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ISSUE BRIEF

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FUTURE CHANGE IN CAREGIVING NETWORKS: HOW FAMILY CAREGIVERS AND DIRECT CARE WORKERS SUPPORT OLDER ADULTS NOW AND IN THE FUTURE

KEY POINTS

- We project that in coming decades family caregivers will continue to provide most of the care received by older adults who need long-term services and supports.
- However, paid care will grow more rapidly than unpaid care as more people reach later life without spouses and with fewer adult children.
- Consequently, out-of-pocket costs for long-term services and supports are projected to grow faster than publicly funded care costs.

BACKGROUND

Most older people who need long-term services and supports (LTSS) rely on family caregivers. These networks are instrumental to older people's ability to remain in the community.[1] If informal care is not available, persons with disabilities may receive paid LTSS or not have their needs met. Health insurance does not cover LTSS costs, and Medicare, the major public insurance program for older Americans, does not cover most LTSS expenses. Medicaid provides LTSS, but it is only available for individuals who meet income and other eligibility requirements.[2] Although children and especially spouses tend to be the most intensive caregivers, all types of friends and family--including siblings, nieces and nephews, in-laws, former spouses, and grandchildren--often step in to help people with LTSS needs.[3] Shifting demographics, including changing marriage patterns and declining fertility rates, are likely to alter the future size and composition of these networks and change the mix of paid and unpaid care that older adults with LTSS needs receive. The concern in the United States and elsewhere is the possibility of an impending "care gap" between the number of these informal caregivers available and the number of baby boomers requiring assistance as they age, with implications for both recipients and family caregivers. Potential outcomes of such a shortfall may include greater unmet need for assistance and greater demand on the formal/paid long-term care system, including the Medicaid program, as Baby Boomers reach ages when functional decline is common.[1]

METHODS

This brief uses estimates from the Health and Retirement Study (HRS)[i] and projections from the Dynamic Simulation of Income Model (DYNASIM), to show how care needs, care networks, and care provided by friends and family members for adults ages 65 and older will change over time.[ii] We show near-term estimates and projections over the next six decades.

We focus on a more narrow measure of old-age disability, which mirrors the "benefit triggers" for tax-advantaged long-term care insurance policies specified in the Health Insurance Portability and Accountability Act of 1966 (HIPAA). These HIPAA-based criteria focus on more significant disability, identifying people with

chronic need for help with two or more ADLs, including incontinence, and adding severe cognitive impairment as a separate criterion. Besides establishing a benchmark for private insurance, the measure has become more common for approximating high need for long-term care services generally and eligibility for Medicaid services specifically, although considerable variation across state programs remains.[1]

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

Our analysis distinguishes between *potential* care networks and *actual* care networks. We define a potential network based on whether someone with LTSS needs has a surviving spouse or partner or any adult children and create four potential care network categories: Both spouse and child, spouse only, child only, and neither spouse or child (others only). An actual care network consists of the people who provide at least some care over the course of a year. More categories are needed to define actual networks than potential networks, as many care partner combinations are possible, including spouse only, spouse and child, child and other, child only, spouse and other, and other only.

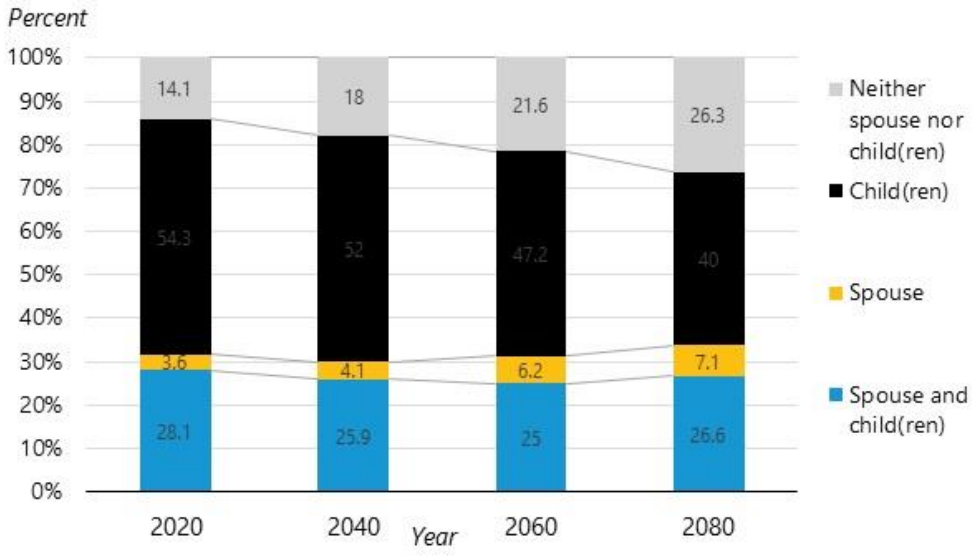
RESULTS

In the coming decades, a greater share of people will enter older years where disability is more likely without a spouse or children to provide care (***Figure 1***). Our projections suggest that among older people with significant LTSS needs,[iii] about 26% will not have a spouse, partner or child in their potential network in 2080, compared with about 14% in 2020.

Because the number of people who never marry or experience a divorce is increasing, the number of unmarried older adults is growing. However, the share of older people who are widowed is falling as the difference between men's and women's mortality has declined. For people born in 1920 who survived to age 65, for example, men could expect to live 15.39 additional years while women could expect to live 19.04 additional years, a difference of 3.65 years.[4] For people born in 1945 and surviving to age 65, remaining life expectancy is 18.22 years for men and 20.79 years for women, a difference of 2.57 years.[4] Over those 25 years, the gap between men and women shrank by more than a year. The convergence in life expectancy for men and women reduces the share of older adults who will be widowed and the time they spend being widowed. This partially offsets growth in people who do not marry or who divorced and do not remarry.

Figure 1. Projected Composition of Potential Care Networks at Ages 65 and Older, People with Significant LTSS Needs, 2020-2080 (%)

Among people ages 65 and older with significant LTSS needs, the share without a surviving spouse or child is expected to grow steadily in coming decades



SOURCE: Urban Institute projections from DYNASIM.

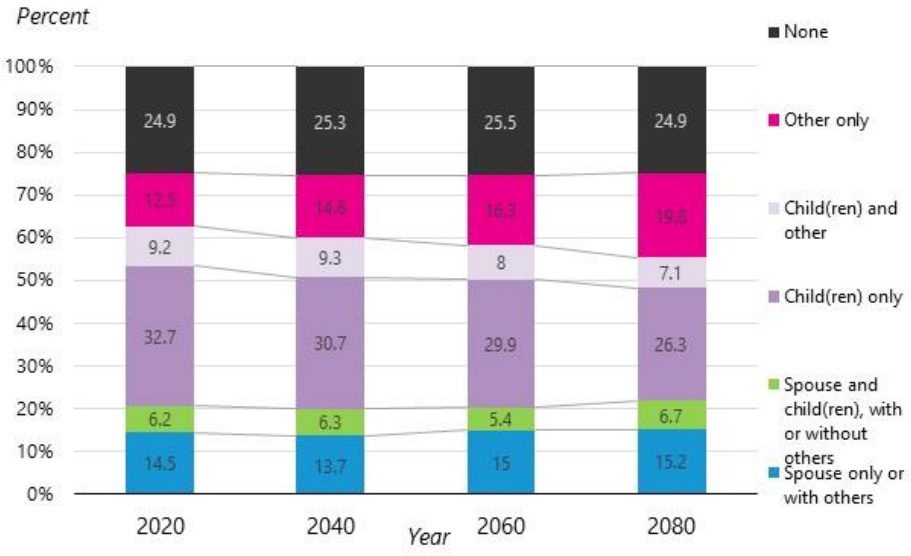
NOTES: Sample consists of people ages 65 and older with significant LTSS needs. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. Unmarried cohabiting partners are included in our definition of spouse.

Based on current caregiving patterns (i.e., the likelihood that someone in a care network actually provides care), we project that the share of older adults with functional limitations who lack spouses or children to care for them will grow over time (***Figure 2***). Spouses still form the base of care providers for people with significant LTSS needs, sometimes caring together with their children. Their ranks are expected to hold steady as widowhood becomes less common. Children providing care without a parent make up the largest slice of the care network, but that share is expected to decline steadily, while the share of people receiving care from someone other than a parent or child is expected to increase modestly.

Many families combine unpaid family care with paid care (***Figure 3***). We expect that people receiving unpaid care alone will continue to make up the vast majority of care recipients. However, the share receiving only unpaid care is expected to decline from about 65% today to about 61% in the second half of the century, when a larger share of families are expected to seek help from paid providers.

Figure 2. Projected Actual Care Providers at Ages 65 and Older, 2020-2080

The share of people with significant LTSS needs who lack a caregiver or rely solely on people who are not their spouse or children is expected to grow in coming decades

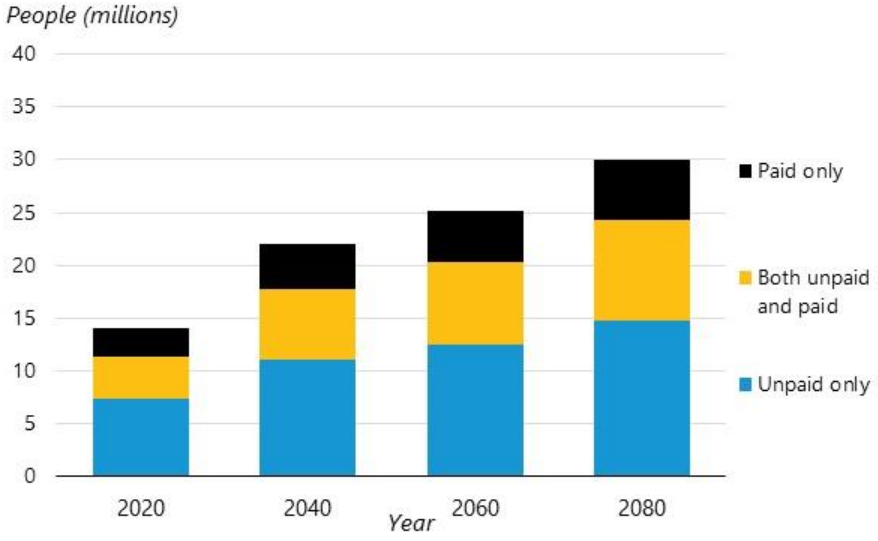


SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample consists of people ages 65 and older with significant LTSS needs. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) a need for substantial supervision for health and safety threats due to SCI. Unmarried cohabiting partners are included in our definition of spouse.

Figure 3. Projected Number of People Ages 65 and Older Receiving Paid Care, Unpaid Family Care, or Both, 2020-2080

The share receiving only unpaid care is expected to fall from about 65% today to about 61% in later years, when larger shares of families are expected to seek help from paid providers



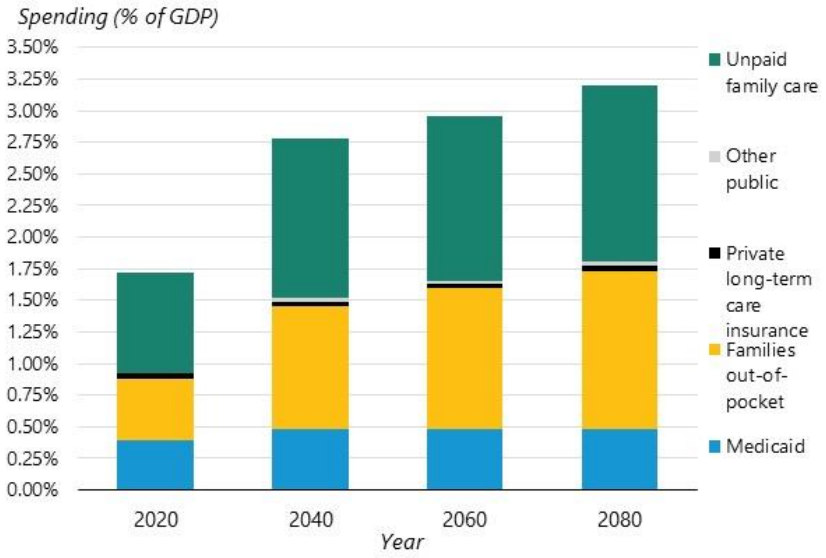
SOURCE: Urban Institute projections from DYNASIM.

NOTES: Projections include people receiving care regardless of the severity of their LTSS needs. Paid care includes nursing home care, residential care ("assisted living"), and paid personal care at home.

This growth in paid care raises the question of who will pay for this assistance. State choices about Medicaid will shape the program's future growth and thus the extent to which families can afford to combine paid and unpaid care.[iv] Nursing home care is the only mandated Medicaid long-term care service, but a major thrust of federal and state Medicaid policy in recent years has been increasing community-based options for Medicaid LTSS. State programs can exercise a number of options, including various waiver programs and state plan benefits for low-income older adults and others with disabilities. Spending for home and community-based services has been increasing for the last two decades, but there is still wide state variation, and in some cases, income and asset allowances for Medicaid enrollees are too low to cover community living expenses.[1] Even if states keep the same level of Medicaid LTSS benefits, we project that families' out-of-pocket contributions will account for a rapidly growing share of the value of LTSS in coming decades (***Figure 4***).

Figure 4. LTSS Spending on Paid Care by Payer, and Unpaid Family Care Contributions, at Ages 65 and Older, 2020-2080 (as % of Gross Domestic Product)

The value of unpaid family care comprises about 46% of the care total in 2020, and falls to about 43% in later years; families' out-of-pocket spending for LTSS is expected to increase rapidly, making up part of this difference



SOURCE: Authors computations from DYNASIM.

NOTES: Projections consist of people receiving care regardless of the severity of their LTSS needs. We value unpaid care by multiplying care hours provided by the average of the prevailing median wages for direct care workers in each recipient's state and the hourly rate that care agencies charge for in-home care.

DISCUSSION

In the coming decades, we anticipate that the number of older adults with unpaid caregivers will double. More older adults will reach the ages when LTSS needs are highest without spouses or children as caregivers. Care demands on extended family are thus likely to grow, and some people with LTSS needs may rely increasingly on paid care. Others may try to accommodate their needs in other ways, such as by relying more on assistive technology like walkers, canes, crutches or home modifications to include more supportive environmental features, such as grab bars or bath seats.[1] Families' out-of-pocket spending burdens are expected to increase as many will turn to residential care options like assisted living to supplement family care. In turn, this may put more pressure on Medicaid to cover these options, and state legislatures to ensure that this care meets individuals' needs. Finally, costs are expected to increase further as demand for paid care grows, particularly as workforce shortages in the LTSS industry are currently an issue and wages may need to increase to attract more individuals to the work.[5]

In companion briefs, we discuss diversity in care needs,[6] the economic value of the unpaid care that family and friends provide,[7] and how care use changes over the course of a disability.[8]

ADDITIONAL METHODOLOGICAL INFORMATION

Favreault and Johnson discuss DYNASIM's LTSS assumptions and capacities in detail.[9] The model simulates unpaid family care using equations estimated on data from the Health and Retirement Study, rules about the Medicaid program, and prices from published sources.[10] The version of the model that we use for these analyses integrates economic and demographic assumptions from a revised baseline released by the Social Security Administration's Office of the Chief Actuary in late 2020.[11] Following the Congressional Budget Office,[12] we assume that state governments will partly but not fully offset any Medicaid erosion that could result from the lack of inflation indexing of various Medicaid parameters.

ENDNOTES

i. HRS is a nationally representative longitudinal study of adults ages 51 and older. It oversamples Black and Hispanic people.

ii. For information about DYNASIM, see the information about our methods at the end of this brief.

iii. We define significant LTSS need as a level of impairment consistent with the definition specified in the Health Insurance Portability and Accountability Act of 1996 for long-term care insurance plans that qualify for tax preferences. One must need either: (1) assistance with at least two activities of daily living (ADLs; among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed due to a condition that is expected to last at least 90 days; or (2) substantial supervision for health and safety threats due to severe cognitive impairment (SCI). This disability threshold does not count ADL limitations that can be resolved with special equipment (e.g., wheelchairs, walkers, handrails, ramps, catheters, and related devices).

iv. Under current law, many key parameters in the Medicaid program are not indexed for inflation, while others grow only with prices rather than with the size of the overall economy, which generally grows faster than prices. As a consequence, all else equal we would anticipate that a smaller share of older adults would be eligible for Medicaid in coming decades unless states or the Federal Government act to combat this erosion. See the information about our methods at the end of this brief for methods for discussion of our Medicaid assumptions.

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