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ASPE RESEARCH BRIEF
HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

LONG-TERM SERVICES AND SUPPORTS FOR OLDER AMERICANS: RISKS AND FINANCING, 2022

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 of all adults (22%), however, will have a disability for more than five years. On average, an American turning 65 today will incur $120,900 in future LTSS costs, measured in today's dollars. Families will pay more than one-third (37%) of the costs themselves out of pocket, with the rest covered by public programs and private insurance. Although most people with LTSS needs will spend relatively little on their care, 14% will spend at least $100,000 out of pocket for future LTSS. But these paid services do not cover all care people need, and consistent with prior research we find that family caregivers provide substantial unpaid care. Valuing unpaid care contributions at the wage of a paid caregiver, we estimate that unpaid family care for older adults with significant disabilities who receive care is worth $204,000 on average, more than the expected cost of all paid LTSS. Without help from unpaid family caregivers, families and public programs would spend much more on LTSS.

Background

Long-term services and supports (LTSS) includes a range of assistance individuals may need to meet their health or personal needs over an extended period.[1] Most LTSS is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called activities of daily living (ADLs), which include such tasks as bathing, dressing, toileting and eating (Katz et al. 1963).[2] Many Americans prefer not to think about this need for assistance or who will provide it. They underestimate the likelihood that they will need help and how much it will cost (Wiener et al. 2015; Kane 2013; Tompson et al. 2013). Even if they recognize the possibility of developing a disability and needing daily help, many Americans mistakenly assume that insurance will cover 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 (Centers for Medicare & Medicaid Services 2015).[3]

Relatively few financing options exist for LTSS. Although Medicaid provides LTSS to those with chronic disabling conditions (Komisar 2013; Tompson et al. 2013),[4] it is available only for individuals who meet income and other eligibility requirements (U.S. Department of Health and Human Services 2015). A private market for LTSS insurance

exists, but less than 8% of Americans have purchased coverage (Freundlich 2014), partly because of high and rising premiums and the exit of insurers from the market (Scism 2015). Sales figures from recent years suggest the market has stagnated or even shrunk (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 people--less than 6% of the population ages 50 and older--had a long-term care policy (National Association of Insurance Commissioners 2019). For some older adults, the costs of LTSS are likely to outstrip retirement savings. Researchers at the Employee Benefit Research Institute found that accounting for LTSS expenses significantly increase the number of retirees projected to have inadequate resources to cover living expenses (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 who cannot afford the full cost of LTSS may increase federal and state spending for LTSS. The Congressional Budget Office projects that if the share of adults ages 65 and older with functional limitations remains constant LTSS expenses (including all paid care financed by Medicaid and other private and public sources, including Medicare payments for post-acute services) could more than double between 2010 and 2050 as the population grows, increasing from 1.3% to 3.0% of gross domestic product (Hagen 2013).

To provide context for policymakers and others considering LTSS financing proposals, this brief presents information about the risk of needing care and associated costs, based on results from a microsimulation model. This model projects the percentage of older adults who will develop a disability and use paid LTSS. For those who use paid LTSS, the model projects how much they will use and for how long. The model also estimates care costs and how they would be financed under current policies. Microsimulation modeling describes the average likelihood of these outcomes, as well as 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 ADLs[5] that is expected to last at least 90 days or a need for substantial supervision for health and safety threats due to severe cognitive impairment.[6] HIPAA does not count ADL limitations that can be resolved with special equipment, such as wheelchairs, walkers, handrails, ramps, catheters, and related devices (Stallard 2011). Estimates of disability prevalence are higher when we include people with less severe disabilities and people with disabilities that can be mitigated with special equipment.

Methods

The findings in this brief--an update of Favreault and Dey (2016)--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. 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. Simulations of these events and outcomes vary with 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 2021; 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, especially in the areas of health, disability (including cognitive impairment and limitations in ADLs and instrumental activities of daily living [IADLs]), LTSS use, and private LTCI coverage.[8] Because we rely on historical data, the projections do not reflect how the COVID-19 pandemic might shift LTSS use.

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 (Fossett and Burke 2010; Genworth 2019; Grabowski et al. 2004; Hansen Hunter and Company 2018; Mollica 2009; Ng et al. 2014).[9] 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; Kim 2022; Newquist, DeLiema and Wilber 2015). The projections include hospice care, which Medicare pays, but excludes other Medicare-financed services that are strictly post-acute (see Box 1). These choices affect payer mix and comparability with other estimates of LTSS expenses, including Favreault and Dey (2016).

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 is clear about Medicare policies on 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 2022) and include all Medicare services delivered in certain settings as LTSS. They make this choice 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, making disaggregation difficult.

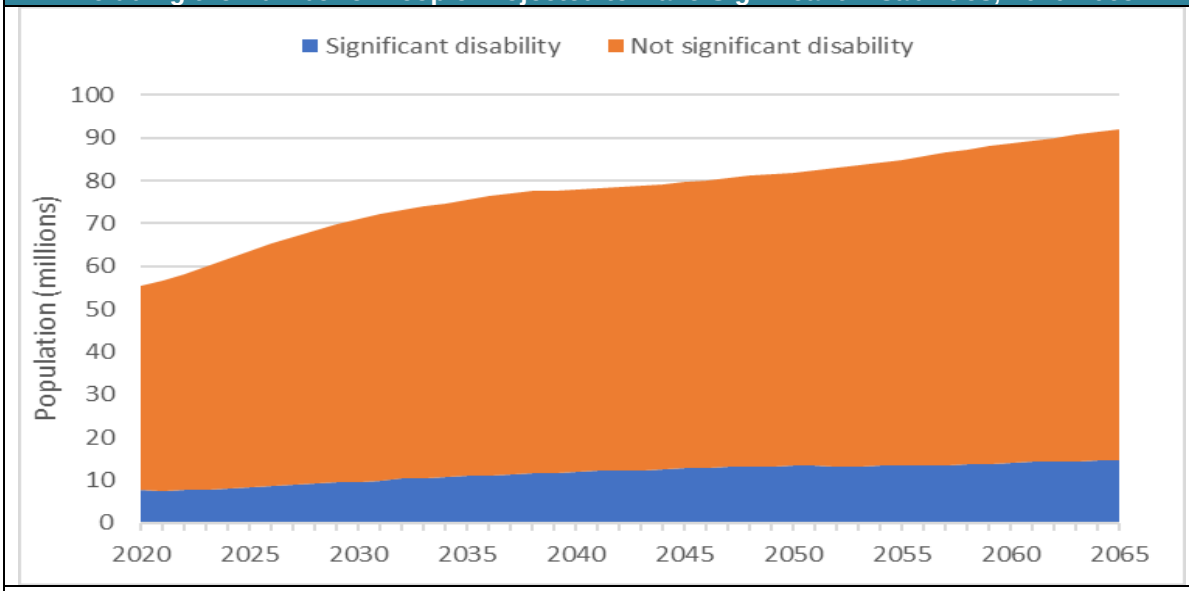
In a departure from Favreault and Dey (2016), we follow Hado and Komisar (2019) and do not include in our projections any incidental care that Medicare finances, with one exception: the projections include the value of Medicare-financed hospice care if it is provided to people meeting a HIPAA-level-of-need threshold.

Finally, we value unpaid family care at the approximate cost of hiring someone to provide care. For each hour of unpaid care provided to a person with significant disabilities, we assign a value equal to the median hourly wage for home care workers in the care recipient's state of residence. This projection is likely a lower bound for the total value of unpaid family care because our estimates ignore administrative hiring costs, any nonwage compensation that paid caregivers receive, and the value of care provided to older adults with less-significant disabilities, which is likely substantial. Additional details about the model's assumptions are available in Johnson (2022).

Results

Figure 1 presents projections of the number of people ages 65 and older and the number with significant disabilities from 2020 to 2065. As expected, given the aging population, the number with significant disabilities is projected to grow substantially, increasing from 7.6 million to almost 14.7 million. In percentage terms, the share of the older population with significant disabilities increases from 14% to 16%.

FIGURE 1. Total Population Ages 65 and Older, Including the Number of People Projected to Have Significant Disabilities, 2020-2065



SOURCE: Authors' tabulations from DYNASIM4, run id982.
NOTE: Estimates are for adults born between 1941 and 1974 who survive to age 65.

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 adults turning 65 between 2021 and 2025.[10] 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 significant need for LTSS; 12% are expected to have needs that last less than a year, and about 22% are expected to have needs that extend beyond five years. Estimates such as these are sensitive to the definition of disability. Many people whose disabilities do not reach higher levels of significance still need and use LTSS. With a more expansive definition, such as one that includes those with one ADL

limitation or only IADLs limitations without severe cognitive impairment, the number of people with LTSS needs would be significantly higher (Freedman and Spillman 2014; Kemper, Komisar and Alecxih 2005/2006).

TABLE 1. Projected Need for LTSS for People Turning 65 in 2021-2025, by Gender, Income, Self-Reported Health Status, and Marital Status

	Life Expectancy at Age 65 (years, full population)	Average Years of LTSS Need (all)	Average Years of LTSS Need Given Some Need	Percent with Some LTSS Need	Distribution of LTSS Needs for the Full Population (%)				
					None	<1 Year	1.00-1.99 Years	2.00-4.99 Years	>5 Years
Total	**20.5**	**3.1**	**5.4**	**56.4**	**43.6**	**11.9**	**7.9**	**14.7**	**22.1**
Gender									
Men	19.1	2.5	5.1	48.6	51.4	11.2	7.1	12.8	17.5
Women	21.9	3.6	5.6	63.7	36.3	12.4	8.6	16.4	26.3
Income Quintile at Age 65									
Lowest	18.2	3.8	6.1	62.9	37.1	12.0	7.8	14.5	28.6
Second	19.1	3.0	5.3	57.3	42.7	12.7	8.2	14.9	21.5
Middle	20.3	3.2	5.8	54.8	45.2	10.1	7.9	14.4	22.4
Fourth	21.0	2.7	4.9	54.3	45.7	11.5	8.4	15.0	19.5
Highest	23.2	2.8	5.1	54.0	46.0	12.8	7.2	14.5	19.6
Health Status at Age 65									
Excellent	22.3	2.8	5.1	55.6	44.4	11.5	7.6	17.0	19.5
Very good	21.4	3.0	5.4	55.5	44.5	11.2	8.5	13.8	22.0
Good	20.4	2.8	5.2	54.1	45.9	12.3	7.4	14.1	20.3
Fair/poor	18.9	3.5	5.7	60.3	39.7	12.2	7.7	15.1	25.3
Marital Status at Age 65									
Married	21.6	2.9	4.7	54.9	45.1	11.9	7.8	14.6	20.6
Unmarried	19.7	3.4	5.4	60.0	40.0	11.9	8.2	15.2	24.7

SOURCES: Authors' tabulations from DYNASIM4, run id982
NOTES: LTSS need is defined as a need for assistance with at least two activities of daily living or supervision due to severe cognitive impairment that is expected to last at least 90 days.

LTSS needs vary substantially by personal characteristics. The average duration of disability is higher for women (3.6 years) than for men (2.5 years). Among women, 64% are likely to develop a significant disability, and 26% will need at least 5 years of care. The proportion needing at least five years of care is especially high among those in the lowest income quintile at age 65 (29%)[11] and those reporting fair or poor health at age 65 (25%). Among those who ever develop a significant disability, the average duration is 5.6 years for women and 5.1 years for men.

Table 2 examines the use of paid LTSS for a significant disability from age 65 onward measured in service days (where 365 days of paid LTSS counts as one year, regardless of whether all care occurs in the same calendar year). Of the average 3.1 years that older adults are projected to have a significant disability, they will receive paid care for about 0.8 years, and unpaid caregivers, such as family and friends, will make up most of the difference.[12] Again, patterns vary by personal characteristics. People who are unmarried at age 65 use more paid services than those who are married (1.0 years, on average, compared with 0.7 years). Those in poor health at age 65 and those with lower income at age 65, many of whom qualify for Medicaid, use more paid services.

TABLE 2. Projected Use of Paid LTSS for People Who Turn 65 in 2021-2025, by Gender, Income Quintile, Self-Reported Health Status, and Marital Status							
	Average Years with Paid LTSS Use	Percent with Any Paid LTSS Use (all)	Distribution of Paid LTSS Use for the Full Population (%)				
			None	<1 Year	1.00-1.99 Years	2.00-4.99 Years	>5 Years
Total	**0.8**	**45.3**	**54.7**	**24.1**	**7.3**	**9.5**	**4.4**
Gender							
Men	0.6	38.9	61.1	22.2	6.2	7.4	3.1
Women	1.0	51.3	48.7	25.9	8.4	11.4	5.6
Income Quintile at Age 65							
Lowest	1.2	49.4	50.7	23.7	6.7	10.6	8.4
Second	0.8	45.6	54.4	26.1	6.7	8.5	4.3
Middle	0.7	44.7	55.3	25.2	6.3	9.3	4.0
Fourth	0.7	44.0	56.1	23.4	8.8	9.0	2.8
Highest	0.7	43.7	56.3	22.9	7.7	10.1	3.1
Health Status at Age 65							
Excellent	0.8	46.1	53.9	23.1	8.6	10.9	3.5
Very good	0.8	45.5	54.5	25.0	7.1	9.1	4.3
Good	0.7	43.2	56.8	23.6	7.4	8.7	3.5
Fair/poor	1.0	47.1	52.9	24.3	6.8	10.2	5.8
Marital Status at Age 65							
Married	0.7	42.5	57.5	23.4	7.1	8.7	3.4
Unmarried	1.0	50.5	49.5	25.9	7.9	10.9	5.9

SOURCES: Authors' tabulations from DYNASIM4, run id982
NOTES: LTSS need is defined as a need for assistance with at least two activities of daily living or supervision due to severe cognitive impairment that is expected to last at least 90 days.

While individuals on average will need 0.8 years of paid LTSS, 55% of older adults will not use any paid LTSS. About 24% of older adults (or about half of paid LTSS users) will receive less than a year of paid LTSS (measured in service days), and about 4% of older adults will use five years or more. These projections are similar to Johnson's (2019) estimates of care use based on recent historical data.

Table 3 presents the average sum of expenditures for LTSS (in 2020 dollars) that could be expected from age 65 until death for the entire population, and Table 4 repeats the analysis for those who use paid LTSS. The tables display this projected sum of expenditures by setting and payer for those reaching age 65 between 2021 and 2025. These estimates differ from a present discounted value (PDV) of expenditures at age 65, the amount that an individual would need to set aside at age 65 to cover future LTSS expenses. The PDV is lower than the sum-of-expenditures measure because it accounts for the investment returns that could be earned on funds set aside at age 65 until LTSS expenses begin, often after age 80. We show PDV projections in the appendix.[13]

We project that total paid LTSS expenses will average $120,900 per person (Table 3).[14] Medicaid is the largest payer of LTSS, averaging $51,800 after age 65 and accounting for 43% of the total. Family out-of-pocket costs are also substantial, averaging $44,800 and accounting for 37% of the total. Payments vary by setting. Medicaid covers more than half (52%) of total costs in institutional settings, whereas out-of-pocket payments by families account for 44% of total community-based expenses.[15]

TABLE 3. Projected Sum of LTSS Expenditures from Age 65 through Death for Adults Who Turn 65 in 2021-2025, by Payer and Setting						
Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$70,100	58	$27,100	48	$43,000	67
Medicaid	51,800	43	18,600	33	33,200	52
Other Public	18,300	15	8,500	15	9,800	15
Private	$50,800	42	$29,400	52	$21,500	33
Out-of-Pocket	44,800	37	24,800	44	20,100	31
Private Insurance	6,000	5	4,600	8	1,400	2
All Payers	**$120,900**	**100**	**$56,500**	**100**	**$64,400**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

Among those who ever use paid LTSS after turning age 65, the average cost is projected at $245,400 (Table 4). Although conditioning on the use of LTSS increases average costs, the cost distribution by payer and setting is very similar to that shown in Table 3.

TABLE 4. Projected Sum of LTSS Expenditures from Age 65 through Death for Users of Paid LTSS Who Turn 65 in 2021-2025, by Payer and Setting						
Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$139,700	57	$52,500	46	$87,200	67
Medicaid	102,900	42	35,500	31	67,400	52
Other Public	36,800	15	17,000	15	19,800	15
Private	$105,700	43	$62,200	54	$43,500	33
Out-of-Pocket	93,500	38	52,800	46	40,700	31
Private Insurance	12,200	5	9,400	8	2,800	2
All Payers	**$245,400**	**100**	**$114,700**	**100**	**$130,700**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

Expected LTSS costs are higher for women than men. Women's costs average $154,300 (Table 5), compared with $85,400 for men (Table 6). When we restrict our analysis to adults with any LTSS expenditures, this average increases to $277,900 for women and $200,400 for men (not shown). Women spend more on LTSS than men because they tend to live longer and thus are more exposed to the risk of needing LTSS. Additionally, married women are often younger than their husbands and more likely to become widowed at older ages, leaving women less likely to receive unpaid spousal care (and more likely to provide it).

TABLE 5. Projected Sum of Expenditures from Age 65 through Death, for Women Who Turn 65 in 2021-2025, by Payer and Setting						
Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$90,000	58	$33,200	47	$57,000	68
Medicaid	68,400	44	23,000	32	45,500	54
Other Public	21,600	14	10,200	14	11,500	14
Private	$64,300	42	$37,700	53	$26,600	32
Out-of-Pocket	56,400	37	31,400	44	25,000	30
Private Insurance	7,900	5	6,300	9	1,600	2
All Payers	**$154,300**	**100**	**$70,800**	**100**	**$83,500**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

TABLE 6. Projected Sum of Expenditures from Age 65 through Death for Men Who Turn 65 in 2021-2025, by Payer and Setting						
Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$48,700	57	$20,600	50	$28,100	64
Medicaid	34,000	40	13,900	34	20,100	46
Other Public	14,700	17	6,700	16	8,000	18
Private	$36,700	43	$20,700	50	$16,000	36
Out-of-Pocket	32,600	38	17,800	43	14,800	34
Private Insurance	4,100	5	2,900	7	1,200	3
All Payers	**$85,400**	**100**	**$41,300**	**100**	**$44,100**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

Table 7 presents the distribution of the sum of expected costs for adults ages 65 and older in 2021-2025 by payer. About 15% of older adults can expect their total LTSS expenses from age 65 onward to amount to more than $250,000, whereas about 8% will have positive but low costs (less than $10,000). A smaller percentage (about 6%) will spend $250,000 or more out of pocket on LTSS. Fourteen percent will spend at least $100,000 out of pocket on LTSS after turning 65.

TABLE 7. Projected Average and Distribution of Sum of LTSS Expenditures from Age 65 through Death for Adults Turning 65 in 2021-2025, by Payer												
Payer	Average Expenditures	Percent of People with Expenditures	Distribution of Sum of LTSS Expenditures (% of people)									
			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	$70,100											
Medicaid	51,800	18.3	81.7	2.4	1.4	1.5	1.1	1.0	1.6	1.5	1.2	6.8
Other Public	18,300	40.9	59.1	13.2	8.6	8.1	3.8	2.2	2.4	1.0	0.6	0.8
Private	$50,800											
Out-of-Pocket	44,800	34.9	65.1	5.9	5.0	4.4	3.2	2.3	3.7	2.3	1.6	6.4
Private Insurance	6,000	3.6	96.4	0.4	0.5	0.6	0.3	0.2	0.5	0.2	0.2	0.6
All Payers	**$120,900**	**49.3**	**50.7**	**8.2**	**5.4**	**5.5**	**3.7**	**2.7**	**3.8**	**2.9**	**2.4**	**14.7**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars.

These figures mask important differences by income. People with lower incomes tend to have more of their costs covered by Medicaid and pay less out of pocket. The DYNASIM4 projections suggest that although Medicaid is used by older adults throughout the age-65 income distribution, it primarily serves those in the bottom two income quintiles (Table 8). For example, about 35% of people in the bottom income quintile at age 65 and 23% of those in the second quintile will receive Medicaid LTSS at some point after turning 65, compared with 6% in the top income quintile. Our projections indicate that adults in upper income quintiles who use Medicaid are typically individuals who have survived through their mid to late 90s, consistent with other research (Borella et al. 2017; DeNardi et al. 2013).

TABLE 8. Projected Average and Distribution of Sum of Medicaid LTSS Expenditures From Age 65 to Death for Adults Who Turn 65 in 2021-2025, by Income Quintile

Income Quintile at Age 65	Average Medicaid Expenditures	Percent of People with Medicaid Expenditures	Distribution of Sum of Medicaid LTSS Expenditures (% of people)									
			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	108,400	35.4	64.6	4.4	2.8	2.4	1.7	1.7	3.6	2.4	2.1	14.3
Second	63,500	22.5	77.5	3.4	1.8	1.7	1.5	1.1	1.7	2.0	1.6	7.6
Middle	47,600	17.6	82.4	2.5	1.4	1.4	1.1	0.9	1.1	1.7	1.2	6.4
Fourth	21,400	9.3	90.7	1.2	0.3	1.4	0.6	0.4	0.9	0.8	0.7	3.1
Highest	14,000	5.7	94.3	0.4	0.4	0.4	0.4	0.6	0.6	0.4	0.2	2.3
All Quintiles	**$51,800**	**18.3**	**81.7**	**2.4**	**1.4**	**1.5**	**1.1**	**1.0**	**1.6**	**1.5**	**1.2**	**6.8**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars.

Family out-of-pocket expenditures, in contrast, are more concentrated within higher income quintiles (Table 9). The average lifetime out-of-pocket LTSS expense in the top quintile is $75,400, compared with $15,400 in the bottom quintile. Again, however, the mean obscures important distributional information. About 10% of people in the top income quintile at age 65 can expect to incur out-of-pocket expenses after turning age 65 that exceed $250,000. In the bottom half of the income distribution, where more people are protected by Medicaid, the expected share with out-of-pocket spending that exceeds $250,000 is less than 5%.

TABLE 9. Projected Average and Distribution of Sum of Family Out-of-Pocket LTSS Expenditures from Age 65 to Death for Adults Turning 65 in 2021-2025, by Income Quintile

Income Quintile at Age 65	Average Out-of-Pocket Expenditures	Percent of People with Out-of-Pocket Expenditures	Distribution of Sum of Out-of-Pocket LTSS Expenditures (% of people)									
			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	15,400	27.6	72.4	5.3	4.7	4.1	2.0	1.9	3.4	1.8	1.0	3.4
Second	34,200	32.9	67.1	6.2	4.5	4.2	4.4	2.3	3.8	1.9	1.2	4.4
Middle	43,200	34.7	65.3	6.1	4.8	4.7	3.5	1.5	3.9	2.0	1.9	6.3
Fourth	57,900	38.1	61.9	6.2	5.7	4.4	2.9	2.5	3.7	2.8	2.0	7.9
Highest	75,400	41.5	58.5	5.6	5.6	4.7	3.5	3.3	3.7	3.1	1.9	10.3
All Quintiles	**$44,800**	**34.9**	**65.1**	**5.9**	**5.0**	**4.4**	**3.2**	**2.3**	**3.7**	**2.3**	**1.6**	**6.4**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars.

Many older adults with care needs receive substantial amounts of unpaid care from family members and friends. Our projections indicate that the value of unpaid family care received by adults born between 2021 and 2025 with significant disabilities averages $91,900 (Table 10). Among people receiving unpaid family care, the average value of care reaches $204,000, more than the value of all paid LTSS. Women receive more unpaid care than men.

TABLE 10. Projected Average Value of Unpaid Family Care from Age 65 through Death for Adults Who Turn 65 in 2021-2025		
	All Adults	Adults Receiving Unpaid Family Care
Total	**$91,900**	**$204,000**
Men	74,200	196,800
Women	108,600	208,800

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: Estimates are reported in 2020 inflation-adjusted dollars and restricted to care received during periods of significant disability. Each hour of unpaid care is valued at the median hourly wage for home care workers in the care recipient's state of residence and summed from age 65 to death.

Conclusion

Most Americans who survive to age 65 can expect to need and use LTSS. Our estimates suggest more than half the population (56%) will have a significant level of disability. On average, the projected duration of LTSS need is 3.1 years, and the projected length of paid LTSS is just less than one year. The average cost of this care is $120,900. 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 strict income and asset criteria many families pay for LTSS out of pocket. Private LTSS insurance has only a modest reach, and it predominantly covers costs for those high in the income distribution. Other public expenditures, such as U.S. Department of Veterans Affairs (VA) care, only help cover small shares of the population with LTSS needs. The value of unpaid care provided by family members and friends to people with significant disabilities exceeds the value of paid care, and unpaid care is even more important when people have less severe disability. Our results highlight the need for better planning for LTSS to accommodate both average and catastrophic financial risks associated with chronic disability.

Differences from Earlier Projections

The results presented here differ from those reported in Favreault and Dey (2016). Compared with the earlier version of our model, which generated Favreault and Dey's projections, our updated model projects longer average durations of LTSS *needs* (3.1 years versus 2.0 years), but the average time spend *receiving* LTSS does not differ much between the two versions. The updated model also projects lower average LTSS expenditures ($120,900 versus $138,100), especially for family out-of-pocket payments. These differences result from some definitional changes between the two analyses and numerous technical changes and updates.

An important substantive change between this brief and Favreault and Dey (2016) is that we removed from our expected cost tables the incidental LTSS that Medicare covers. As Box 1 discusses, Medicare generally does not pay for long-term care when it is the only service a person needs. However, some people 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.

Much of the shift in the projections result from data updates and changes in the way we specified model equations. 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 re-estimated many of the model parameters so that they use more recent data from the Health and Retirement Study and other data sources. As we re-estimated some parameters, we sometimes changed equation specification, which altered our projections. These changes increased families' sensitivity to costs when making LTSS decisions, reducing some paid LTSS use by lower-income families, especially when they would have to pay out of pocket. They also reduced service use at older ages. When projecting the duration of LTSS needs, we now focus more on days in need rather than years in need to better capture partial-year impairments. Additionally, we removed some post-acute services from our LTSS estimates and improved our algorithm of assigning costs to payers, which increased the significance of other public payers, such as the VA and programs funded by the Older Americans Act.

In addition, the updated model improves our projections of severe cognitive impairment, which partly determines the projected population with significant disabilities at risk of receiving LTSS. We closely compare our dementia projections with the literature on the distribution of the duration of impairment (for example, Brookmeyer et al. 2002, Larson et al. 2004). Although the literature on cognitive impairment has been growing rapidly in recent years, estimates on the length of time with a severe cognitive impairment 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.

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. LTSS 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) (Office of the Assistant Secretary for Planning and Evaluation 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 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 at the U.S. Department of Health and Human Services, 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 the brief we reference this level of need as “significant LTSS needs.”

7. DYNASIM4's LTSS projections draw information from a wide range of cross-sectional and longitudinal sources, including the Health and Retirement Study, Medicare Current Beneficiary Study, and National Health and Aging Trends Survey.

8. Capturing trends in LTSS outcomes is challenging. When there is a clear trend, such as the decline in mortality, DYNASIM4 follows the Social Security trustees' assumptions. Otherwise, DYNASIM4 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. As the population becomes better educated, for example, the model assigns the rates for more highly educated adults to more people, but the rate for an adult with a certain level of education does not change.

9. DYNASIM4 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 LTCI--use higher-cost providers.

10. Multiple cohorts are used to provide a sample that is large enough for subpopulation analysis.

11. We define income quintile by income relative to the federal poverty level. This measure recognizes that married couples need more resources than single adults but acknowledges that shared living arrangements allow couples to economize, so a couple needs less than twice as much as a single adult. The measure includes earnings, pensions, Social Security, Supplemental Security Income, and asset income (defined as the annuitized value of financial assets) received by individuals and, if married, their spouses.

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. Dollar amounts are rounded to the nearest $100, reflecting the inherent uncertainty surrounding the projections. PDV estimates, which are reported in Tables A1-A9, use the Social Security trustees' ultimate real interest rate of 2.5%. Because the trustees assume long-range price growth averages 2.6%, this real discount rate is equivalent to a nominal long-run discount rate of about 5.1%.

14. We restrict our cost estimates to people with significant disabilities, except that we count nursing home care costs regardless of a resident's disability status and we count residential care costs for residents who report difficulty with at least two ADLs (or are severely cognitively impaired), instead of requiring them to need assistance with two or more ADLs. Because our cost estimates use a somewhat less stringent disability requirement than our estimates of the receipt of paid LTSS, our projection of the share of older adults with LTSS expenditures slightly exceeds our projection of the share who receive any paid LTSS (49.3% in Table 7 versus 45.3% in Table 2).

15. The relative share of costs borne by different payers is sensitive to whether and how residential care is incorporated into these projections. Some researchers exclude from LTSS cost estimates the housing component of residential care, which is included in our estimates. The NHEA exclude some related sectors completely (Hartman, Kornfeld and Catlin 2010). Removing the housing component of residential care or removing residential care completely reduces out-of-pocket costs and families' share of spending.

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Appendix: Projections of LTSS Expenditures Using a Present Discounted Value Measure

TABLE A1. Projected PDV of Expenditures from Age 65 through Death for Adults Who Turn 65 in 2021-2025, byPayer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Dollars	Percentage of total	Dollars	Percentage of total	Dollars	Percentage of total
Public	$42,200	60	$17,400	53	$24,800	67
Medicaid	31,500	45	12,400	38	19,100	52
Other Public	10,700	15	5,000	15	5,700	15
Private	$27,600	40	$15,600	47	$12,100	33
Out-of-Pocket	24,000	34	12,800	39	11,300	31
Private Insurance	3,600	5	2,800	8	800	2
All Payers	**$69,800**	**100**	**$33,000**	**100**	**$36,900**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

TABLE A2. Projected PDV of Expenditures from Age 65 through Death for Adults Who Turn 65 in 2021-2025 and Use Paid LTSS, by Payer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$83,700	59	$33,300	50	$50,300	67
Medicaid	62,200	44	23,400	35	38,700	52
Other Public	21,500	15	9,900	15	11,600	16
Private	$58,100	41	$33,600	50	$24,600	33
Out-of-Pocket	50,800	36	28,000	42	22,900	31
Private Insurance	7,300	5	5,600	8	1,700	2
All Payers	**$141,700**	**100**	**$66,900**	**100**	**$74,800**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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. Components do not always sum to totals because of rounding.

TABLE A3. Projected PDV of Expenditures from Age 65 through Death for Women Who Turn 65 in 2021-2025, by Payer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$52,800	61	$21,000	52	$31,900	69
Medicaid	40,400	47	15,100	37	25,300	55
Other Public	12,400	14	5,900	15	6,600	14
Private	$34,000	39	$19,400	48	$14,600	31
Out-of-Pocket	29,500	34	15,800	39	13,700	30
Private Insurance	4,500	5	3,600	9	900	2
All Payers	**$86,800**	**100**	**$40,400**	**100**	**$46,400**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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 A4. Projected PDV of Expenditures from Age 65 through Death for Women Who Turn 65 in 2021-2025 and Use Paid LTSS, by Payer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$93,000	60	$35,700	49	$57,300	69
Medicaid	70,900	45	25,400	35	45,500	54
Other Public	22,100	14	10,300	14	11,800	14
Private	$63,200	40	$37,100	51	$26,200	31
Out-of-Pocket	55,100	35	30,500	42	24,600	29
Private Insurance	8,100	5	6,600	9	1,600	2
All Payers	**$156,300**	**100**	**$72,800**	**100**	**$83,500**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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 A5. Projected PDV of Expenditures from Age 65 through Death for Men Turning 65 in 2021-2025, by Payer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$30,900	60	$13,700	55	$17,300	65
Medicaid	22,000	43	9,600	38	12,500	47
Other Public	8,900	17	4,100	16	4,800	18
Private	$20,800	40	$11,300	45	$9,500	35
Out-of-Pocket	18,200	35	9,500	38	8,700	32
Private Insurance	2,600	5	1,800	7	800	3
All Payers	**$51,700**	**100**	**$25,000**	**100**	**$26,800**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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 A6. Projected PDV of Expenditures from Age 65 through Death for Men Who Turn 65 in 2021-2025 and Use Paid LTSS, by Payer and Setting

Payer	All Settings		Community-Based (includes residential care)		Nursing Facility	
	Average ($)	Percentage of total	Average ($)	Percentage of total	Average ($)	Percentage of total
Public	$70,500	58	$30,000	51	$40,600	65
Medicaid	49,900	41	20,700	35	29,300	47
Other Public	20,600	17	9,300	16	11,300	18
Private	$51,000	42	$28,700	49	$22,300	36
Out-of-Pocket	44,900	37	24,400	42	20,500	33
Private Insurance	6,100	5	4,300	7	1,800	3
All Payers	**$121,500**	**100**	**$58,600**	**100**	**$62,800**	**100**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations. Residential care is included in community-based care, not nursing-facility care. 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 A7. Projected Average and Distribution of PDV of LTSS Expenditures from Age 65 through Death for Adults Who Turn 65 in 2021-2025, by Payer

Payer	Average Expenditures	Percent of People with Expenditures	Distribution of PDV of LTSS Expenditures (% of people)									
			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	$42,200											
Medicaid	31,500	18.3	81.7	3.0	1.8	1.7	1.5	1.3	1.9	1.6	1.2	4.3
Other Public	10,700	40.9	59.1	17.3	10.2	7.4	2.9	1.3	1.2	0.4	0.1	0.1
Private	$27,600											
Out-of-Pocket	24,000	35.5	65.2	8.3	5.6	5.7	3.3	2.8	3.3	2.0	1.3	2.5
Private Insurance	3,600	3.6	96.4	0.6	0.7	0.6	0.5	0.3	0.3	0.2	0.1	0.4
All Payers	**$69,800**	**49.3**	**50.7**	**10.4**	**6.4**	**6.9**	**3.7**	**3.2**	**4.3**	**3.0**	**2.4**	**9.0**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations.

TABLE A8. Projected Average and Distribution of PDV of Medicaid LTSS Expenditures from Age 65 to Death for Adults Who Turn 65 in 2021-2025, by Income Quintile

Income Quintile at Age 65	Average Expenditures	Percent of People with Expenditures	Distribution of PDV of LTSS Expenditures (% of people)									
			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	71,625	35.4	64.6	5.4	2.8	3.2	2.4	2.8	3.6	2.3	2.7	10.2
Second	37,433	22.5	77.5	4.5	2.0	2.0	1.8	1.8	2.3	1.9	0.8	5.3
Middle	27,378	17.6	82.4	3.1	1.8	1.7	1.6	1.0	1.8	1.5	1.4	3.7
Fourth	11,463	9.3	90.7	1.2	1.5	0.9	1.0	0.5	1.2	1.3	0.5	1.1
Highest	6,904	5.7	94.3	0.5	0.6	0.8	0.8	0.4	0.6	0.8	0.5	0.7
All Quintiles	$31,517	18.3	81.7	3.0	1.8	1.7	1.5	1.3	1.9	1.6	1.2	4.3

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations.

TABLE A9. Projected Average and Distribution of PDV of Family Out-of-Pocket LTSS Expenditures From Age 65 to Death for Adults Turning 65 in 2021-2025, by Income Quintile

Income Quintile at Age 65	Average Expenditures	Percent of People with Expenditures	Distribution of PDV of LTSS Expenditures (% of people)									
			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	6,021	28.9	72.5	7.1	5.4	4.2	2.8	2.3	2.5	1.7	0.9	0.6
Second	19,057	33.7	67.2	8.1	5.2	6.9	3.0	2.8	2.8	1.2	1.2	1.5
Middle	24,000	34.9	65.3	8.4	5.3	6.0	3.2	2.3	3.2	2.5	1.2	2.5
Fourth	31,577	38.5	61.9	9.6	5.4	5.3	3.7	3.3	3.5	2.4	2.2	2.7
Highest	40,737	42.0	58.5	8.2	6.7	6.3	3.9	3.1	4.6	2.4	1.2	5.0
All Quintiles	**$24,029**	**35.5**	**65.2**	**8.3**	**5.6**	**5.7**	**3.3**	**2.8**	**3.3**	**2.0**	**1.3**	**2.5**

SOURCES: Authors' tabulations from DYNASIM4, run id982.
NOTES: PDV = present discounted value. Estimates are reported in 2020 inflation-adjusted dollars. We use a real discount rate of 2.5% (5.1% nominal) in these calculations.

This Research Brief, authored by Richard W. Johnson (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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