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LONG-TERM SERVICES AND SUPPORTS FOR OLDER AMERICANS: RISKS AND FINANCING, 2020

Most Americans underestimate the risk of developing a disability and needing long-term services and supports (LTSS). Using microsimulation modeling, we estimate that over half (56%) of Americans turning 65 today will develop a disability serious enough to require LTSS, although many will need assistance for less than three years. About one in five adults, however, will have a disability for more than five years. On average, an American turning 65 today will incur \$137,800 in future LTSS costs, which could be financed by setting aside \$80,200 today. When we include residential care in the calculations, families will pay more than half (almost 59%) of the costs themselves out-of-pocket, with the rest covered by public programs and private insurance. While most people with LTSS needs will spend relatively little on their care, almost two in ten will spend at least \$100,000 out-of-pocket for future LTSS. Consistent with prior research, we find that family caregivers provide large amounts of care. When we value the unpaid care contributions of family and friends of older adults with severe disabilities at a replacement wage, we estimate that the value of the care they provide (\$111,000) is approximately equal to the expected cost of paid LTSS. Without help from these caregivers, families' out-of-pocket LTSS costs would be much higher.

Background

Long-term services and supports (LTSS) includes a range of services and supports individuals may need to meet their health or personal needs over a long period of time. Most LTSS is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called "Activities of Daily Living" (or ADLs) which include such everyday tasks as bathing, dressing, toileting and eating (Katz et al. 1963). Many Americans prefer not to think about this need for assistance or who will provide it. They underestimate how likely it is they will need it and how much it will cost (Wiener et al. 2015; Kane 2013; Tompson et al. 2013). Even if they correctly consider the chances of becoming disabled and needing daily help, many Americans mistakenly assume their health insurance covers these costs. However, health insurance does not cover LTSS costs, and Medicare, the major public insurance program for older Americans, does not cover most LTSS expenses (CMS 2015).

While Medicaid provides LTSS to those with chronic disabling conditions (Komisar 2013; Tompson et al. 2013),⁴ it is only available for individuals who meet income and other eligibility requirements (HHS 2015). A private market for LTSS insurance exists, but less than 8% of Americans have purchased it (Freundlich 2014), in part due to high

and rising premiums, and exit of insurers from the market (Scism 2015). Sales figures from recent years suggest there has been stagnation, or even decline, in the market (Cohen 2016; Schmitz and Giese 2019; Ujvari 2018). In 2018, just 276,000 people received benefits from long-term care insurance (LTCI) and about 6.58 million peopleless than 6% of the population ages 50 and older--had a long-term care policy (NAIC 2019). For some older adults, the costs of LTSS are likely to outstrip retirement savings. Researchers at the Employee Benefit Research Institute found that projected LTSS expenses greatly contributed to projections of retirement deficits (VanDerhei 2015).

As the United States population ages, a growing number of older adults will likely need and use LTSS. Most Americans who receive paid LTSS pay some share out-of-pocket. Those with longer spells may pay out-of-pocket until they qualify for Medicaid. Reliance on Medicaid for those that cannot afford the full costs of LTSS may result in increased federal and state spending for LTSS. According to projections produced by the Congressional Budget Office, due to population growth, LTSS expenses (including all paid care, Medicaid and other private and public sources of payment, including Medicare payments for post-acute services) could more than double from 1.3% of gross domestic product (GDP) in 2010 to 3% of GDP in 2050 if the rate of functional limitations among those age 65 and older remains constant (Hagen 2013).

This Brief presents information about the risk of needing care and associated costs to provide context for policymakers and others considering LTSS financing proposals. A microsimulation model was used to describe the future care needs of Americans. This model projected what percentage of older adults will develop a disability, have LTSS needs, use paid LTSS, and among those that use paid LTSS, how much they use and for how long. It estimates care costs, and how they would be financed under current policies. Microsimulation modeling provides not only the average likelihood of these outcomes, but also describes the distribution of these needs and costs. Throughout this Brief we focus on significant disabilities that result in LTSS needs at the threshold for benefits under a tax-qualified LTCI policy, set in the Health Insurance Portability and Accountability Act (HIPAA): a need for assistance with at least two ADLs⁵ that is expected to last at least 90 days or need for substantial supervision for health and safety threats due to severe cognitive impairment (SCI).⁶ Stallard (2011) notes that HIPAA does not count ADL limitations that can be resolved with special equipment (e.g., wheelchairs, walkers, handrails, ramps, catheters, and related devices). Estimates of disability prevalence are higher when we include those with less severe disabilities and those that can be resolved with special equipment.

Methods

The findings in this Brief--an update of our revised 2016 Research Brief--are derived from analyses using the Urban Institute's Dynamic Simulation of Income Model 4 (*DYNASIM4*), a microsimulation model designed to analyze retirement and aging issues over time. Starting with a representative sample of individuals and families, the model "ages" cohorts year-by-year, simulating such demographic events as births, deaths, marriages and divorces, and such economic and health events as labor force participation, earnings, hours of work, disability onset and recovery, retirement, and use

and costs of LTSS based on demographic and other characteristics of the population.⁷ As the model ages the population, it calibrates many key demographic and economic outcomes to the intermediate assumptions of the Social Security and Medicare Trustees' Reports (Board of Trustees, Federal Old-Age and Survivors Insurance and Federal Disability Insurance Trust Funds 2019; Boards of Trustees, Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds 2019). Data to inform the model are drawn from the Health and Retirement Study (HRS), specifically in the areas of health, disability status (including limitations in ADLs and instrumental activities of daily living [IADLs] and cognitive impairment), LTSS use, and private LTCI coverage.⁸ Because we rely on historic data and 2019 trustees report assumptions, the projections do not account for the 2020 novel coronavirus outbreak's on-going demographic and economic effects.

BOX 1: Should We Include Medicare as a Payer for LTSS?

Many adults are confused about whether Medicare covers personal assistance if they develop LTSS needs (also referred to as long-term care needs).

The Centers for Medicare & Medicaid Services (CMS) is quite clear about Medicare policies on in its website (https://www.medicare.gov/coverage/long-term-care), which states the following:

- "Medicare doesn't cover long-term care (also called custodial care), if that's the only care you need. Most nursing home care is custodial care."
- "You pay 100% for non-covered services, including most long-term care."
- "Long-term care is a range of services and support for your personal care needs. Most long-term care isn't medical care. Instead, most long-term care is help with basic personal tasks of everyday life, sometimes called activities of daily living."

Because Medicare does not cover LTSS when it is the only care people need, some analysts exclude Medicare when describing who pays for LTSS (Hado and Komisar 2019). However, several prominent government publications describe Medicare as an important LTSS payer (Hagen 2013; Colello 2017) and include all Medicare services delivered in certain settings as LTSS. They choose to do so because National Health Expenditure Accounts (NHEA) data enable researchers to determine the settings in which care is delivered, but not to determine whether the care is non-medical; disaggregation is challenging.

In a departure from our 2016 brief, we follow Hado and Komisar (2019) and do not include any incidental care that Medicare pays for in our projections in this 2020 Brief.

Current and past LTSS prices are set equal to average or median prices reported in the literature by state of residence, setting (home care, residential care, nursing home), and whether Medicaid is the payer (Genworth 2019; Fossett and Burke 2010; Grabowski et al. 2004; Hansen Hunter and Company 2018; Mollica 2009; Ng et al. 2014). Importantly, these base projections incorporate the full cost of residential care, including room and board in addition to costs associated with meeting care needs. They also incorporate home care services that families purchase in private transactions, which are rapidly evolving and which some other studies undercount (Doty 2017; HomecarePulse 2019; Newquist, DeLiema and Wilber 2015). Also, the projections exclude services that Medicare pays for that are strictly post-acute (see Box 1). These choices affect comparability with other estimates of LTSS expenses, including our own in 2016, and payer mix. Finally, we value unpaid family care using a replacement cost framework, specifically assigning the state-specific median hourly wage for home care workers for each hour of care for a person with disabilities. Because we focus on care to people

with significant disabilities, our estimate is a lower-bound for the value of unpaid family care; assistance is frequently provided to older Americans with lower levels of disability that are not reflected in the total. Additional details about the model's assumptions are available in Favreault and Johnson (2020).

Results

Figure 1 presents projections of the number of persons age 65 and older, including the number with significant levels of disability from 2020 to 2065. As expected, given the aging population, the number with significant disability is expected to grow from 7.2 million to almost 14.3 million. In percentage terms, the share of the aged population with disabilities increases from about 13% to about 15%.

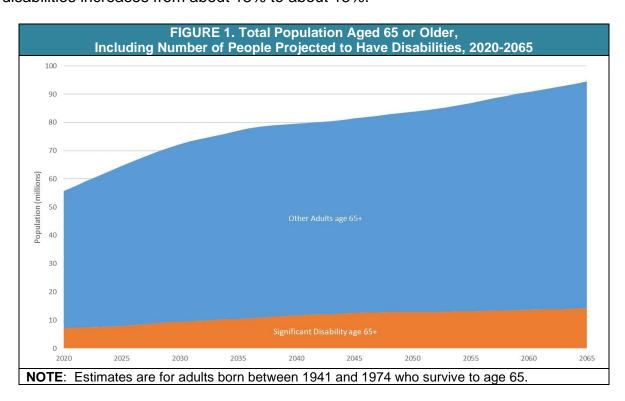


Table 1 displays expected LTSS needs from age 65 to death. It presents life expectancy at age 65 and the mean and distribution of the duration of disability for those turning 65 in 2020-2024. The typical person in this cohort who is alive at age 65 can expect to live another 20.5 years. Fifty-six percent can anticipate having at least some needs for LTSS; 10% are expected to have needs that last less than a year, and about 22% are expected to have needs that extend beyond five years. It is important to bear in mind that estimates such as these are sensitive to one's definition of disability. Many people whose disabilities do not reach higher levels of significance still need and use LTSS. With a more expansive definition, for example one that includes those with one ADL limitation and/or multiple IADLs limitations, the number of people with LTSS needs would be significantly higher (Kemper, Komisar and Alecxih 2005/2006; Freedman and Spillman 2014).

			Need for LT							
	Life		Average		orted Health Status at Age 65 Distribution for All					
	Expectancy at Age 65 (full population)	Average Years of LTSS Need (all)	Years of LTSS Need Given Any Need	Percent with Any LTSS Need	None	<1 Year	1.00-1.99 Years	2.00-4.99 Years	>5 Years	
Total	20.5	2.8	5.0	56.2	43.8	10.3	8.7	15.2	21.9	
Gender										
Men	19.1	2.3	4.5	50.9	49.1	9.9	8.7	14.2	18.0	
Women	21.7	3.2	5.3	61.1	38.9	10.7	8.7	16.2	25.6	
Income Quintile a	t Age 65									
Lowest	17.7	3.4	5.6	61.6	38.4	10.7	8.5	14.2	28.3	
Second	19.3	3.0	5.2	57.3	42.7	9.5	9.8	14.9	23.1	
Middle	20.2	2.8	4.9	55.8	44.2	11.4	9.1	14.3	21.0	
Fourth	21.0	2.5	4.7	53.1	46.9	10.2	8.3	15.4	19.2	
Highest	23.1	2.5	4.6	54.1	45.9	10.0	8.1	16.8	19.3	
Health Status at A	ge 65									
Excellent	22.3	2.6	4.8	55.4	44.7	10.3	8.8	15.2	21.0	
Very good	21.6	2.7	5.0	53.9	46.1	10.3	8.5	13.8	21.4	
Good	20.1	2.8	5.1	55.1	44.9	9.6	8.5	15.4	21.6	
Fair/Poor	18.6	3.0	5.0	60.5	39.5	11.3	9.1	16.8	23.3	
Marital Status at A	Age 65									
Married	21.5	2.6	4.7	55.2	44.8	10.7	8.9	15.7	20.0	
Unmarried	19.8	3.2	5.4	59.0	41.0	9.8	8.7	15.1	25.4	

LTSS needs vary substantially by subpopulation. The average duration of disability is much higher for women than for men--about 3.2 years for all women as compared to 2.3 year for all men. Among women, 61% are likely to develop a chronic disability, and the share needing at least five years of care is 26%. Similarly, the proportion needing at least five years of care is higher among those in the lowest income quintile at age 65 (28%),¹¹ and among those reporting fair or poor health at age 65 (23%). Among those who ever develop a disability, the average duration increases to 5.3 years for women and 4.6 years for men, respectively.

	TABLE 2. Projected Use of Paid LTSS for Persons Turning 65 in 2020-2024, by Gender, Income Quintile, Self-Reported Health Status at Age 65, and Marital Status at Age 65											
	Average Years	Percent with Any	Distribution for All									
	with Paid LTSS Use	Paid LTSS Use (all)	None	<1 Year	1.00-1.99 Years	2.00-4.99 Years	>5 Years					
Total	1.1	47.3	52.7	19.7	8.3	12.4	6.8					
Gender												
Men	0.9	41.4	58.6	18.4	7.9	10.3	4.9					
Women	1.3	52.8	47.2	20.9	8.8	14.5	8.7					
Income Quintile												
Lowest	1.4	50.1	49.9	17.5	8.7	14.6	9.3					
Second	1.2	48.3	51.7	20.1	7.3	12.7	8.2					
Middle	1.1	45.1	54.9	19.1	7.5	11.5	7.0					
Fourth	0.9	45.3	54.7	20.3	8.5	11.3	5.2					
Highest	1.0	47.7	52.3	20.9	9.4	12.2	5.2					
Health Status												
Excellent	1.1	46.0	54.0	19.4	7.7	12.6	6.3					
Very good	1.1	46.5	53.5	19.7	8.3	12.1	6.5					
Good	1.1	46.3	53.7	19.4	8.0	12.2	6.8					
Fair/Poor	1.2	50.1	49.9	20.3	9.1	13.1	7.7					
Marital Status												
Married	1.0	45.7	54.3	20.0	8.2	12.0	5.6					
Unmarried	1.3	51.1	48.9	19.9	8.9	13.5	8.9					

Table 2 examines use of paid LTSS for a disability from age 65 onward measured in service days (where one year is 365 days of paid LTSS--regardless of whether all the days occurred in the same calendar year). Of the average 2.8 years that an older adult

will have a severe disability, they will receive paid care for about 1.1 year, and informal caregivers only, such as family and friends, will make up most of the difference. Again, patterns vary by a range of characteristics. For example, people who are unmarried at age 65 use more paid services than those who are married at age 65, an average of 1.3 years compared to 1.0 years. Those that have poorer health or lower income at age 65 use more paid services.

While on average, individuals will need 1.1 years of paid LTSS, 53% of older adults will not use paid LTSS at all. About 20% will use less than a year (measured in service days), and about 7% will use five years or more. These projections are similar to Johnson's (2019) estimates of care use based on recent historic data.

TABLE 3A. Average Sum (\$2020) of LTSS Expenditures from Age 65 through Death Projected for Adults Turning 65 in 2020-2024										
Payer	Total Exp	oenditures		nity-Based sidential care)	Nursing Facility					
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage				
Public	\$53,100	38.5%	\$12,500	22.1%	\$40,600	50.0%				
Medicaid	50,800	36.9%	12,100	21.4%	38,700	47.7%				
Other Public	2,300	1.7%	400	0.7%	1,900	2.3%				
Private	\$24,700	61.5%	\$44,100	77.9%	\$40,600	50.0%				
Out-of-Pocket	80,600	58.5%	41,700	73.7%	38,900	47.9%				
Private Insurance	4,100	3.0%	2,400	4.2%	1,700	2.1%				
Total Paid	\$137,800	100.0%	\$56,600	100.0%	\$81,200	100.0%				

SOURCES: Authors' tabulations from DYNASIM4, run id974.

NOTES: Residential care is included in community-based, not nursing facilities. LTSS prices are state and setting-specific, based on Genworth (2019), Hansen Hunter and Company PC (2018), and other sources. Nursing home and residential care prices are adjusted for wage inflation; home care prices grow with the average of wage and price inflation.

Table 3A and Table 3B present the average sum of expenditures (in 2020 dollars) that could be expected for LTSS from age 65 until death (thus mostly reflecting future years) for the whole population and then for those with a significant level of disability using paid LTSS. The table displays this projected sum of expenditures (from age 65 onward) by setting and payer for those reaching age 65 over the next five years. Unlike many other estimates, the table includes residential care costs and home care that families pay for in private transactions. This differs from the present discounted value (PDV), the amount that an individual would need to set aside at age 65 to pay for LTSS expenses.¹³

TABLE 3B. Average Sum (\$2020) of Expenditures from Age 65 through Death Projected for Users of Paid LTSS Who Turn 65 in 2020-2024										
Payer	Total Exp	penditures		nity-Based sidential care)	Nursing Facility					
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage				
Public	\$121,000	42.4%	\$33,000	27.3%	\$87,000	52.7%				
Medicaid	97,000	34.2%	23,000	19.0%	73,000	44.5%				
Other Public	5,000	1.6%	1,000	0.8%	4,000	2.1%				
Private	\$163,000	57.4%	\$88,000	72.7%	\$77,000	47.0%				
Out-of-Pocket	156,000	54.9%	84,000	69.4%	74,000	45.1%				
Private Insurance	7,000	2.5%	4,000	3.3%	3,000	1.8%				
Total Paid \$278,000 100.0% \$114,000 100.0% \$163,000 100.0%										

Table 3A and Table 3B combine care that is received at home and that which is received in residential care into a single category of "community care," which is contrasted with institutional care, to provide assistance with a significant level of

disability.¹⁴ On average, about \$137,800 will be spent per person on paid LTSS or \$80,200 in PDV (Table A1).

Medicaid is the largest public payer of LTSS (\$50,800; 37% of total LTSS spending). However, most spending for LTSS is paid for out-of-pocket, averaging about \$80,600, or 59% of total LTSS expenditures. Payer predominance varies by setting, however. For example, Medicaid pays for about half of the total for institutional settings. For community expenses, in contrast, out-of-pocket payments by families comprise the majority, about 74%.¹⁵

As shown in Table 3B, among those who ever use paid LTSS, the average cost will be about \$278,000 or \$161,400 in PDV (Table A2). Although the costs by payer and setting are higher once we condition on use of LTSS, the distribution is very similar to that shown in Table 3A.

As a large body of literature finds (Reinhard et al. 2019; Spillman et al. 2014), family caregivers are a crucial resource to older adults with disabilities. Many older adults with severe disabilities are able to stay in their homes much longer than they could have on their own (Spillman 2016)--sometimes even until their deaths--because they are supported by family and friends (Spillman, Favreault and Allen 2020). The estimated value of unpaid care is about \$111,000 when including all people, or \$192,600 considering those receiving unpaid care.

TABLE 4A. Average Sum (\$2020) of Expenditures from Age 65 through Death Projected for Men Turning 65 in 2020-2024										
Payer	Total Ex	penditures	Community-Based (includes residential care)			Nursing Facility				
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage				
Public	\$40,500	39.5%	\$9,700	21.0%	\$30,800	54.6%				
Medicaid	37,700	36.8%	9,400	20.3%	28,300	50.2%				
Other Public	2,800	2.7%	300	0.6%	2,500	4.4%				
Private	\$62,000	60.5%	\$36,500	79.0%	\$25,600	45.4%				
Out-of-Pocket	59,200	57.8%	34,300	74.2%	25,000	44.3%				
Private Insurance	2,800	2.7%	2,200	4.8%	600	1.1%				
Total Paid	\$102,500	100.0%	\$46,200	100.0%	\$56,400	100.0%				

Expected LTSS costs are higher for women than for men. Women's costs average \$171,000 (Table 4B) compared to \$102,500 for men (Table 4A). These could be financed by setting aside about \$97,000 for women (Table A5) and about \$62,000 for men (Table A3). However, when we focus on those with any LTSS expenditures, this average jumps to approximately \$309,000 for women and \$236,000 for men (not shown). These estimates are equivalent to about \$176,000 and \$142,000, respectively, in present value terms (Table A6 and Table A4). Part of the reason for women's higher costs is simply their longer life expectancy at age 65 and potential exposure to the need of LTSS. However, another factor is that married women are often younger than their husbands and more likely to be widowed at older ages. Women are thus less likely to receive--and more likely to provide--unpaid spousal care.

TABLE 4B. Average Sum (\$2020) of Expenditures from Age 65 through Death Projected for Women Turning 65 in 2020-2024										
Payer	Total Exp	penditures		nity-Based sidential care)	Nursin	Nursing Facility				
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage				
Public	\$65,100	38.1%	\$15,100	22.7%	\$49,900	47.7%				
Medicaid	63,200	37.0%	14,700	22.1%	48,500	46.4%				
Other Public	1,900	1.1%	400	0.6%	1,400	1.3%				
Private	\$105,900	61.9%	\$51,300	77.3%	\$54,700	52.3%				
Out-of-Pocket	100,600	58.8%	48,600	73.2%	52,100	49.8%				
Private Insurance	5,300	3.1%	2,700	4.1%	2,600	2.5%				
Total Paid	\$171,000	100.0%	\$66,400	100.0%	\$104,600	100.0%				

Table 5 presents the distribution associated with Table 3A's and Table 3B's sum of expected costs for those ages 65 and older in 2020-2024. Approximately 18% of older adults can expect their LTSS expenses from age 65 onward to amount to more than \$250,000, while about 6% will have positive but low costs (<\$10,000). When looked at by payer source, a much smaller percentage (approximately 11%) will spend \$250,000 or more on LTSS out-of-pocket.

TAE	TABLE 5. Distribution of Sum (\$2020) of LTSS Expenditures from Age 65 through Death Projected for Adults Turning 65 in 2020-2024											
	Distribution of Sum (\$2020) of LTSS Expenditures (% of people)											
Payer	Average Expend.	Percent of Average People None <\$10,000 \$10,000- \$25,000- \$50,000- \$75,000- \$100,000- \$150,000- \$200,000- \$250,000-									>\$250,000	
Public	\$53,100											
Medicaid	50,800	20.5	79.5	1.9	1.4	1.7	1.5	1.4	2.2	1.9	1.5	7.2
Other Public	2,300	11.5	88.6	9.6	0.5	0.2	0.3	0.3	0.4	0.1	0.1	0.2
Private	\$84,700											
Out-of-Pocket	80,600	40.1	59.9	5.0	4.8	4.5	3.5	2.7	3.8	2.9	2.4	10.6
Private Insurance	4,100	3.1	96.8	0.3	0.5	0.5	0.3	0.4	0.4	0.3	0.2	0.4
Total Paid	\$137,800	47.7	52.3	5.9	4.8	4.1	3.1	2.7	3.7	3.1	2.6	17.8

However, these figures mask differences by income. People with lower incomes are more likely to have more of their costs covered by Medicaid and pay less on average out-of-pocket. Table 6A and Table 6B focus on Medicaid and family out-of-pocket expenses for those turning 65 in 2020-2024. The mean sum and the distribution of the sum are shown by income quintile at age 65. The DYNASIM projections suggest that although Medicaid is used by older adults in all income quintiles at age 65, it primarily serves those in the bottom two quintiles. For example, about 39% of people in the bottom income quintile at age 65 will ever use Medicaid LTSS, compared to less than 8% in the top quintile at that age. Those in upper income quintiles who use Medicaid are typically individuals who have survived until their mid to late 90s, consistent with other research (DeNardi et al. 2013, Borella et al. 2017). ¹⁶

	TABLE 6A. Mean and Distribution of Sum (\$2020) of Lifetime Medicaid LTSS Expenditures Projected for Adults Turning 65 in 2020-2024											
	Distribution of Sum (\$2020) of Medicaid LTSS Expenditures (% of people)											
Income Quintile	Average Expend.	Percent of rage People None <\$10,000 \$10,000 \$25,000 \$50,000 \$75,000 \$100,000 \$150,000 \$200,000 >\$250,000										
Lowest	98,000	39.3	60.7	4.3	3.1	3.6	2.1	2.5	4.1	3.9	2.6	13.1
Second	71,000	27.4	72.6	2.3	2.3	1.9	2.2	1.7	2.8	1.9	2.2	10.0
Middle	54,000	21.6	78.4	2.4	0.9	1.8	2.0	1.4	2.2	2.0	1.1	7.9
Fourth	32,000	13.7 86.3 1.1 0.8 1.2 1.3 1.0 1.2 1.2 1.1 4.8										
Highest	18,000	7.6 92.4 0.2 0.6 0.5 0.4 0.6 1.3 0.8 0.7 2.4										
Total	\$51,000	20.5	79.5	1.9	1.4	1.7	1.5	1.4	2.2	1.8	1.5	7.2

Family out-of-pocket expenditures, in contrast, are more concentrated in the higher quintiles. The average out-of-pocket LTSS expense in the top quintile is approximately \$121,000 compared to closer to \$38,000 in the bottom quintile. But again the mean obscures important distributional information. About 17% of people in the top income quintile at age 65 can expect out-of-pocket expenses in excess of a quarter million dollars. In the bottom quintile, where more are protected by Medicaid, the expected share with very high spending is closer to 5%.

TA	TABLE 6B. Mean and Distribution of Sum (\$2020) of Lifetime Family Out-of-Pocket LTSS Expenditures Projected for Adults Turning 65 in 2020-2024											
	Distribution of Sum (\$2020) of LTSS Expenditures (% of people)											
Payer	Average Expend.	Percent of People with Expend.	None	<\$10,000	\$10,000- \$24,999	\$25,000- \$49,999	\$50,000- \$74,999	\$75,000- \$99,999	\$100,000- \$149,999	\$150,000- \$199,999	\$200,000- \$249,999	>\$250,000
Lowest	38,000	31.5	68.5	5.6	3.9	5.0	3.0	2.5	3.0	2.5	1.5	4.5
Second	60,000	40.5	59.5	4.8	6.5	4.8	4.3	2.9	4.8	2.2	2.2	8.1
Middle	78,000	39.7	60.3	5.5	4.2	4.2	3.7	2.4	3.9	3.2	2.6	10.1
Fourth	82,000	00 41.9 58.1 5.3 5.1 4.0 4.0 2.9 3.0 3.3 2.5 11.9										
Highest	121,000	0 46.9 53.1 4.3 4.7 4.7 2.9 2.8 4.4 3.2 3.0 16.9										
Total	\$77,000	40.1	59.9	5.0	4.8	4.5	3.5	2.7	3.8	2.9	2.4	10.6

Conclusion

Most Americans who survive to age 65 can expect to need and use LTSS--our estimates suggest more than half the population (roughly 56%) will have a significant level of disability. On average, the projected duration of LTSS need is 2.8 years, and the projected length of paid LTSS is just over one year. The average cost of this care is \$137,800. However, a number of people can expect to need LTSS for many years and to have care costs that total hundreds of thousands of dollars. Average long-term care costs can be out of reach for many Americans. Medicaid is an important payer of LTSS, but because it serves only those who meet income and asset criteria, many families pay for LTSS out-of-pocket. We project that the share of LTSS spending paid by Medicaid will grow modestly as a share of the economy, while the share paid out-of-pocket will grow even more rapidly over the next 30 years. Private LTSS insurance has only a modest reach, and it predominantly covers costs for those high in the income distribution. Similarly, other public expenditures (for example, including U.S. Department of Veterans Affairs care) only help to cover small shares of the population with longterm care needs. Critically, assistance provided by family members and friends with this care is roughly equal in value to paid care during periods when one has significant

disabilities--and far exceeds paid care in periods of less severe disability. The results presented here highlight the need for better planning for LTSS to accommodate both average and catastrophic financial risks associated with chronic disability.

Reasons for Differences from Our Earlier Brief

One important substantive change between this brief and the 2016 version is that we removed incidental LTSS that Medicare covers from our expected cost tables. As Box 1 discusses, Medicare generally does not pay for long-term care when it is the only service a person needs. However, sometimes a person may have some of their LTSS needs met through the course of receiving post-acute care. Given recent Medicare payment rule changes, we expect that this type of overlap will be less common in coming years.

After factoring in our changes to the treatment of services covered by Medicare, the LTSS cost estimates expressed as sums in this brief are modestly higher than those from our earlier brief (Favreault and Dey 2016), largely because we examine later cohorts in later years. Inflation is thus an important contributor to the differences. Between 2015 and 2020, prices increased by about 10.5% and wages increased by about 17.3%; wage growth is a good proxy for LTSS cost growth because LTSS is so labor intensive. So, all else equal, we would expect long-run LTSS costs to increase by about 11%-17% between the last brief and this one.

The differences in present values of care costs at age 65--the amount required to set aside to prepay care, accounting for the fact that the lump sum could earn interest--are greater than the differences in the sums of care costs between the prior brief and this one. This is due to sustained drops in interest rates in recent years. Correspondingly, the Social Security trustees reduced their assumed long-range interest rates. When we discount future care costs, we now use a rate of 2.5% rather than 2.9% in the prior brief. This change increases the amount one needs to set aside earlier in life to pay for later life care--even absent any other changes in risk.

Ordinarily, longevity changes would also contribute to differences across cohorts. As the members of each successive generation reach retirement, they live a little bit longer than their predecessors. Even if most will spend much of that additional life generally healthy, many will spend some portion of it disabled. According to the 2019 Social Security Trustees Report, men turning age 65 in 2020 can expect to live about 0.36 years longer than those turning age 65 in 2015; for women, the difference is about 0.33 years longer. However, the 2015 trustees report, on which the earlier analyses were based, had more optimistic longevity assumptions than the 2019 trustees report. It projected that men born in 1955 would live an average of 19.68 additional years, while the more recent report projected they would live an average of 19.05 more years--a reduction of 0.63 years. For women, the projection was 21.94 years in the 2015 trustees report, compared to 21.56 in the 2019 trustees report, a reduction of 0.38 years. These two factors--increased longevity across cohorts but moving to more pessimistic longevity growth assumptions--thus largely offset for women but lead to a net reduction in lifespans and thus LTSS risk for men.

We also made many technical changes and updates between the two analyses. For example, we updated the DYNASIM starting sample to rely on later panels of the Survey of Income and Program Participation. We also use more recent state-specific price data (Genworth 2019, Hansen Hunter and Company 2018). Further, we reestimated many of the parameters so that they use more recent data from the HRS and other data sources. As we re-estimated some of the parameters, we sometimes changed equation specification, mostly notably for our model of SCI. We closely compare our dementia projections with the literature on distribution of duration of impairment (for example, Brookmeyer et al. 2002, Larson et al. 2004). Although literature on cognitive impairment has been growing rapidly in recent years, estimates on the distribution of durations severely impaired is still limited. As more data become available and this literature evolves, we will continue to update these functions, given that dementia is such a significant driver of the need for LTSS, and especially paid care.

These technical changes plus a definitional change (focusing more on days in need rather than years in need to better capture partial year impairments) led to a notable increase in the expected duration of time with LTSS needs relative to our earlier brief: 2.8 years in this brief compared to 2.0 years in the prior versions. However, our estimates of LTSS costs and utilization are less affected. Utilization of paid services is much easier to measure and benchmark than LTSS need, which is more subjective. LTSS need is often measured in yearly or even two-year increments, as opposed to days and months of service use. Further, subtle changes to definitions can change the estimates markedly.

Despite these differences, our substantive conclusions remain unchanged: older adults face significant risk of needing LTSS, potentially incurring large out-of-pocket costs and requiring unpaid help from family members.

End Notes

- 1. Long-term services and supports is also sometimes called "long-term care."
- 2. Services may be provided in a person's home, in the community, or in residential facilities (e.g., nursing homes or assisted living facilities) (ASPE 2012).
- 3. Most LTSS is not medical care, but rather help with basic personal tasks of everyday life. Medicare does not cover this LTSS (also called custodial care), if that is the only care needed. Most nursing home care is custodial care. Medicare does cover care in a LTSS hospital, skilled nursing care in a skilled nursing facility, eligible home health services, and hospice and respite care.
- 4. In a recent representative survey of Americans aged 40-70 conducted by GfK on behalf of the Office of the Assistant Secretary for Planning and Evaluation (ASPE), only 25% of respondents correctly identified Medicaid as the government program that pays the most for LTSS in the United States.

- 5. The ADLs enumerated in the statute are eating, toileting, transferring, bathing, dressing, and continence.
- 6. Throughout we reference this level of need as "significant LTSS needs," or "higher levels of disability."
- 7. DYNASIM's LTSS projections draw information from a wide range of crosssectional and longitudinal sources, including the HRS, Medicare Current Beneficiary Study, and National Health and Aging Trends Survey.
- 8. One challenge is how to capture trends in LTSS outcomes. When there is a clear trend, such as the decline in mortality, DYNASIM follows the Trustees' assumptions. Otherwise, DYNASIM assumes that the underlying propensity to develop LTSS needs or use LTSS continues at current levels, but that the aggregate rates observed change as the composition of the population shifts. For example, as the population becomes better educated, more people in the population will experience the rates for more highly educated adults, but the rate for an adult with a certain level of education will not change.
- 9. DYNASIM varies LTSS prices somewhat based on income, so that some lower-income families use lower-cost providers--especially for home care--and some higher-income families--especially those covered by private LTSS insurance--use higher-cost providers.
- 10. Multiple cohorts are used to provide a larger enough sample size for subpopulation analysis.
- 11. Income quintile is based on income relative to poverty. This accounts for economies of scale for households with more than one person. It includes earnings, pensions, Social Security, Supplemental Security Income, and asset income (defined as the annuitized value of financial assets using a multivariate annuity function) for both oneself and, if married, one's spouse.
- 12. Use of unpaid services is substantial at both the HIPAA and non-HIPAA disability levels, while use of paid services is more concentrated at the HIPPA-level.
- 13. All age 65 plus cost projections are presented in constant 2020 dollars. Dollar amounts are rounded to the nearest \$100 or \$1000, depending on the metric, reflecting the inherent uncertainty surrounding the projections. Tables expressed in PDV are in the Appendix (Tables A1-A9). PDV is computed using the Social Security Trustees' ultimate real interest rate of 2.5%. (Because the trustees assume long-range price growth to average 2.6%, this amounts to a nominal long-run discount rate of about 5.1%.)
- 14. Both Table 3A and Table 3B focuses on the HIPAA-level of need, with a few exceptions: nursing home care costs are counted regardless of disability status, residential care is included only if an individual reports difficulty with at least two

ADLs or is severely cognitively impaired, home care costs are only included for those meeting HIPAA criteria.

- 15. As noted earlier, the relative share of costs borne by different payers is quite sensitive to whether and how residential care is incorporated in these projections. Some researchers prefer to exclude the housing component of residential care which is included in these estimates. The NHEA exclude some related sectors altogether (Hartman, Kornfeld and Catlin 2010). Removing the housing component of residential care (Appendix Table A10A)--or removing residential care altogether (Appendix Table A10B)--reduces out-of-pocket costs markedly and thus reduces the percent families pay relative to public and other payers.
- 16. This addresses the literature on the distributional effects of Medicaid LTSS programs (Baird et al. 2014; Warshawsky 2014; Wiener et al. 2013; Willink et al. 2019).

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Appendix: Projections of LTSS Expenditures Using Present Discounted Value

TABLE A1. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Adults Turning 65 in 2020-2024										
Payer	Total Ex	penditures		nity-Based sidential care)	Nursing Facility					
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage				
Public	\$32,300	40%	\$8,600	25%	\$23,700	51%				
Medicaid	30,900	39%	8,300	24%	22,600	49%				
Other Public	1,400	2%	300	1%	1,100	2%				
Private	\$47,900	60%	\$25,400	75%	\$22,400	49%				
Out-of-Pocket	45,400	57%	23,900	70%	21,400	46%				
Private Insurance	2,500	3%	1,500	4%	1,000	2%				
Total Paid	\$80,200	100%	\$34,000	100%	\$46,100	100%				

TABLE A2. Avera	TABLE A2. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Adults who Use Paid LTSS and Turn 65 in 2020-2024										
Payer	Total Exp	penditures		nity-Based sidential care)	Nursin	Nursing Facility					
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage					
Public	\$64,300	39.8%	\$16,600	24.2%	\$47,700	51.5%					
Medicaid	61,500	38.1%	16,100	23.5%	45,400	49.0%					
Other Public	2,800	1.7%	500	0.7%	2,300	2.5%					
Private	\$97,100	60.2%	\$52,000	75.8%	\$45,000	48.5%					
Out-of-Pocket	92,200	57.1%	49,000	71.4%	43,100	46.5%					
Private Insurance	surance 4,900 3.0% 3,000 4.4% 1,900 2.0%										
Total	\$161,400	100.0%	\$68,600	100.0%	\$92,700	100.0%					

TABLE A3	TABLE A3. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Men Turning 65 in 2020-2024										
Payer	Total Ex	penditures		nity-Based sidential care)	Nursin	g Facility					
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage					
Public	\$25,600	41.4%	\$6,700	23.6%	\$18,830	56.0%					
Medicaid	23,900	38.6%	6,500	22.9%	17,330	51.6%					
Other Public	1,700	2.7%	200	0.7%	1,500	4.5%					
Private	\$36,300	58.6%	\$21,700	76.4%	\$14,800	44.0%					
Out-of-Pocket	34,500	55.7%	20,300	71.5%	14,400	42.9%					
Private Insurance	1,800	2.9%	1,400	4.9%	400	1.2%					
Total	\$61,900	100.0%	\$28,400	100.0%	\$33,600	100.0%					

TABLE A4. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Men Who Use LTSS at the HIPAA-Level and Turn 65 in 2020-2024												
Payer	Total Ex	penditures		nity-Based sidential care)	Nursing Facility							
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage						
Public	\$57,900	40.7%	\$14,800	22.6%	\$43,100	56.1%						
Medicaid	54,000	38.0%	14,300	21.9%	39,700	51.7%						
Other Public	3,900	2.7%	500	0.8%	3,400	4.4%						
Private	\$84,300	59.3%	\$50,600	77.4%	\$33,700	43.9%						
Out-of-Pocket	80,300	56.5%	47,500	72.6%	32,800	42.7%						
Private Insurance	4,000	2.8%	3,100	4.7%	900	1.2%						
Total	\$142,200	100.0%	\$65,400	100.0%	\$76,800	100.0%						

TABLE A5. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Women Turning 65 in 2020-2024												
Payer	Total Exp	penditures		nity-Based sidential care)	Nursing Facility							
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage						
Public	\$38,600	39.7%	\$10,300	26.3%	\$28,400	49.0%						
Medicaid	37,500	38.5%	10,000	25.5%	27,600	47.6%						
Other Public	1,100	1.1%	300	0.8%	800	1.4%						
Private	\$58,700	60.3%	\$28,900	73.7%	\$29,600	51.0%						
Out-of-Pocket	55,600	57.1%	27,300	69.6%	28,100	48.4%						
Private Insurance	3,100	3.2%	1,600	4.1%	1,500	2.6%						
Total	\$97,300	100.0%	\$39,200	100.0%	\$58,000	100.0%						

TABLE A6. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Women Who Use LTSS at the HIPAA-Level and Turn 65 in 2020-2024												
Payer	Total Exp	penditures		nity-Based sidential care)	Nursing Facility							
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage						
Public	\$69,000	39.3%	\$17,900	25.2%	\$51,000	48.8%						
Medicaid	67,100	38.2%	17,400	24.5%	49,600	47.5%						
Other Public	1,900	1.1%	500	0.7%	1,400	1.3%						
Private	\$106,500	60.7%	\$53,100	74.8%	\$53,500	51.2%						
Out-of-Pocket	100,900	57.5%	50,200	70.7%	50,800	48.6%						
Private Insurance	5,600	3.2%	2,900	4.1%	2,700	2.6%						
Total	\$175,500	100.0%	\$71,000	100.0%	\$104,500	100.0%						

TAB	TABLE A7. Distribution of PVD (\$2020) of LTSS Expenditures from Age 65 through Death Projected for Adults Turning 65 in 2020-2024													
	Distribution of Sum (\$2020) of LTSS Expenditures (% of people)													
Payer	Average Expend.	Percent of People with Expend.	None	<\$10,000	\$10,000- \$24,999	\$25,000- \$49,999	\$50,000- \$74,999	\$75,000- \$99,999	\$100,000- \$149,999	\$150,000- \$199,999	\$200,000- \$249,999	>\$250,000		
Public	\$37,100													
Medicaid	29,800	20.4	79.6	2.5	2.0	2.6	1.9	2.0	2.6	1.7	1.4	3.8		
Other Public	1,300	11.5	88.5	10.0	0.3	0.4	0.3	0.2	0.2	0.1	0.0	0.1		
Private	\$46,500													
Out-of-Pocket	44,300	40.4	59.6	7.6	5.3	6.4	3.9	3.3	4.2	2.7	2.1	5.0		
Private Insurance	2,200	3.1	96.9	0.5	0.6	0.5	0.5	0.3	0.3	0.1	0.1	0.2		
Total	\$83,600	50.2	49.8	8.1	5.8	6.0	4.0	3.1	4.8	3.5	2.9	12.0		

TAI	BLE A8. N	<i>l</i> lean and				\$2020) c Turning				SS Expe	nditures		
	Distribution of Sum (\$2020) of LTSS Expenditures (% of people)												
Payer	Average Expend.	Percent of People with Expend.	None	<\$10,000	\$10,000- \$24,999	\$25,000- \$49,999	\$50,000- \$74,999	\$75,000- \$99,999	\$100,000- \$149,999	\$150,000- \$199,999	\$200,000- \$249,999	>\$250,000	
Lowest	68,800	41.6	58.4	5.6	4.6	3.8	3.5	4.0	5.4	2.9	2.5	9.4	
Second	40,100	27.1	73.0	3.2	2.2	3.8	2.5	2.2	3.3	2.0	2.5	5.3	
Middle	30,000	21.1	78.9	2.6	2.1	3.2	2.0	2.1	2.0	1.7	1.5	4.0	
Fourth	15,200	13.2	86.8	1.6	1.2	1.9	1.3	1.4	2.1	1.5	0.7	1.5	
Highest	8,300	7.1	92.9	0.4	0.8	1.3	0.7	1.0	1.1	0.6	0.5	0.7	
Total	\$29,800	20.4	79.6	2.5	2.0	2.6	1.9	2.0	2.6	1.7	1.4	3.8	

TABLE A9. Mean and Distribution of PVD (\$2020) of Lifetime Family Out-of-Pocket LTSS Expenditures Projected for Adults Turning 65 in 2020-2024

		Distribution of Sum (\$2020) of LTSS Expenditures (% of people)											
Payer	Average Expend.	Percent of People with Expend.	None	<\$10,000	\$10,000- \$24,999	\$25,000- \$49,999	\$50,000- \$74,999	\$75,000- \$99,999	\$100,000- \$149,999	\$150,000- \$199,999	\$200,000- \$249,999	>\$250,000	
Lowest	23,400	33.1	66.9	8.0	5.8	5.4	3.8	2.6	3.2	1.6	0.9	1.9	
Second	33,100	40.4	59.7	8.4	6.4	7.8	3.0	4.3	3.3	2.3	1.9	3.0	
Middle	40,300	39.2	60.8	7.8	4.3	5.3	4.6	4.0	4.3	2.5	1.7	4.7	
Fourth	46,900	41.7	58.3	7.8	4.7	6.2	3.3	3.0	5.8	3.2	2.6	5.1	
Highest	64,200	47.2	52.8	6.6	5.5	7.4	4.8	3.1	4.4	3.6	2.9	8.9	
Total	\$42,900	40.4	59.6	7.6	5.3	6.4	3.9	3.3	4.2	2.7	2.1	5.0	

TABLE A10A. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Adults Who Turn 65 in 2020-2024, Including Only One-Third of Residential Care Projections

Paver	Total Ex	penditures		nity-Based sidential care)	Nursing Facility		
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage	
Public	32,300	44.0%	8,600	31.5%	23,700	51.4%	
Medicaid	30,900	42.1%	8,300	30.4%	22,600	49.0%	
Other Public	1,400	1.9%	300	1.1%	1,100	2.4%	
Private	41,100	56.0%	18,700	68.5%	22,400	48.6%	
Out-of-Pocket	38,600	52.6%	17,200	63.0%	21,400	46.4%	
Private Insurance	ance 2,500 3.4%		1,500	5.5%	1,000	2.2%	
Total	73,400	100.0%	27,300	100.0%	46,100	100.0%	

NOTE: Table A10A and Table A10B show two alternative estimates to Table A1. In the first (Table A10A), only one-third of family residential care costs are included, reflecting that some prefer to exclude the housing component of residential care. Using this approach, the out-of-pocket share declines (from 57% in Table A1 to 53%), and shares to all other payers increase. In the second (Table A10B), no family residential care costs are included. This approach compares more directly to estimates that rely on NHEA data, as they exclude most residential care, as it is not considered health care (Hartman, Kornfeld and Catlin 2010). Using this approach, the out-of-pocket share declines (from 57% in Table A1 to 50%), and shares to all other payers again increase mechanically.

TABLE A10B. Average PVD (\$2020) of Expenditures from Age 65 through Death Projected for Adults Who Turn 65 in 2020-2024, Including No Residential Care Costs

Payer	Total Ex	penditures		nity-Based sidential care)	Nursing Facility		
	Dollars	Percentage	Dollars	Percentage	Dollars	Percentage	
Public	\$32,300	46.1%	\$8,600	35.8%	\$23,700	51.4%	
Medicaid	30,900	44.1%	8,300	34.6%	22,600	49.0%	
Other Public	1,400	2.0%	300	1.3%	1,100	2.4%	
Private	\$37,800	53.9%	\$15,400	64.2%	\$22,400	48.6%	
Out-of-Pocket	35,300	50.4%	13,900	57.9%	21,400	46.4%	
Private Insurance	2,500	3.6%	1,500	6.3%	1,000	2.2%	
Total Paid	\$70,100	100.0%	\$24,000	100.0%	\$46,100	100.0%	

NOTE: Table A10A and Table A10B show two alternative estimates to Table A1. In the first (Table A10A), only one-third of family residential care costs are included, reflecting that some prefer to exclude the housing component of residential care. Using this approach, the out-of-pocket share declines (from 57% in Table A1 to 53%), and shares to all other payers increase. In the second (Table A10B), no family residential care costs are included. This approach compares more directly to estimates that rely on NHEA data, as they exclude most residential care, as it is not considered health care (Hartman, Kornfeld and Catlin 2010). Using this approach, the out-of-pocket share declines (from 57% in Table A1 to 50%), and shares to all other payers again increase mechanically.

This Research Brief, authored by Melissa Favreault (Urban Institute) and Judith Dey (U.S. Department of Health and Human Services), presents information about the risk of needing care and associated costs to provide content for policymakers and others considering long-term care financing proposals.

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IMPROVING HEALTH AND LONG-TERM CARE MODELING CAPACITY

Reports Available

Economic Hardship and Medicaid Enrollment in Later Life: Assessing the Impact of Disability, Health, and Marital Status Shocks

HTML https://aspe.hhs.gov/basic-report/economic-hardship-and-medicaid-

enrollment-later-life-assessing-impact-disability-health-and-marital-status-

shocks

PDF https://aspe.hhs.gov/pdf-report/economic-hardship-and-medicaid-

enrollment-later-life-assessing-impact-disability-health-and-marital-status-

shocks

Extended LTSS Utilization Makes Older Adults More Reliant on Medicaid Issue Brief

HTML https://aspe.hhs.gov/basic-report/extended-ltss-utilization-makes-older-

adults-more-reliant-medicaid-issue-brief

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Most Older Adults Are Likely to Need and Use Long-Term Services and Supports Issue Brief

HTML https://aspe.hhs.gov/basic-report/most-older-adults-are-likely-need-and-

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Risk of Economic Hardship Among Older Adults Issue Brief

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The Risk and Costs of Severe Cognitive Impairment at Older Ages: Literature Review and Projection Analyses

HTML https://aspe.hhs.gov/basic-report/risk-and-costs-severe-cognitive-

<u>impairment-older-ages-literature-review-and-projection-analyses</u>

PDF https://aspe.hhs.gov/pdf-report/risk-and-costs-severe-cognitive-

impairment-older-ages-literature-review-and-projection-analyses

Long-Term Services and Supports for Older Americans: Risks and Financing, 2020 Research Brief

HTML https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-

americans-risks-and-financing-2020-research-brief

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Projections of Risk of Needing Long-Term Services and Supports at Ages 65 and Older

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services-and-supports-ages-65-and-older

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services-and-supports-ages-65-and-older

The Risk and Costs of Severe Cognitive Impairment at Older Ages: Key Findings from our Literature Review and Projection Analyses Research Brief

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impairment-older-ages-key-findings-our-literature-review-and-projection-

analyses-research-brief

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