ASPE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

ISSUE BRIEF

August 2, 2023

CHANGES IN CAREGIVING NETWORKS OVER THE COURSE OF DISABILITY

KEY POINTS

- Care networks evolve over the course of a person's disability. New caregivers often step in when a family member's needs escalate.
- People who reside in the community who have significant disabilities are more likely than those without significant disabilities to live with their children.
- Around the time of their death, nearly 85% of people with significant long-term services and support needs receive unpaid family care.
- People without spouses or children are more likely to go without care, turn to assisted living, or rely on Medicaid.

BACKGROUND

Most people who need long-term services and supports (LTSS) first rely on unpaid assistance from members of their family before supplementing unpaid care with assistance from paid helpers. Some rely exclusively on care from family throughout the course of their disability.[1] Family care takes many forms, including companionship and light help, direct care, and assistance with complex medical tasks.[2] As we have shown in prior research,[3] care networks can be quite diverse. Although children and especially spouses tend to be the most intensive caregivers, all types of friends and family often step in to help people with LTSS needs.

For many families, co-residence is part of a continuum of care, although many families choose to co-reside as more LTSS needs develop. Co-residence facilitates the sharing of resources among family members and sometimes prevents people with LTSS needs from falling into poverty.[4]

METHODS

This brief aims to help us understand when and how older adults rely on their families for care, and when they turn to paid care at home or in congregate settings. Using estimates from the Health and Retirement Study (HRS)[i] to understand current relationships and projections from the Dynamic Simulation of Income Model (DYNASIM) to project into the future, we describe the diversity in care needs, care networks, and paid care for adults ages 51 and older.

We focus on older adults with significant LTSS needs using a definition that 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 activities of daily living (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.[ii,5] For some figures we look at those that actually receive care, and thus include all persons with disabilities receiving care.

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 nor 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 children, children and others, children only, spouse and others, and others only.

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).

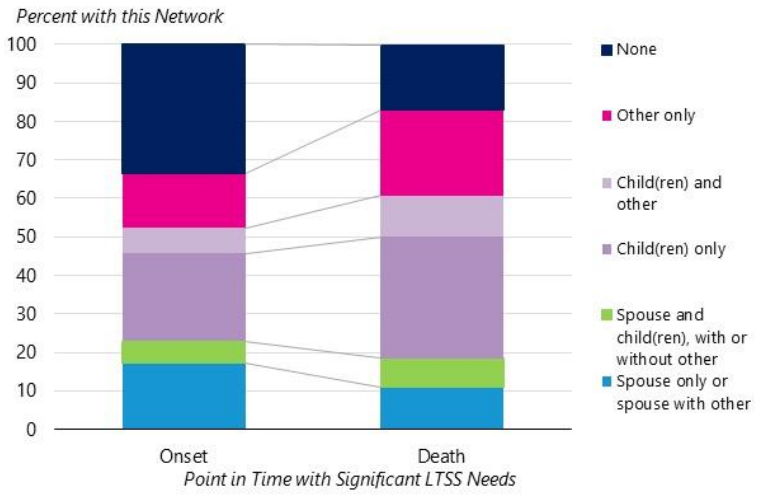
FINDINGS

Family Caregivers Typically Provide Help First

Spouses and adult children are the primary caregivers for older adults with significant LTSS needs (***Figure 1***). In their first year with significant LTSS needs, roughly two-thirds (68%) of people receive some unpaid family care, and just over half receive care from a combination of spouses and children. Others--siblings, grandchildren, neighbors, friends--often step in to assist when a spouse or children are not available. Around the time of a person's death, nearly 85% of people with significant LTSS needs receive unpaid family care, with about three-fifths receiving care from a spouse or children. At the onset of disability, children and others play a smaller role than they do when the death of the care recipient approaches. Children and others tend to replace spouses as the primary caregiver as care recipients reach older ages, when the need for intensive assistance is usually greatest and many care recipients have become widowed.

Figure 1. Composition of Unpaid Care Networks at Onset of Significant LTSS Needs and Death, People Born between 1960 and 1964

Family care networks evolve over time, with children often playing a larger role later in the course of disability as some older adults become widowed or their spouses develop LTSS needs



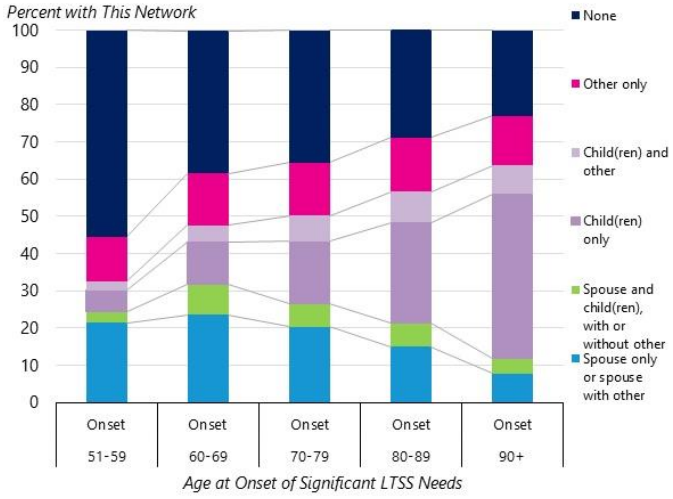
SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample consists of people ages 51 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. None means that no care network was identified in the HRS survey.

The composition of the unpaid care network varies with the age of the care recipient (***Figure 2***). As people grow older, they are more likely to need intensive care for their significant LTSS needs. They are also more likely to be widowed or have spouses with disabilities of their own.[5] Spouses remain the primary care providers for those who are married and whose spouses are not disabled, but children and others assume larger roles in the care network as care recipients age. For example, more than half of those whose significant LTSS needs begin in their fifties do not use unpaid care at that time, compared with only a quarter of those whose needs begin in their nineties. Spouses provide the majority of care at onset for those in their fifties, while children are the main providers for people who develop severe LTSS needs in their nineties.

Figure 2. Composition of Unpaid Care Networks at Onset of Significant LTSS Needs by Age at Onset, People Born between 1960 and 1964

Children play an especially larger role in the care network for people who develop LTSS needs at older ages



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample consists of people ages 51 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.

Paid Direct Care Workers Support Many Families, Sometimes Through Medicaid or Residential Care

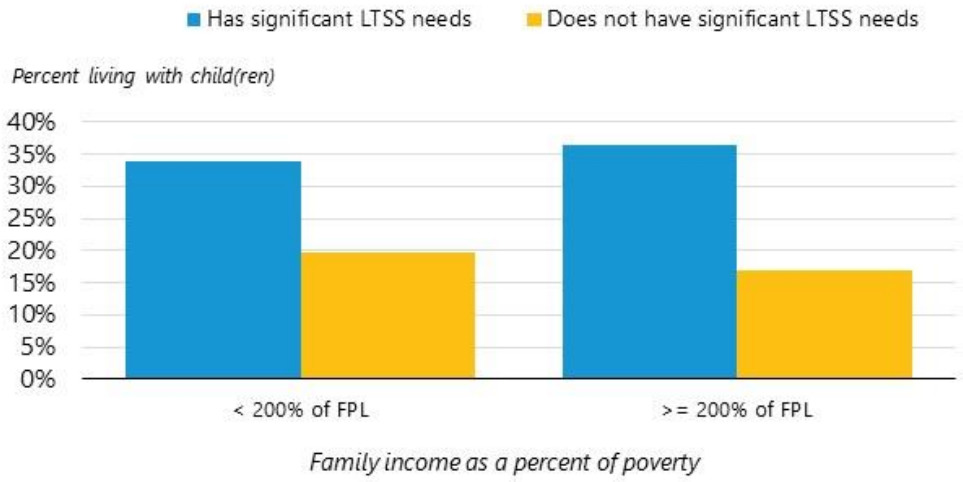
Some Families Use Residential Options, like Assisted Living or Living with their Children

As adults' care needs evolve, patterns of caregiving and care receipt often change. Many families choose to live together or supplement unpaid care with paid care. These options can take a variety of forms, as a family member ages or their needs escalate. Among people with private insurance, moving to a facility from the community is the most common transition, but one recent study found that moving back to the community accounts for about a third of transitions, and some people make multiple transfers.[iii,6]

At older ages, people in the community who have significant LTSS needs are more likely than those without significant LTSS needs to live with their children, regardless of income (***Figure 3***). For people without significant LTSS needs, higher incomes reduce the likelihood that they live with their children.

Figure 3. Co-residence with Children by Family Income and Presence of Significant LTSS Needs, 2016 (%)

People with significant LTSS needs are more likely to live with their children, regardless of income



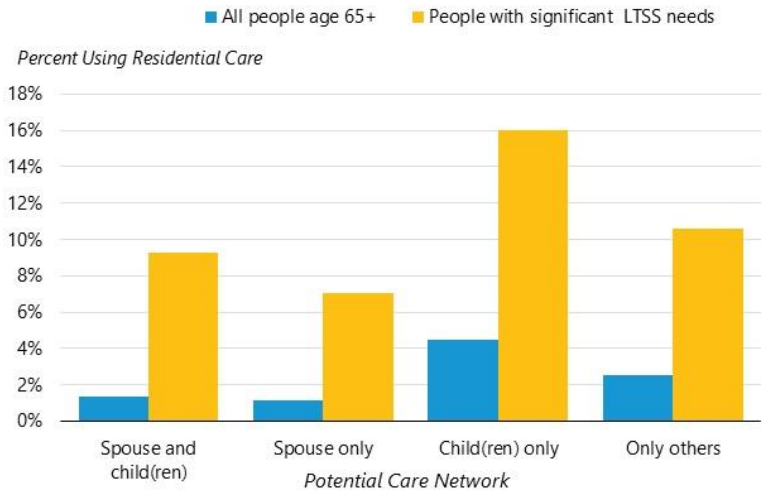
SOURCE: Urban Institute estimates from HRS.

NOTES: Sample consists of people ages 65 and older who are not in a nursing home or assisted living. 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.

Freedman and Spillman describe a continuum of housing options for people with LTSS needs.[7] Many remain in traditional housing, some use senior or retirement housing, others use assisted living, and those with the most severe disabilities often rely on nursing home care. Those who opt for assisted living usually must pay out-of-pocket. Use of residential care, here specified as use of an assisted living facility as defined by the National Center of Health Statistics,[8] is especially common among those who do not have spouses in their potential care network (***Figure 4***). Both before and after we restrict the sample population to people with significant LTSS needs, we see that those without a spouse in their potential network are markedly more likely to use assisted living than other older adults.

Figure 4. Use of Assisted Living by Potential Care Network and Presence of Significant LTSS Needs, 2021-2024

People without spouses are more likely to use assisted living



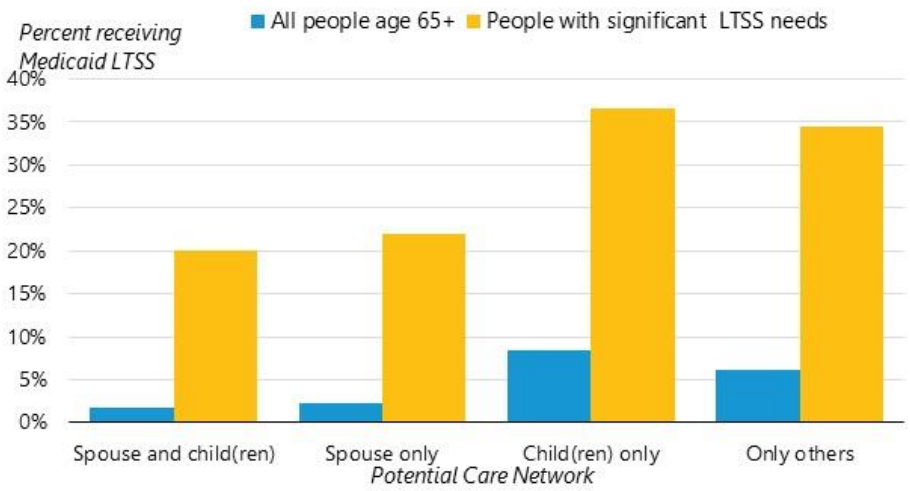
SOURCE: Urban Institute projections from DYNASIM.
NOTES: Sample consists of people ages 65 and older. The analysis defines significant LTSS need as either: (1) a need for assistance with at least 2 ADLs (among eating, toileting, transferring, bathing, dressing, and continence) that cannot be performed 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.

Medicaid, the Largest Public Payer, Has Income and Asset Requirements and Varies by State

For those needing paid care, Medicaid is often an important source of financing. People with significant LTSS needs are almost twice as likely to turn to Medicaid if they are not married than if their potential care network includes a spouse (***Figure 5***). However, it is likely that the relationship between marital status and Medicaid receipt depends on other factors, like income and assets, that also change with age.

Figure 5. Use of Medicaid LTSS, by Potential Care Network and Presence of Significant LTSS Needs

People without spouses are more likely to rely on Medicaid for LTSS



SOURCE: Urban Institute projections from DYNASIM.
NOTES: Sample consists of people ages 65 and older in 2021-2024. 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.

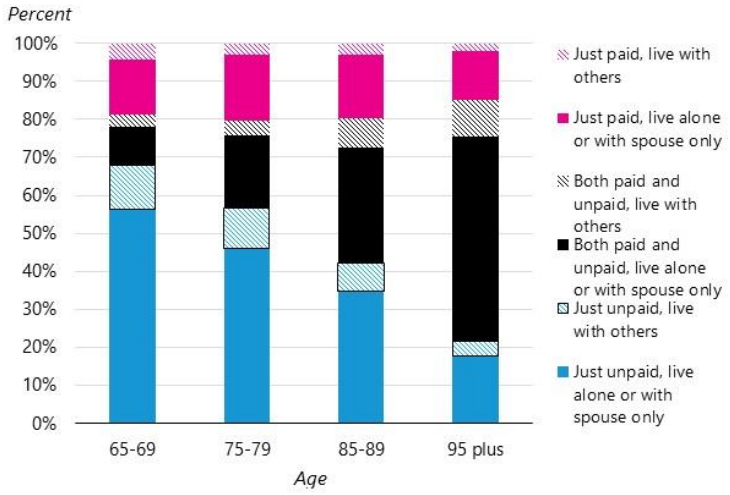
From other analyses, we know that many Medicaid LTSS beneficiaries had low incomes most of their lives. These people often turn to paid help from Medicaid early in their disability spell. Those with more resources may spend down to Medicaid after paying for care or other medical expenses out-of-pocket. Using HRS data, Johnson shows that those most likely to develop disabilities had low resources long before using Medicaid.[9] Other research has shown that the relatively modest number of Medicaid enrollees who had relatively high income earlier in life usually survived to quite old ages.[10,11] Access to Medicaid LTSS differs significantly across the states,[12,13,14,15] and living in a higher-spending state is associated with a relatively small chance of going without needed care.[16]

Many Older Adults with LTSS Needs Use Both Family Care and Paid Care

Care from a combination of providers is common for those with significant and less significant needs (***Figure 6***). Especially as people reach older ages, they often combine family care, paid care, and co-residence, defined here as living with someone other than a spouse or partner, often an adult child. More than half of people using care in their late sixties live alone or with just their spouse and rely solely on unpaid care. Among people in their late nineties, the majority combine paid and unpaid care.

Figure 6. Joint Use of Unpaid Family Care, Paid Care, and Co-residence by Age among those Using Any of the Three Care Types, 2016-2020 (Pooled Years, Selected Ages)

As care recipients age, they become increasingly likely to combine paid and unpaid care



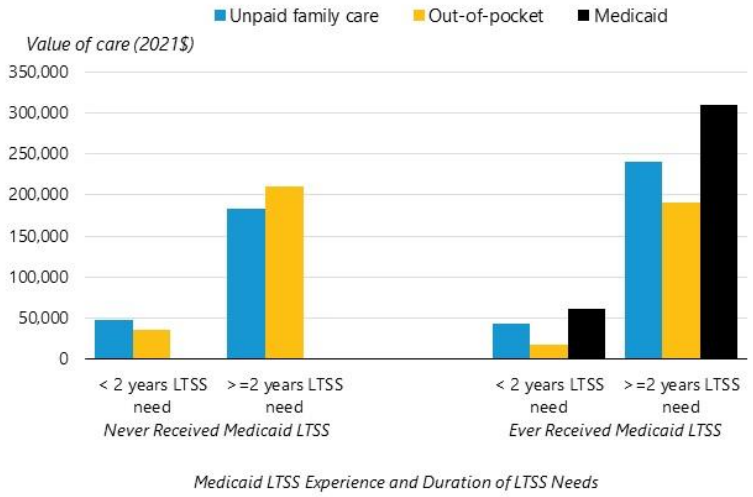
SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample consists of people ages 65 and older in 2016 to 2020 who receive paid or unpaid care. We consider everyone in residential care and nursing homes to be receiving paid care. "Living alone" is defined as living with no one except a spouse or partner. "Living with others" is defined as living with at least one person other than a spouse or partner.

Those who receive paid care financed by Medicaid also receive substantial amounts of unpaid care from their families and make significant contributions to the cost of their care out-of-pocket (***Figure 7***). For many families, the care journey is not a single binary choice between paid and unpaid care, but rather a dynamic process in which they shift between care types as care needs escalate and family and economic circumstances change. Further, families that rely on Medicaid at some point make out-of-pocket contributions to their paid LTSS that are comparable to those who never rely on Medicaid. For some, these out-of-pocket payments arise because they have to "spend down" to Medicaid, often spending for LTSS or other health care needs.[vi,17] State Medicaid benefit packages may not always be sufficient to meet care needs, forcing families to pay out-of-pocket for supplemental care while receiving Medicaid.

Figure 7. Value of Unpaid Family Care, Medicaid LTSS, and Out-of-Pocket Family Spending, by Duration of LTSS Need and Medicaid LTSS Experience, People Born between 1956 and 1960 Who Ever Have Significant LTSS Needs

The value of unpaid family care is higher for people with significant LTSS needs that last more than 2 years who use Medicaid than for those who do not use Medicaid



SOURCE: Urban Institute projections from DYNASIM.

NOTES: Sample consists of people who survive until age 51. Care values are reported in 2021 inflation-adjusted dollars. Family care is valued at the average of the state-specific median hourly rate that care agencies charge for in-home care and the median state wage for direct care workers reported by the Bureau of Labor Statistics. 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.

DISCUSSION

Understanding how care receipt changes over time can help policy-makers better understand and support family caregivers and identify individuals that may be more at risk for having unmet LTSS needs. Family and paid caregiving networks evolve through the course of an older adult's experience with LTSS needs. At the onset of needs, spouses and children are the most common care providers. As needs escalate and families change (due to widowhood or the onset of disability for a spouse, for example), co-residence and paid caregivers, including in assisted living settings and through Medicaid, often play increasingly important roles. For many families, both caregiving and economic burdens are substantial, even when they receive help from Medicaid.

In companion briefs, we discuss diversity in care needs,[18] the economic value of the unpaid care that family and friends provide,[19] and how care needs and networks are likely to change in coming decades.[20]

ADDITIONAL METHODOLOGICAL INFORMATION

Favreault and Johnson describe DYNASIM.[21] The release of the model that we use is runid 981, which incorporates economic and demographic assumptions from an interim baseline produced by Social Security's Office of the Chief Actuary.[22] It uses data from the HRS, Medicaid rules, and price information from published studies.[23]

ENDNOTES

i. The HRS is a longitudinal study of adults ages 51 and older. It oversamples Black and Hispanic people as well as Florida residents.

ii. 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 ADLs; among eating, toileting, transferring, bathing, dressing, and continence) that cannot by 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 limitations in performing ADLs that can be resolved with special equipment (e.g., wheelchairs, walkers, handrails, ramps, catheters, and related devices).

iii. This study estimated the chances of transferring between a facility and paid care in the community among a sample of people with private long-term care insurance coverage.

iv. Wiener et al. estimate that nearly half (47%) of people spending down to Medicaid did not use LTSS, a third used nursing home care only, 14% used both nursing home and personal care, and the remaining 7% used personal care alone. Those not using LTSS may have faced high out-of-pocket medical spending or other urgent expenses (e.g., home or vehicle repair).

REFERENCES

1. Spillman B.C., Favreault M., Allen E. (2020). Family Structures and Support Strategies in the Older Population: Implications for Baby Boomers (Issue Brief). Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. https://aspe.hhs.gov/system/files/pdf/264806/SnapshotIB.pdf.
2. Reinhard S.C., Levine C., Samis S. (2012). Home Alone: Family Caregivers Providing Complex Care. Washington, DC: AARP Public Policy Institute.
3. Spillman B.C., Favreault M., Allen E. (2020). Family Structures and Support Strategies in the Older Population: Implications for Baby Boomers (Issue Brief). Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. https://aspe.hhs.gov/system/files/pdf/264806/SnapshotIB.pdf.
4. Rendall M.S., Speare A.Jr. (1995). Elderly Poverty Alleviation through Living with Family. *Journal of Population Economics*, 8(4): 383-405.
5. Spillman B.C., Allen E.H., Favreault M. (2020). Informal Caregiver Supply and Demographic Changes: Review of the Literature. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. https://aspe.hhs.gov/reports/informal-caregiver-supply-demographic-changes-review-literature-0.
6. Chance M., Gordon M., Nitz D., Pahl A., Schmitz A. (2009). Transfer Rates Between Long Term Care Claim Settings. Seattle, WA: Milliman, Inc. https://www.soa.org/globalassets/assets/Files/Research/Projects/research-transfer-rates-ltc.pdf.
7. Freedman V.A., Spillman B.C. (2014). The Residential Continuum from Home to Nursing Home: Size, Characteristics and Unmet Needs of Older Adults. *Journals of Gerontology, Series B: Psychological Sciences & Social Sciences*, 69(7): S42-S50.
8. Harris-Kojetin L., Sengupta M., Park-Lee E., Valverde R. (2013). Long-Term Care Services in the United States: 2013 Overview. National Health Care Statistics Reports, Number 1. Hyattsville, MD: U.S. Department of Health and Human Services, National Center for Health Statistics.
9. Johnson R.W. (2019). What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports? Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. https://aspe.hhs.gov/system/files/pdf/261036/LifetimeRisk.pdf.
10. Borella M., De Nardi M., French E. (2017). Who Receives Medicaid in Old Age? Rules and Reality. *Fiscal Studies*, 39(1): 65-93.
11. Johnson R.W., Favreault M.M. (2021). Economic Hardship and Medicaid Enrollment in Later Life: Assessing the Impact of Disability, Health, and Marital Status Shocks. [Project Report, U.S. Department of Health and Human Services.]
12. Feder J., Komisar H.L. (2012). The Importance of Federal Financing to the Nation's Long-Term Care Safety Net. https://www.thescanfoundation.org/sites/default/files/georgetown_importance_federal_financing_ltc_2.pdf.
13. Gonçalves J., Weaver F., Konetzka R.T. (2018). Measuring State Medicaid Home Care Participation and Intensity Using Latent Variables. *Journal of Applied Gerontology*. doi.org/10.1177%2F0733464818786396.
14. Murray C., Tourtellotte A., Lipson D., Wysocki A. (2021). Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf.
15. Watts M.O., Musumeci MB., Chidambaram P. (2021). State Variation in Medicaid LTSS Policy Choices and Implications for Upcoming Policy Debates (Issue Brief). Kaiser Family Foundation. https://www.kff.org/report-section/state-variation-in-medicaid-ltss-policy-choices-and-implications-for-upcoming-policy-debates-issue-brief/.

16. Kemper P., Weaver F., Short P.F., Shea D., Kang H. (2008). Meeting the Need for Personal Care among the Elderly: Does Medicaid Home Care Spending Matter? *Health Services Research*, 43(1pt2): 344-62.
17. Wiener J.M., Anderson W., Khatutsky G., Kaganova Y., O'Keefe J. (2013). Medicaid Spend Down: New Estimates and Implications for Long-Term Services and Supports Financing Reform: Final Report. Research Triangle Park, NC: RTI International.
18. Favreault M., Dey J., Anderson L., Lamont H., Marton W. (2021). Diversity in Caregiving Needs and Networks: Differences by Race-Ethnicity in the Care Older Adults Receive (Issue Brief). Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
19. Favreault M., Johnson R., Dey J., Anderson L., Lamont, H., Marton W. (2021). The Economic Value of Unpaid Care Provided to Older Adults with Needs for Long-Term Services and Supports (Issue Brief). Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
20. Favreault M., Dey J., Anderson L., Lamont H., Marton W. (2021). Future Change in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults with Needs for Long-Term Services and Supports at Present in the Future (Issue Brief). Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
21. Favreault M.M., Johnson R.W. (2020). Projections of Risk of Needing Long-Term Services and Supports at Ages 65 and Older. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
22. Goss S.C., Glenn K.P. (2020). Updated Baseline for Actuarial Status of the OASI and DI Trust Funds, Reflecting Pandemic and Recession Effects--INFORMATION. Memorandum to A. Saul and D. Black. Baltimore, MD: Office of the Chief Actuary, Social Security Administration. https://www.ssa.gov/OACT/solvency/UpdatedBaseline_20201124.pdf.
23. Genworth. (2020). Cost of Care Survey 2020: Median Cost Data Tables. Richmond, VA: Genworth. https://pro.genworth.com/riiproweb/productinfo/pdf/282102.pdf.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Assistant Secretary for Planning and Evaluation

200 Independence Avenue SW, Mailstop 447D
Washington, D.C. 20201

For more ASPE briefs and other publications, visit:
aspe.hhs.gov/reports

ABOUT THE AUTHORS
Melissa M. Favreault, Ph.D., works at the Urban Institute.

Judith Dey, Ph.D., Lauren Anderson, Helen Lamont, Ph.D., and William Marton, Ph.D., work in the Office of Behavioral Health, Disability, and Aging Policy in the Office of the Assistant Secretary for Planning and Evaluation.

SUGGESTED CITATION
Favreault, M., Dey, J., Anderson, L., Lamont, H., & Marton, W. Changes in Caregiving Networks over the Course of Disability: How Family Caregiving Networks Evolve After Onset of Needs for Long-Term Services and Supports (Issue Brief). Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. August 2, 2023.

Subscribe to ASPE mailing list to receive email updates on new publications:
aspe.hhs.gov/join-mailing-list

For general questions or general information about ASPE:
aspe.hhs.gov/about