



LTSS CHOICES

Home and Community-Based Services for Older Adults

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About this Series

This Fact Sheet is part of the AARP Public Policy Institute's LTSS Choices initiative. This initiative includes a series of reports, blogs, videos, podcasts, and virtual convenings that seeks to spark ideas for immediate, intermediate, and long-term options for transforming long-term services and supports (LTSS). We will explore a growing list of innovative models and evidence-based solutions—at both the national and international levels—to achieve system-wide LTSS reform.

We recognize the importance of collaborating and partnering with others across the array of sectors, disciplines, and diverse populations to truly transform and modernize the LTSS system. We invite new ideas and look forward to opportunities for collaboration.

For all questions and inquiries, please contact Susan at LTSSChoices@aarp.org.

What Are Home and Community-Based Services?

Long-term services and supports (LTSS) provide help with day-to-day tasks that support people with functional limitations and/or cognitive impairments (see sidebar).¹ Historically, most LTSS was provided in nursing homes and other institutional settings. Over the past 20 years, however, LTSS systems have begun to rebalance toward home and community settings, and today more public LTSS dollars go to home and community-based services (HCBS) than to institutional LTSS.

HCBS is an umbrella term that includes a wide range of services that help people remain in their homes with the supports they need (see sidebar). Paid HCBS often complements the work family caregivers perform, which could also be considered HCBS. People who receive HCBS often live in their own homes or with family and can reside in standard market-rate housing or subsidized housing communities. They can also live in assisted living communities, or other community-based congregate living settings.

¹Edem Hado and Harriet Komisar, *Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, August 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/08/long-term-services-and-supports.doi.10.26419-2Fppi.00079.001.pdf>.

Common LTSS Tasks

Help with Activities of Daily Living (ADLs)	Help with Instrumental Activities of Daily Living (IADLs)
<ul style="list-style-type: none"> • Bathing • Dressing • Eating • Toileting 	<ul style="list-style-type: none"> • Shopping • Managing finances • Household tasks • Medication management

Common Types of HCBS

In-Home	Community-Based
<ul style="list-style-type: none"> • Personal/home care • Home health • Home modifications 	<ul style="list-style-type: none"> • Transportation • Meal services • Adult day services

No two HCBS recipients are the same, and the type, amount, intensity, and length of services a person receives can vary depending on the individual’s functional needs, financial resources, availability of family caregiver support, and their own preferences. In any case, HCBS can often make the difference as to whether a person can stay in their home and community, which is where most Americans ages 50+ (77 percent) prefer to be.²

HCBS Recipients and Providers

Most people who receive HCBS are older adults and people of all ages with disabilities. In 2018, for example, about 12.6 million American adults living in the community needed LTSS, of whom more than half (6.7 million) were over age 65.³ Almost half of all older adults turning 65 will use paid LTSS sometime after turning 65 and before the end of life.⁴

Much of the work of HCBS is performed by direct care workers, including personal care aides and home health aides, among others. More than one million workers provide this support across HCBS settings. More than half of HCBS workers are Black or Hispanic/Latino, and 87 percent are women. Direct care work is difficult and low paid, and job turnover and vacancy rates are high. As a result, recruiting and retaining a high-quality HCBS workforce persists as a challenge.

Research from the Centers for Disease Control and Prevention also shows that certain HCBS settings serve more diverse populations compared to other settings. For example, more than half of adult day service participants are Black, Hispanic/Latino, or Asian American/Pacific Islander, compared to about one in four nursing home residents.⁵

² Joanne Binette and Kerri Vasold, *2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus* (Washington, DC: AARP, August 2018), <https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html>.

³ Hado and Komisar, *Long-Term Services and Supports*.

⁴ U.S. Department of Health and Human Services, *Long-Term Services and Supports for Older Americans: Risks and Financing, 2020* (Washington, DC: HHS, January 2021), <https://aspe.hhs.gov/system/files/pdf/265126/LTSSQI/AmRB.pdf>.

⁵ Lauren Harris-Kojetin, et al., *Long-Term Care Providers and Services Users in the United States, 2015–2016* (Hyattsville, MD: National Center for Health Statistics, February 2019) https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf.

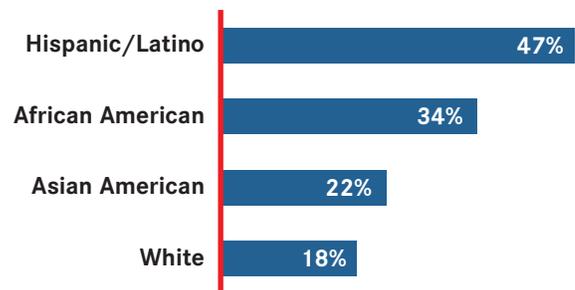
The Role of Family Caregivers

Family support underpins the entire LTSS system. Unpaid family caregivers furnish the majority of ADL and IADL supports to older adults and people with disabilities. As of 2020, more than 40 million adults served as family caregivers (defined as including friends and neighbors in addition to relatives), and about one in six adults in the United States support a person over age 50. Most (95 percent) older adults who need help receive support from family caregivers, and almost two-thirds rely exclusively on family caregivers for assistance with daily living activities.⁶ While a small segment of family caregivers are paid through Medicaid and/or VA programs, the vast majority of family caregiver support is unpaid.

In 2017, family caregivers provided an estimated 37 billion hours of unpaid support to adults who need help with everyday activities. The estimated economic value of their unpaid contributions was approximately \$470 billion.⁷ For context, the value of this support is three to four times the amount Medicaid spends on LTSS in a given year.

On top of this unpaid, hands-on support, family caregivers also contribute money out-of-pocket, including for people who receive paid HCBS and live in the community, and those who live in nursing homes. More than three in four family caregivers (78 percent) incurred at least some out-of-pocket costs as a result of caregiving, according to a 2021 AARP national study.⁸ These caregivers spent, on average, approximately \$7,242 on caregiving expenses (e.g., rent or mortgage payments, home modifications, medical costs). Black, Hispanic/Latino, and Asian American and Pacific Islander family caregivers experience a greater financial strain from caregiving costs because their out-of-pocket spending makes up a much higher percentage of their annual household income (figure 1).

FIGURE 1. PERCENT OF HOUSEHOLD INCOME SPENT ON OUT-OF-POCKET CAREGIVING COSTS BY RACE/ETHNICITY



Source: AARP national study of caregiving out-of-pocket costs, 2021.

HCBS Financing

People receive HCBS by paying for services and supports privately, either out-of-pocket themselves or with help from family, through enrollment in public coverage, or through private long-term care insurance.

Medicaid is the primary source of public HCBS funding, with more than \$50 billion going to HCBS for older adults and people with physical disabilities in recent years. State governments and the Older Americans Act also provide some HCBS to older adults. There is a common misperception that Medicare—the national health insurance program for people ages 65 and older as well as some younger

⁶Susan C. Reinhard et al., *Valuing the Invaluable: 2019 Update, Charting a Path Forward* (Washington, DC: AARP Public Policy Institute, November 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>

⁷Ibid.

⁸Laura Skufca and Chuck Rainville, *Caregiver Out-of-Pocket Costs Study* (Washington, DC: AARP, 2021), https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf

people with long-term disabilities—pays for these services and supports. But as older adults with LTSS needs inevitably find, Medicare does not cover most LTSS costs, with only a subset of HCBS services (e.g., home health services) covered for a limited duration. Thus, paying out of pocket is a primary means of acquiring LTSS, although other sources provide targeted funding, as described below.

Medicaid HCBS

While every state and the District of Columbia include HCBS in their Medicaid program, they are not required to do so. Under federal Medicaid law, Title XIX of the Social Security Act, most HCBS are included as an **optional** benefit, while other types of care, such as nursing home services, are categorized as **mandatory** benefits. In other words, nursing home care is an **entitlement** for eligible Medicaid beneficiaries, but HCBS is not. The optional nature of these services gives states much discretion toward what types of HCBS to offer, the scopes and limits of those services, and how many people can receive HCBS under the program.

The eligibility requirements for Medicaid HCBS vary across states but tend to be strict. Eligibility has two prongs: financial and functional. To be eligible financially, individuals must have very limited incomes and assets, with dollar-amount thresholds determined by states. Functional eligibility quantifies which activities a person needs help with and to what extent. Eligibility for most Medicaid HCBS requires a functional need at the level of nursing home care, for which states develop the exact criteria.

- Under **1915(c) waivers**, states can serve a limited geographic area (e.g., where certain services are less accessible), define the range of benefits, and tailor services to specific groups (e.g., older people, people with brain injuries). To be eligible for services, individuals must require a nursing home level of care. About 830,000 older adults and people with physical disabilities participate in a 1915(c) waiver. In addition to the 1915(c) waiver, other waivers and state plan authorities are available for states to choose from and carry different flexibilities and limitations. These include the 1115 demonstration waiver, the 1915(i) state plan, and the 1915(k) Community First Choice option.
- The **personal care services** program is an optional Medicaid benefit that states may use to provide assistance with daily living activities. Thirty-four states operated these programs in fiscal year 2018, serving nearly 1.2 million individuals.⁹
- The **home health care** benefit covers primarily skilled nursing services and physical and other therapies. Home health is a **mandatory** Medicaid benefit for eligible individuals and served about 616,800 people in 2018.¹⁰ Medicare also has a home health benefit, but this is largely available as post-acute care after an inpatient hospital stay rather than a long-term arrangement.

Since fiscal year 2013, more than half of Medicaid LTSS dollars have gone to HCBS. This reflects a years' long trend toward rebalancing LTSS from nursing homes to the home and community. State spending on HCBS versus nursing home care, however, varies widely, in part due to the optional status of HCBS in Medicaid. In addition, historically, a lower share of LTSS dollars for older adults and people with physical disabilities has gone to home and community-based settings compared to other populations.

⁹Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending* (Washington, DC: Kaiser Family Foundation, 2020), <https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/>.

¹⁰Ibid.

Older Americans Act Funding

Older Americans Act (OAA) programs, administered by State Units on Aging and/or Area Agencies on Aging (AAAs), provide critical services such as home-delivered and congregate meals, in-home assistance (e.g., chore, homemaker), support for family caregivers, and other supportive services for people who are generally ages 60 and older.¹¹ For example, in 2019, more than 1.5 million older adults received congregate meals, and over 883,000 received home-delivered meals.

OAA programs collectively have a much smaller budget compared to Medicaid HCBS. For fiscal year 2021, Congress appropriated about \$1.56 billion for state and community programs on aging, including \$951 million for nutrition, \$392 million for supportive services, and \$189 million to support family caregivers.¹² In addition, COVID-19 relief legislation provided more than \$1 billion in supplemental funding to OAA programs, primarily for nutrition. Anyone over the age of 60 is technically eligible to receive services through OAA, but states and AAAs typically target services to more vulnerable, lower-income residents in their areas.

Veterans Affairs

The U.S. Department of Veterans Affairs (VA) plays a key role in supporting older veterans in the home and community. In 2020, VA spent \$3 billion on HCBS through the Veterans Health Administration and provided services to more than 370,000 veterans (most of whom are 65+).¹³ Thousands more veterans may pay for HCBS using disability compensation payments, through a monthly disability pension, or with other VA-funded cash benefits.

VA coverage of HCBS includes services the department provides directly (e.g., VA Adult Day Health Care) and those from non-VA providers for whom VA pays for services (e.g., homemaker services). For more than a decade, VA has maintained a self-directed model for veterans who need personal care services and/or help with ADLs. During the COVID-19 pandemic, VA reports that enrollment in self-directed care increased by 22 percent.¹⁴

State Funding

Many states use general revenue funds to provide services for people whose incomes or assets are too high for them to qualify for Medicaid HCBS but too low to be able to afford private services. States also have greater freedom in establishing functional eligibility and setting other rules with their own funds compared to Medicaid funds. As of 2018, the national state spending on these programs was \$1.7 billion.¹⁵

¹¹ Kathleen Ujvari, Wendy Fox-Grage, and Ari Houser, *Older Americans Act* (Washington, DC: AARP Public Policy Institute, 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/02/older-americans-act.pdf>.

¹² Administration for Community Living, Department of Health and Human Services. Fiscal Year 2022, https://acl.gov/sites/default/files/about-acl/2021-06/FY%202022%20ACL%20Justification%20of%20Estimates%20for%20Appropriations%20Committees_Final.pdf.

¹³ U.S. Department of Veterans Affairs, FY 2022 Budget Request, <https://www.va.gov/budget/docs/summary/fy2022VAbudgetVolumellmedicalProgramsAndInformationTechnology.pdf>.

¹⁴ Ibid.

¹⁵ AARP Public Policy Institute and Advancing States 2019 LTSS Economic Survey (unpublished).

Expanding HCBS

Over the years, access to HCBS has greatly expanded to accommodate older adults' and people with disabilities' overwhelming preference to age in their own homes and communities rather than in institutional settings.¹⁶ While challenges remain toward providing HCBS to all who need them, several service delivery models and policy solutions have helped expand access and improve services, and could continue to do so in the future.

Assisted Living

This type of housing generally offers personal care and supportive services 24 hours a day, some health care, and meals in congregate residential settings. There were about 28,900 assisted living communities in 2018, serving approximately 811,500 residents.¹⁷ The cost of assisted living varies across states and individual communities, but the annual median cost is nearly \$50,000.¹⁸ Most residents pay out of pocket for assisted living. As of 2018, about one in six assisted living residents relied on Medicaid to pay for services (and federal law prohibits the use of Medicaid dollars to pay for room and board).¹⁹

Self-Directed Services

States have the flexibility to offer recipients of Medicaid and state-funded HCBS the option of directing their own services, mainly by hiring and training their own workers (sometimes including family members) and deciding when and how they receive services. More than 1.2 million participants in public programs were self-directing their own LTSS in 2019.²⁰

Programs of All-Inclusive Care for the Elderly

Programs of All-Inclusive Care for the Elderly (PACE) provide comprehensive health care and LTSS for their enrollees, most of whom are dually eligible for Medicare and Medicaid. PACE organizations receive capitated payments from their respective state agency (for the Medicaid rate) and the Centers for Medicare & Medicaid Services (for the Medicare rate). With those dollars, PACE organizations provide all needed care for PACE enrollees and take on the full risk of doing so. Availability of PACE is determined (and limited) by geography. Current program rules limit enrollment only to those living in a PACE organization's service area; eligible individuals who don't live in those areas cannot access PACE. Some states also place enrollment caps for PACE, further limiting access and growth. As of 2020, about 55,000 individuals were enrolled in PACE, more than double the enrollment count from 2012.

¹⁶ Joanne Binette and Kerri Vasold, 2018 Home and Community Preferences Survey: A National Survey of Adults Age 18-Plus (Washington, DC: AARP Research, August 2018), https://www.aarp.org/content/dam/aarp/research/surveys_statistics/liv-com/2018/home-community-preferences-survey.doi.10.26419-2Fres.00231.001.pdf.

¹⁷ National Center for Assisted Living, *Facts & Figures* (Washington, DC: National Center for Assisted Living), <https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Pages/default.aspx>.

¹⁸ Genworth, *Cost of Care Survey, 2020*, <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>.

¹⁹ While state Medicaid programs can cover HCBS (e.g., personal care and supportive services), Medicaid does not pay for room and boards costs of assisted living facilities.

²⁰ Susan C. Reinhard et al., *LTSS 2020 Scorecard Short Report* (Washington, DC: AARP, 2020), http://www.longtermcarecard.org/~/_media/Microsite/Files/2020/LTSS%202020%20Short%20Report%20PDF%20923.pdf.

Medicare Advantage Supplemental Benefits

Following legislative and regulatory changes to the Medicare Advantage (MA) program's supplemental benefits in 2018, some MA enrollees may be able to access coverage for some HCBS through their MA plan. The number of MA plans offering HCBS benefits has grown in recent years, but overall plan and beneficiary participation remains low. For example, from 2020 to 2021, the share of MA plans offering coverage for in-home support services grew from 6 percent to 12 percent, while the share of plans providing coverage for adult day services increased from 2 percent to 4 percent. Among plans that offer an HCBS benefit, the types and levels of service a plan covers can be limited, and plans can limit the benefits to only some enrollees. HCBS are not available in fee-for-service Medicare.

Telehealth Expansion

Prior to 2020, most HCBS were delivered in person. Due to the COVID-19 pandemic, all types of health care and LTSS providers, including HCBS providers such as home care and adult day services, adopted telehealth and other remote means to limit potential exposure among staff and individuals receiving services. While telehealth helped monitor some HCBS participants and kept them connected to support and socialization opportunities, these remote services have clear limitations. For example, one cannot perform hands-on support with activities of daily living via telehealth. In addition, not all older adults and people with disabilities have the same access to technology and the Internet. Challenges such as lack of access to high-speed Internet and computers have raised concerns about the role of telehealth in creating and/or deepening long-existing disparities.

Subsidized Rental Housing for Older People

The federal government funds service coordinators in federally subsidized housing projects serving older people to help residents age in place. The principal program is the US Department of Housing and Urban Development's (HUD)'s Section 202 housing program, which focuses specifically on subsidized rental housing for older adults. Nationally, more than 400,000 Section 202 housing units serve very low-income older adults.²¹ More than 1.6 million households with an older adult receive some sort of HUD subsidy. According to a HUD analysis, only 34 percent of income-eligible older adults received the rental assistance they qualified for in 2015.²² Some states are expanding their capacity to offer a complete range of services in 202 housing, given that these programs generally provide little personal care or oversight.

Looking Forward

HCBS expanded significantly over the past decade, and the need and demand for HCBS will only continue to increase over the next 10 years. The 65+ population is both growing and getting older, with population data having long indicated significant growth in the 75+ population through 2030. This alone will increase demand for LTSS across all settings. At the same time, the COVID-19 pandemic has made clear the systemic problems that have long existed in nursing homes and other institutional settings. As a result, demand for this type of support could decline over the long term even as the

²¹ Linda Couch, *Section 202: Supportive Housing for the Elderly* (Washington, DC: LeadingAge, 2018), https://nlihc.org/sites/default/files/AG-2018/Ch04-S07_Section-202_2018.pdf.

²² US Department of Housing and Urban Development, *Worst Case Housing Needs: 2017 Report to Congress* (Washington, DC: US Department of Housing and Urban Development, 2017), <https://www.huduser.gov/portal/sites/default/files/pdf/worst-case-housing-needs.pdf>.

overall demand for LTSS increases. Federal data show that nursing home occupancy has not recovered to pre-pandemic levels, while utilization of other health care and LTSS settings has since rebounded. Continued low demand for nursing home care will only increase the need for strong HCBS options.

Policymakers have begun to respond to this. The March 2021 American Rescue Plan Act will provide an estimated \$12.7 billion to state Medicaid HCBS programs, and as of November 2021 states have submitted their spending plans to CMS, which is reviewing and approving the plans.²³ This investment has the capacity to be transformative to state HCBS systems, and it will be critical to ensure that states strategically invest in HCBS to meet the needs of older adults both today and over the next several years.

About the Authors

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<https://doi.org/10.26419/ppi.00153.001>

²³Centers for Medicare & Medicaid Services, *Strengthening and Investing in Home and Community Based Services for Medicaid Beneficiaries* (Baltimore, MD: CMS, 2021), <https://www.medicare.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicare-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html>.