34	38	16	8	4	100
Paid home care	39	11	0.7	61	28	7	3	1	100
Residential care	6	2	0.1	94	4	1	0	1	100
Long-term nursing home care	42	19	1.0	58	9	11	5	3	100
Long-term Medicaid-financed nursing home care	17	6	0.4	83	5	4	1	1	100
Services Users									
Any paid LTSS	100	43	2.4	0	57	25	12	6	100
Paid home care	100	28	1.8	0	72	19	7	2	100
Residential care	100	38	2.5	0	62	21	8	10	100
Long-term nursing home care	100	43	2.3	0	21	25	10	8	100
Long-term Medicaid-financed nursing home care	100	38	2.1	0	28	25	9	4	100

SOURCE: Author's estimates from the HRS.

NOTES: The analysis followed HRS respondents from 1993 to 2014. The sample was restricted to adults ages 70-79 in 1993 who reported no more than 1 ADL limitation in 1993 and were followed until death. Paid LTSS included nursing home stays of at least 90 days, paid home care, and residential care. The analysis counted only LTSS received by adults with 2 or more ADL limitations or SCI. ADLs included getting in and out of bed, dressing, walking across a room, bathing or showering, eating, and using the toilet.

TABLE 8. Incidence and Duration of Severe LTSS Needs by Personal Characteristics (%)
(adults ages 70-79 in 1993 who report no more than 1 ADL limitation in 1993)

	Any (%)	More Than 2 Years (%)	Mean Number of Years	Duration in Years (%)					
				None	Some, But No More Than 2	2 to 4	4 to 6	More Than 6	All
Sex									
Men	65	28	1.6	35	36	16	8	4	100
Women	78	44	2.6	22	34	19	13	12	100
Marital Status in 1993									
Not married	77	42	2.5	23	34	19	13	10	100
Married	70	33	1.9	30	36	17	9	7	100
Race and Ethnicity									
NonHispanic White	72	36	2.0	28	36	18	11	7	100
NonHispanic Black	80	52	3.3	20	27	18	13	21	100
Hispanic	77	44	2.8	23	32	16	10	18	100
Education									
Not high school graduate	73	41	2.5	27	31	19	11	11	100
High school graduate only or some college	73	34	2.0	27	38	17	11	6	100
Bachelor's degree or more	68	34	1.8	32	34	19	10	5	100
Financial Wealth									
Negative or zero	74	43	2.7	26	30	19	9	15	100
\$1-\$20,000	74	40	2.3	26	34	18	13	9	100
\$20,001-\$100,000	72	37	2.0	28	35	20	11	6	100
More than \$100,000	70	28	1.7	30	41	15	9	4	100
Nonhousing Wealth									
No more than \$5,000	76	46	2.9	24	30	19	11	16	100
\$5,001-\$50,000	73	40	2.2	27	33	19	13	8	100
\$50,001-\$200,000	71	33	1.9	29	37	18	10	5	100
More than \$200,000	70	30	1.8	30	39	16	9	5	100
Household Income									
No more than \$13,500	76	44	2.8	24	31	16	13	15	100
\$12,5001-\$20,000	72	40	2.2	28	32	20	12	8	100
\$20,001-\$40,000	73	35	2.0	27	38	18	10	7	100
More than \$40,000	68	29	1.7	32	38	16	9	4	100

SOURCE: Author's estimates from the HRS.

NOTES: The analysis followed HRS respondents from 1993 to 2014. The sample was restricted to adults ages 70-79 in 1993 who reported no more than 1 ADL limitation in 1993 and were followed until death. The analysis classified individuals as having severe LTSS needs if they received paid or unpaid LTSS and had 2 or more ADL limitations or SCI. The analysis counted only those nursing home stays that lasted at least 90 days. Wealth and income were measured in constant 2014 dollars at the baseline 1993 interview. We also adjusted household wealth and income for family size by dividing those measures by 1.41 when respondents were married.

TABLE 9. Probability of Receiving Any Paid LTSS before and after Age 85 by Personal Characteristics (%) <i>(adults ages 70-79 in 1993 who report no more than 1 ADL limitation in 1993)</i>				
	Any Paid LTSS		More Than 2 Years of Paid LTSS	
	Ever	By Age 85	Ever	By Age 85
All	48	23	21	7
Sex				
Men	37	19	11	4
Women	57	27	28	10
Marital Status in 1993				
Not married	55	28	26	10
Married	43	20	18	5
Race and Ethnicity				
NonHispanic White	48	22	19	7
NonHispanic Black	53	32	30	12
Hispanic	48	26	24	12
Education				
Not high school graduate	47	26	21	9
High school graduate only or some college	49	22	21	6
Bachelor's degree or more	48	22	20	6
Financial Wealth				
Negative or zero	46	27	22	8
\$1-\$20,000	48	26	22	10
\$20,001-\$100,000	50	20	21	6
More than \$100,000	48	20	16	4
Nonhousing Wealth				
No more than \$5,000	49	31	23	12
\$5,001-\$50,000	48	24	21	7
\$50,001-\$200,000	48	19	21	6
More than \$200,000	47	19	17	5
Household Income				
No more than \$13,500	47	29	23	12
\$12,5001-\$20,000	48	23	22	8
\$20,001-\$40,000	49	22	20	6
More than \$40,000	47	20	18	5
SOURCE: Author's estimates from the HRS.				
NOTES: The analysis followed HRS respondents from 1993 to 2014. The sample was restricted to adults ages 70-79 in 1993 who reported no more than 1 ADL limitation in 1993 and were followed until death. See note to Table 8 for more details.				

TABLE 10. Probability of Receiving Nursing Home Care by Personal Characteristics (%) <i>(adults ages 70-79 in 1993 who report no more than 1 ADL limitations in 1993)</i>					
	At Least 90 Days of Care	At Least 90 Days of Care by Age 85	More Than 2 Years of Care	At Least 90 Days of Medicaid-Financed Care	More Than 2 Years of Medicaid-Financed Care
All	32	15	14	13	5
Sex					
Men	23	12	7	6	2
Women	40	17	19	17	7
Marital Status in 1993					
Not married	39	19	19	19	7
Married	28	12	11	9	3
Race and Ethnicity					
NonHispanic White	33	15	14	12	4
NonHispanic Black	32	19	16	21	9
Hispanic	22	10	12	13	6
Education					
Not high school graduate	30	16	13	17	6
High school graduate only or some college	35	14	15	12	4
Bachelor's degree or more	29	14	11	4	3
Financial Wealth					
Negative or zero	31	17	14	18	7
\$1-\$20,000	36	18	16	16	6
\$20,001-\$100,000	33	11	14	12	4
More than \$100,000	29	12	11	3	1
Nonhousing Wealth					
No more than \$5,000	33	21	16	23	10
\$5,001-\$50,000	36	16	15	17	6
\$50,001-\$200,000	32	12	14	9	3
More than \$200,000	28	11	11	3	1
Household Income					
No more than \$13,500	31	17	15	20	9
\$12,5001-\$20,000	35	16	15	18	6
\$20,001-\$40,000	33	14	14	9	3
More than \$40,000	28	12	12	5	2
SOURCE: Author's estimates from the HRS.					
NOTES: The analysis followed HRS respondents from 1993 to 2014. The sample was restricted to adults ages 70-79 in 1993 who reported no more than 1 ADL limitation in 1993 and were followed until death. See note to Table 8 for more details.					

TABLE 11. Duration of Nursing Home Care by Receipt of Medicaid-Financed Care <i>(adults ages 70-79 in 1993 who report no more than 1 ADL limitation in 1993 and later enter a nursing home)</i>						
	Mean Number of Years	Distribution of Duration of Nursing Home Care				
		90-180 Days	181-365 Days	More Than 1 Year, No More Than 2 Years	More Than 2 Years, No More Than 4 Years	More Than 4 Years
All	2.3	21	16	21	25	18
Any Medicaid-Financed Nursing Home Care						
Yes	3.2	8	11	23	28	30
No	1.7	29	18	19	23	10
SOURCE: Author's estimates from the HRS.						
NOTES: The analysis followed HRS respondents from 1993 to 2014. The sample was restricted to adults ages 70-79 in 1993 who reported no more than 1 ADL limitation in 1993 and were followed until death. Paid LTSS included nursing home stays of at least 90 days.						

This Research Brief, written by Richard W. Johnson from Urban Institute, provides new evidence on the lifetime risk that older adults will need LTSS and receive paid services and supports. Using longitudinal household survey data from 1995 to 2014 from the Health and Retirement Study, we estimated the likelihood that adults ever develop disabilities after age 65 and receive paid care, including paid home care, residential care (such as assisted living), nursing home care, and Medicaid-financed nursing home care, and the duration of need and care spells. Our results show that 70% of adults who survive to age 65 develop severe LTSS needs before they die and 48% receive some paid care over their lifetime. Many older people with severe LTSS needs rely exclusively on family and unpaid caregivers, and most paid care episodes are relatively short. Only 24% of older adults receive more than 2 years of paid LTSS care, and only 15% spend more than 2 years in a nursing home. However, the lifetime risk of receiving paid care is not evenly distributed across the population. Lengthy spells of severe LTSS needs and paid care are much more common among older adults with few financial resources than their wealthier counterparts.

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