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ASPE RESEARCH BRIEF

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

ASSESSING THE OUT-OF-POCKET AFFORDABILITY OF LONG-TERM SERVICES AND SUPPORTS

One of the most significant financial risks facing the older population is the possibility of developing severe disabilities and needing long-term services and supports (LTSS). Most older people who need prolonged assistance with self-care or everyday activities rely on unpaid help from families and friends (Schulz and Eden 2016; Wolff et al. 2016). When family care is insufficient, older adults with disabilities generally turn to paid LTSS options. Most prefer to receive care at home from paid helpers or move to an assisted living environment instead of entering a nursing home, which is commonly viewed as a last resort (Barrett 2014; Wiener et al. 2015). The choice largely depends on the seriousness of the disability and the financial resources available to cover LTSS.

For many older people with severe disabilities, any type of paid LTSS is unaffordable because paid care is expensive, public programs with broad enrollment like Medicare do not generally cover LTSS costs, and relatively few people have private insurance coverage that can help defray expenses (Cohen 2016; Johnson 2016b). Consequently, many LTSS expenses are paid by Medicaid, the federal-state government health program for low-income people with virtually no assets (Congressional Budget Office 2013; Kaiser Family Foundation 2016; O'Shaughnessy 2014).

Policymakers and advocates have tried for decades to improve the way LTSS is financed to protect people from catastrophic expenses, make it easier to obtain paid help at home, support family caregivers, and reduce Medicaid LTSS spending. Earlier unsuccessful efforts include the U.S. Bipartisan Commission on Comprehensive Health Care (1990), also known as the Pepper Commission after its first chair, Rep. Claude Pepper (D-FL); the Clinton Administration's 1993 health reform plan (Wiener et al. 2001); and the 2010 Affordable Care Act, which included the never-implemented Community Living Assistance Services and Supports Act that would have created a national program of voluntary long-term care insurance (LTCI). More recently, the Bipartisan Policy Center (2016) and the Long-Term Care Financing Collaborative (2016) have proposed LTSS financing reforms that combine public insurance for catastrophic LTSS costs with initiatives to promote private LTCI coverage for other LTSS expenses to encourage families to pre-fund some of their future expenses. Another possible option would be to expand Medicaid coverage for people with little wealth.

The effectiveness of these policy options depends on the duration and intensity of LTSS that people with disabilities need, the financial resources available to people with

disabilities, and the details of the coverage provided. Evaluating LTSS financing options requires reliable information on how financial resources, LTSS risks, and the duration of LTSS needs are distributed across the older population. Important questions to answer include: What portion of the financial risk would be covered by public or private insurance and what portion would remain an out-of-pocket liability? How long would people wait before LTSS coverage begins? How long would coverage last? Do most older people with disabilities have significant financial resources before they develop LTSS needs, enabling them to pre-fund future LTSS expenses, or do most have little savings?

This brief summarizes recent research on older adults' LTSS risks and financial resources that the Urban Institute completed for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Except where noted, the studies used data from the Health and Retirement Study (HRS), a large, nationally representative survey that has been tracking older Americans since 1992.

Our research findings reveal that most paid LTSS spells are relatively short, but that people with limited financial resources receive more paid LTSS than other people because they generally develop disabilities at younger ages. Relatively few older adults with disabilities can afford to purchase paid LTSS without dipping into their savings, and only about one-half could cover two years of paid home care or nursing home care with their own resources even if they depleted all their available assets. Medicaid eligibility rules often prevent enrollees receiving home and community-based services (HCBS) to keep enough income to cover basic living expenses, preventing many low-income and moderate-income people with disabilities from remaining in the community, where most prefer to live.

People with Little Wealth Disproportionately Receive Long-Term Services and Supports

In 2014, 16 percent of adults ages 65 and older and 40 percent of adults ages 85 and older had severe LTSS needs, defined as receiving paid or unpaid LTSS and either being severely cognitively impaired or having difficulty with two or more activities of daily living (ADLs) because of a physical, mental, emotional, or memory problem that is expected to last at least three months (Johnson 2017). ADLs include getting in and out of bed, dressing, bathing or showering, walking across a room, and using the toilet. This disability threshold approximates that specified in the Health Insurance Portability and Accountability Act for collecting tax-free benefits from a private LTCI policy.

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 care in a single year. Johnson (2017) estimates that **70 percent of adults who survive to age 65 develop severe LTSS needs before they die**.

Nearly half (48 percent) of adults who survive to age 65 receive some paid LTSS over their lifetime (Johnson 2017). Twenty-nine percent receive paid home care after age 65, 5 percent move into assisted living, and 28 percent receive at least 90 days of nursing home care, including 13 percent who receive long-term Medicaid-financed nursing home care. Many older people with serious disabilities receive only unpaid family care. In 2014, only 52 percent of older adults with severe LTSS needs received any paid LTSS.

Most spells of severe LTSS needs and paid LTSS use are relatively short. Four in ten adults who develop severe LTSS needs experience such disability for no more than two years. Only about a quarter of all adults who survive to age 65 experience more than four years of severe LTSS needs. About one-half of paid LTSS users receive care for no more than two years. Only 28 percent of older adults who receive paid LTSS receive care for more than four years.

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. Five percent of paid LTSS users receive care for more than ten years.

LTSS risks are not distributed evenly across the older population. Older adults with few financial resources are more likely to have severe LTSS needs than those with more resources. However, socioeconomic disparities in the lifetime risk of severe LTSS needs are smaller than disparities at any single age because higher socioeconomic status people are more likely to survive to older ages when LTSS needs are common.

Relatively long disability spells are common among people with limited income and wealth. Severe LTSS needs last more than four years for 47 percent of older adults with very little nonhousing wealth--no more than $5,000--when they developed severe LTSS needs, but last that long for only 35 percent of those with substantial nonhousing wealth--more than $200,000 (Johnson 2017). People with limited financial resources tend to develop disabilities at younger ages than people with more resources.

People with limited financial resources are more likely to receive paid LTSS for many years than those with more income and wealth. Among people who obtain paid LTSS after age 65, those with no financial wealth just before they began receiving care are nearly three times as likely to receive paid LTSS for more than ten years than those with more than $200,000 of financial wealth (17 percent versus 6 percent) (Johnson 2017).

Many Older People with Long-Term Services and Supports Needs Have Little Wealth

Income and wealth vary significantly among older adults, affecting their ability to meet various challenges, including obtaining LTSS if necessary. Many older adults with LTSS needs had little wealth even before they developed disabilities, especially if they

developed disabilities when they were relatively young, before turning 80. Examining asset holdings for a sample of adults ages 51-59 with no physical limitations, Johnson (2016a) found that median household wealth was only about half as much for those who subsequently developed two or more ADL limitations over the next 20 years as for those who never reported any limitations. One-quarter of those who eventually developed two or more ADL limitations held less than $30,400, in 2015 inflation-adjusted dollars. Wealth shortfalls among adults in their 50s who become disabled before age 80 are evident at last ten years before they develop any disabilities. Consequently, efforts to encourage people to set aside funds to cover future LTSS expenses might have limited impact because those with the highest expenses would not be able to contribute much.

Pre-disability wealth shortfalls are less pronounced for people who develop disabilities after age 80 than for those who become disabled at earlier ages. However, older adults who receive Medicaid-financed nursing home care after age 75 hold much less wealth before they develop disabilities than those who never become disabled. Median 1993 total household wealth is only $77,500 for adults ages 70-75 without any limitations who subsequently receive Medicaid-financed nursing home care by ages 89-94, less than half as much as the median wealth for those who never develope any limitations (Johnson 2016a).

Household wealth usually plunges after disability onset. Johnson (2016a) followed a sample of adults from 1993 to 2012 who were ages 70-75 in 1993 and did not have any limitations at that time. After controlling for year, age, education, sex, race and ethnicity, and marital status, he found that adults who developed two or more ADL limitations had 34 percent less total household wealth two years before disability onset than those who never developed two or more ADL limitations. When they first reported two or more ADL limitations, they had 58 percent less wealth.

Who Can Afford Long-Term Services and Supports?

Most older adults who lack private LTCI and have too many financial resources to qualify immediately for Medicaid can cover their LTSS expenses for a short time. Johnson and Wang (2017) estimated how long older adults who were not already on Medicaid could afford to purchase LTSS, without private LTCI, before they run out of money. The analysis used median nationwide care prices in 2014 and assumed that paid home care recipients obtained 90 hours of care per month--the median amount received by users. The study found that 40 percent of adults ages 65 and older living in the community had enough income from Social Security, employer pensions, and other sources to fully cover paid home care costs and other community living expenses without dipping into their savings (Table 1). Assisted living is somewhat more affordable, with 49 percent being able to cover those costs out of their monthly incomes, because assisted living includes room and board. However, only 14 percent of older adults with severe LTSS needs have enough income to fully cover nursing home care.

Paid LTSS is less affordable for older people living in the community with severe LTSS needs, who tend to have less income than older adults in better health. Only 22 percent

could fully cover paid home care, 30 percent could fully cover assisted living, and 5 percent could fully cover nursing home care with their incomes.

People with insufficient incomes to fully cover paid LTSS expenses could dip into their wealth to help defray costs. Financial wealth is more liquid than real assets and thus can more easily be used to cover costs, but relatively few older adults hold many financial assets. About half of adults ages 65 and older without enough income to cover costs could fund no more than a year of assisted living or nursing home care or more than 19 months of paid home care before depleting their financial assets. Older adults with severe LTSS needs generally have much less savings--one-third hold no financial assets--and thus could finance only short-term stays; about one-half with insufficient income could fund no more than two months of assisted living or nursing home care and no more than three months of paid home care by spending all their financial assets.

Overall, about two-thirds of older adults living in the community who are not on Medicaid have enough income and financial assets to cover two years of paid home care or assisted living, and about one-half have enough to cover two years of nursing home care. Among older people with severe LTSS needs, only about one-half could cover two years of paid home care or assisted living before they depleted all their savings, and about three in ten could cover two years of nursing home care.

Using Home Equity to Finance Long-Term Services and Supports

About three-quarters of adults ages 65 and older own a home and could use their home equity to cover LTSS expenses (Lindner 2016). Selling a home is complicated and time-consuming, however, and many people report that they are reluctant to use their homes to pay for LTSS (Wiener et al. 2015). Using home equity is even more difficult for paid home care users because they need somewhere to live and for married people in nursing homes because their spouses need to remain in their home. Moreover, homeownership rates are much lower among older people with disabilities. Only about one-half of adults ages 65 and older with two or more ADL limitations own a home (Lindner 2016).

Johnson and Wang (2017) estimated how long older adults living in the community who are not on Medicaid could self-finance LTSS costs if they liquidated all their available household wealth, including their home, other real estate, businesses, and vehicles, and devoted it to LTSS and necessary living expenses. The analysis excluded home equity for estimates of home care affordability and for estimates of married people's nursing home care affordability.[1] Although most adults ages 65 and older without enough income to cover LTSS costs could fund many years of assisted living, one-half could fund no more than four years of paid home care and no more than three years of nursing home care, because it would be difficult for them to spend their home equity on care--especially home care--and nursing home care is expensive. LTSS is much less affordable for people with disabilities, who have much less wealth. The median amount of care that older adults with severe LTSS needs who lack enough income to cover paid LTSS could fund with all their available resources is 13 months of nursing home care, 14 months of paid home care, and about four-and-one-half years of assisted living.

When the analysis accounted for all available household wealth, most older adults living in the community could self-finance LTSS for at least two years. However, only about one-half of older adults with severe LTSS needs could cover at least two years of paid home care or nursing home care with their own resources.

The potential to use home equity to finance nursing home stays varies widely across the country because of regional differences in homeownership rates, home values, and nursing home costs. Using data from the American Community Survey, Lindner (2016) found that the potential is relatively low in places with depressed home values, such as Michigan and other parts of the rustbelt, and areas hit hard by the home foreclosure crisis, including Nevada and Florida. Older adults cannot purchase much nursing home care in Alaska and New York, where nursing home care is especially expensive. By contrast, the potential to finance nursing home care with home equity is greater in places with high housing values and reasonably high homeownership rates, such as Honolulu, San Diego, Seattle, and the District of Columbia. Using only their home equity, seniors could finance, on average, nearly four times as many nursing home nights in the District of Columbia as in Orlando.

Medicaid's Role in Financing Long-Term Services and Supports

For older people who meet Medicaid's disability and financial eligibility requirements, the program covers LTSS costs, including HCBS, nursing home care, and, in some states, assisted living. Eligibility rules vary across states, but only people with little income and virtually no assets other than a home, automobile, household goods, life insurance, and burial funds qualify. People with income above the threshold can generally "spend-down" to Medicaid eligibility by contributing toward the cost of their care until their income net of out-of-pocket health care spending falls below the threshold. The only income that nursing home residents on Medicaid can retain is a small personal needs allowance, but this requirement is not particularly burdensome for single people because nursing homes provide room and board.

Medicaid enrollees who wish to remain at home and receive assistance from paid helpers face the challenge of covering their community living expenses with the program's income allowances. States permit HCBS beneficiaries to retain some income to cover living expenses, but these income allowances are often too low to support independent living. Johnson and Lindner (2016) found that 48 percent of older households with incomes below four times the federal poverty level spend more than their state's Medicaid HCBS income allowances, and 29 percent spend at least 50 percent more than the allowances. Single adults are more likely than couples to spend more than they would be permitted to keep by Medicaid HCBS, because the income allowances granted to spouses are generally much larger than the maintenance needs allowances provided to Medicaid HCBS enrollees. These findings suggest that many states do not allow Medicaid HCBS enrollees to retain enough income to cover community living expenses, potentially limiting access to the program. Raising Medicaid HCBS income allowances could enable more older adults with disabilities to remain in the community and receive the care they need.

Medicaid rules also make it more difficult for LTSS users to transition onto the program while in assisted living than in nursing homes (Greene et al. 2013; O'Keeffe 2010). Unlike many assisted living facilities, almost all nursing homes accept Medicaid (Park-Lee et al. 2011). In addition, Medicaid covers the full cost of nursing homes, including room and board costs. In any other kind of residential elder care setting, however, Medicaid only covers "services," not room and board costs. Consequently, if an assisted living facility accepts Medicaid, the amount that Medicaid pays must fully cover the service component and residents must be able to retain enough income to cover room and board charges. However, room and board costs in assisted living often exceed the Medicaid income eligibility limit or the community maintenance allowance that Medicaid permits.

The treatment of housing wealth under Medicaid is complicated. In most states, a Medicaid applicant's home is exempt from the Medicaid eligibility asset test if it is the applicant's principal residence and its value is not too high. This exemption typically extends to long-stay nursing home residents who plan to return to their home when their nursing home care ends (Karp, Sabatino, and Wood 2005). However, federal law requires states to try to recover Medicaid LTSS expenses from the estates of deceased recipients ages 55 and older, including any assets transferred to other people up to five years before Medicaid enrollment. A beneficiary's principal residence would typically be the main object of estate recovery since the only other exempt assets in the estate would be personal property (such as clothing, jewelry, and furniture) and, possibly, an automobile. States have some discretion about how strictly they implement estate recovery, including whether to attempt to recover from estates that do not pass through probate and whether to place liens on a home before a beneficiary dies to ensure recovery. Federal law also requires states to waive or defer estate recovery if a surviving spouse, disabled child, or other close family member (such as an adult child) who provided unpaid home care to the beneficiary is living in the home.

Most states have recovered only a small portion of their Medicaid LTSS expenditures (Wood and Klem 2007), partly because many long-term nursing home residents sell their homes before they die and use the proceeds to pay privately for nursing home care. It is impractical for long-stay nursing home residents on Medicaid to retain their homes because Medicaid does not leave nursing home residents with enough personal financial resources to pay property taxes or homeowner's insurance or meet the other financial obligations of homeownership

Conclusions

Although most older people will develop disabilities before they die and need LTSS, they generally rely mostly on family caregivers. Only about one-half of older adults develop severe disabilities and receive paid LTSS. Most spells of paid LTSS are relatively short, with one-half of paid LTSS users receiving paid care for less than two years. Only about one in four users of paid LTSS, or one in eight older adults overall, receive paid care for more than four years. Nonetheless, a small share of the older population receives paid LTSS, usually nursing home care, for ten or more years.

The risk of using paid LTSS is spread unevenly across the older population. People with few financial resources receive more paid LTSS than other people because those with little income and wealth generally develop disabilities at younger ages. Many older people who developed disabilities before age 80 had accumulated little household wealth in their 50s, many years before they had any LTSS needs. For planning purposes, most older people should expect to have to dip into their savings to cover paid LTSS and most of those who actually develop disabilities will do so. However, only about one in three older adults with severe LTSS needs have enough income from Social Security, employer-provided pensions, and other sources to cover assisted living, and only about one in four have enough income to cover paid home care.

Assisted living is more affordable than paid home care because paid home care users cannot sell their homes to finance their care and must pay the relatively high costs of independent community living out-of-pocket, typically including homeownership costs. However, older people who develop severe disabilities are less likely to own homes than those who do. Only about one-half of older people with disabilities could finance two years of paid home care or nursing home care with their own resources, even if they depleted all their available household wealth.

The findings from our studies have important implications for LTSS financing options. Efforts to promote pre-funding of future LTSS expenses, through private LTCI coverage or voluntary participation in newly created public programs, may not be particularly effective because most people with the highest expenses did not accumulate much wealth before they developed LTSS needs and thus could not afford to set much money aside. Catastrophic plans that kick in after two years of LTSS spending may not help many older people, especially those with limited financial resources, because many people with disabilities cannot fund two years of paid LTSS on their own and only about a quarter of older adults receive paid LTSS for more than two years. More widespread purchases of LTCI coverage could generate significant future Medicaid savings, however, given that Medicaid finances much of the paid LTSS provided to long-term users. Finally, increasing Medicaid income allowances for HCBS beneficiaries could make community living more affordable for low-income and moderate-income older adults with disabilities and keep more people out of nursing homes.

Endnotes

1. The analysis assumed that people would join their spouses in assisted living.

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Tables

TABLE 1. Affordability of LTSS by Type and Disability (adults ages 65 and older)	Paid Home Care	Assisted Living	Nursing Home
All Older Adults			
Percentage who could cover LTSS costs with their monthly income	40	49	14
Median number of months that those with insufficient income could cover LTSS costs with their income and financial wealth	19	12	11
Percentage who could cover LTSS costs with their income and financial wealth for at least 2 years	68	71	48
Median number of months that those with insufficient income could cover LTSS costs with their income and all available household wealth	43	106	34
Percentage who could cover LTSS costs with their income and all available household wealth for at least 2 years	74	87	63
Older Adults with Severe LTSS Needs			
Percentage who could cover LTSS costs with their monthly income	22	30	5
Median number of months that those with insufficient income could cover LTSS costs with their income and financial wealth	3	2	2
Percentage who could cover LTSS costs with their income and financial wealth for at least 2 years	49	51	29
Median number of months that those with insufficient income could cover LTSS costs with their income and all available household wealth	14	56	13
Percentage who could cover LTSS costs with their income and all available household wealth for at least 2 years	56	75	44

SOURCE: Johnson and Wang (2017).
NOTES: Estimates are restricted to a sample of 9,966 HRS respondents ages 65 and older living in the community in 2014 who were not on Medicaid. The analysis used median LTSS prices, assumed that paid home care recipients obtained 90 hours of care per month, and accounted for community living expenses. Computations of paid home care affordability excluded the net value of a primary residence for both married and single people, and computations of nursing home affordability excluded the net value of a primary residence for married people. The analysis classified individuals as having severe LTSS needs if they received LTSS and had 2 or more ADL limitations or severe cognitive impairment.

This Research Brief, written by Richard W. Johnson from Urban Institute, summarizes recent research on older adults' LTSS risks and financial resources that the Urban Institute completed for ASPE. Except where noted, the studies used data from the Health and Retirement Study, a large, nationally representative survey that has been tracking older Americans since 1992.

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WHERE DO PEOPLE WITH DISABILITIES LIVE?

Reports Available

Assessing the Out-of-Pocket Affordability of Long-Term Services and Supports Research Brief

HTML https://aspe.hhs.gov/basic-report/assessing-out-pocket-affordability-long-term-services-and-supports-research-brief

PDF https://aspe.hhs.gov/pdf-report/assessing-out-pocket-affordability-long-term-services-and-supports-research-brief

How Many Older Adults Can Afford To Purchase Home Care?

HTML https://aspe.hhs.gov/basic-report/how-many-older-adults-can-afford-purchase-home-care

PDF https://aspe.hhs.gov/pdf-report/how-many-older-adults-can-afford-purchase-home-care

How Much Nursing Home Care Can Home Equity Finance?

HTML https://aspe.hhs.gov/basic-report/how-much-nursing-home-care-can-home-equity-finance

PDF https://aspe.hhs.gov/pdf-report/how-much-nursing-home-care-can-home-equity-finance

Later-Life Household Wealth Before and After Disability Onset

HTML https://aspe.hhs.gov/basic-report/later-life-household-wealth-and-after-disability-onset

PDF https://aspe.hhs.gov/pdf-report/later-life-household-wealth-and-after-disability-onset

Older Adults' Living Expenses and the Adequacy of Income Allowances for Medicaid Home and Community-Based Services

HTML https://aspe.hhs.gov/basic-report/older-adults-living-expenses-and-adequacy-income-allowances-medicaid-home-and-community-based-services

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What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?

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