IssueBrief

MACPAC

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# Spending and Utilization for Medicaid Home- and Community-Based Services

Medicaid home- and community-based services (HCBS) are designed to allow people with long-term services and supports (LTSS) needs to live in their homes or a home-like setting in the community. While all states operate HCBS programs and provide services to a diverse population, there is limited research and data on how spending and utilization, a measure of access to HCBS, vary across subpopulation groupings of LTSS users. LTSS subpopulation groupings include individuals belonging to at least one of the following groups: intellectual and developmental disabilities (I/DD) or autism spectrum disorder (ASD); under age 65 with potentially disabling conditions; older adults; brain injuries; mental illness or serious emotional disturbance (SED) or substance use disorder (SUD); and HIV/AIDS.[1]

Access to HCBS has been a long-standing policy priority for the Commission. In the June 2022 report to Congress, the Commission discussed a Medicaid access monitoring framework that captures four key domains of access: (1) provider availability and accessibility, (2) use of services, (3) beneficiary perceptions and experiences of care, and (4) administrative complexity (MACPAC 2022). The Commission discussed analyzing Medicaid spending and utilization, which is a measure of the second access domain that addresses use of services, among LTSS subpopulation groupings. To this end, we have undertaken a foundational analysis of Medicaid HCBS spending and utilization data from calendar years (CY) 2019 through 2021. Our objectives for this analysis are to understand how many Medicaid beneficiaries use HCBS, the proportion of the total Medicaid population they comprise, the differences that exist across LTSS subpopulation groupings who use HCBS (e.g., types of HCBS used or demographic characteristics), and Medicaid spending and utilization patterns for HCBS users from CY 2019 to 2021.

In this brief, we focus on HCBS users and expenditures. First, we provide background on the provision of HCBS and limitations among existing analyses on HCBS spending and utilization. Then, we describe the methodology for this analysis and discuss key findings across subpopulation groupings of HCBS users.

## Background

LTSS refers to both institutional care and HCBS. It encompasses a wide range of nonmedical services and supports for people who need help performing activities of daily living (ADLs) because of physical, cognitive, mental, or other disabilities and conditions. Medicaid is the primary payer of LTSS, covering over half of total LTSS expenditures nationally in federal fiscal year (FY) 2019 (Murray et al. 2021). HCBS is an optional benefit and all states choose to cover some HCBS. States may authorize HCBS through an amendment to their state plan, but most states cover HCBS via Section 1915(c) waivers and Section 1115 demonstrations (MACPAC 2023). States can choose to operate one or multiple HCBS programs under several authorities simultaneously to serve different populations. Some states choose state plan options to serve a larger number of individuals, while others use waivers as an option to comprehensively serve the needs of select LTSS subpopulation groupings. States must also choose whether to administer HCBS through fee-for-service (FFS) or managed care delivery systems, or both.

### HCBS users and services

Medicaid beneficiaries who use LTSS are a diverse group, spanning a range of ages, with different types of physical and cognitive disabilities, and various service and support needs. In CY 2021, HCBS users accounted for

2.6 percent of the total Medicaid population or over 2.5 million individuals.[2,3] States vary in the types of services they offer HCBS users and in how those services are defined, with over 60 specific and distinct services available to HCBS users (Peebles and Bohl 2014). To facilitate national analyses of HCBS users and expenditures by service type, researchers classified these services into 18 taxonomy categories.[4] In an analysis of HCBS waiver utilization by taxonomy category in 2010, case management; home-based services; and equipment, technology, and modifications were the most commonly used taxonomy services among HCBS waiver users (Peebles and Bohl 2014).

The Centers for Medicare & Medicaid Services (CMS) provides a list of 12 subpopulation groupings from which states can choose to serve HCBS populations for Section 1915(c) waivers (CMS 2022). In our review of waivers, we found that many serve more than one of these subpopulation groupings, so for the purpose of this analysis we consolidated them into six subpopulation groupings: I/DD or ASD; under age 65 with potentially disabling conditions; older adults; brain injuries; mental illness, SED, or SUD; and HIV/AIDS.[5] This organization mirrors other studies that used similar groupings and allows for comparisons across similar populations (O'Malley Watts et al. 2022, Ross et al. 2021). The services that HCBS users require vary both across and within subpopulation groupings by type, intensity, and cost, depending on the recipient's health and functional status, the nature and severity of their disability, the setting in which they reside, and the availability of formal and informal supports.

## HCBS expenditures

As a component of LTSS, Medicaid spending on HCBS surpassed spending on institutional care starting in FY 2013 (CMS 2023). In CY 2021, Medicaid programs spent approximately $82.5 billion on HCBS compared to about $66.6 billion on institutional care.[6] Among HCBS users, total spending on HCBS per user in CY 2021 was more than $32,000 and total spending on institutional LTSS per user was more than $45,000.

Spending on LTSS varies by population, and some beneficiary populations account for a disproportionate share of LTSS expenditures relative to their share of LTSS users. For example, beneficiaries with I/DD or ASD accounted for 52.5 percent of HCBS spending but only accounted for 30.7 percent of HCBS users in CY 2021 (Figure 2). However, limited research on spending and utilization across LTSS subpopulations has prevented us from identifying the extent of these differences and stratifying these findings by factors that may influence access to HCBS.

## Analysis

While research exists on use and spending of LTSS in Medicaid, there is relatively little detailed information across various demographic characteristics, LTSS subpopulation groupings, HCBS taxonomy categories, and delivery systems (Chidambaram and Burns 2023, Greener et al. 2023, Murray et al. 2023, Rooney et al. 2023). Absent additional research, it is challenging to identify the extent to which differences in use and spending in Medicaid LTSS occur across these different groups. Through previous MACPAC work, state and federal officials, as well as national experts, shared the need to identify potential differences in utilization and spending among LTSS subpopulation groupings, but data are lacking. Stakeholders emphasized the importance of stratifying data by, for example, race and ethnicity or geographic location to identify differences. One expert noted that these data would allow policymakers to monitor and ensure all populations are adequately served.

In 2017, MACPAC, in collaboration with Mathematica, analyzed HCBS use and spending patterns for Medicaid FFS HCBS users and beneficiary subgroups from 2010 through 2013 using Medicaid Analytic eXtract (MAX) data (Peebles et al. 2017).[7] However, due to data quality concerns with the MAX files, the study did not include HCBS delivered under a state plan or managed care. In the 2017 report, Mathematica suggested expanding research efforts to classify state plan services to the HCBS taxonomy categories (Peebles et al. 2017). This brief updates the 2017 study using data from the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), and summarizes HCBS utilization and spending by subpopulation groupings.

# Methodology

We partnered with Mathematica to analyze TAF data for calendar years 2019 through 2021, the most recent years that were available when we started the project.[8] The TAF include eligibility, demographic, and claims information for all Medicaid beneficiaries. We used the TAF Demographics and Eligibility (DE) file, Other Services (OT) file, Inpatient (IP) file, and Long-Term Care (LT) file for this analysis. In addition, we used the Race and Ethnicity Imputation (REI) TAF companion file to supplement the state-reported TAF race and ethnicity variable.

There are several approaches to identifying HCBS users and their expenditures (MACPAC 2024). For this analysis, we adapted the methodology from several existing approaches; therefore, the results are not directly comparable to other published reports mentioned throughout this brief. We adapted the methodology developed for CMS's LTSS Expenditures and Users Reports to identify Section 1915 claims and the KFF State Health Facts approach to identify Section 1115 demonstration claims for select states that do not deliver HCBS under Section 1915 authorities (Stepanczuk et al. 2024a, Chidambaram and Burns 2023). We also used the HCBS taxonomy approach to isolate Section 1115 demonstration HCBS claims and to identify service categories under Section 1915 and 1115 HCBS authorities (Rooney et al. 2023). For more information on the various methodological approaches to identifying HCBS users and expenditures, please see MACPAC's publication on *Methodological Approaches for Analyzing Use and Spending in Medicaid Long-Term Services and Supports: A Comparative Review* (MACPAC 2024).

## LTSS claims

To identify HCBS and institutional LTSS claims, we adapted the approach used in the TAF-based LTSS Expenditure and User Reports (Stepanczuk et al. 2024a). To determine whether a claim was paid for by an HCBS authority (i.e., Sections 1915(c), 1915(i), 1915(j), and 1915(k) of the Social Security Act), we relied on the claim's program type, waiver type, HCBS service type, or benefit type. Because what a state reports in these four data elements can conflict, we employed a hierarchical approach tested and validated by the LTSS Expenditure and User Reports, which prioritizes the program type code found on the claim, followed by the waiver type code, HCBS service code, and benefit type code. For four states without Section 1915(c) waivers—Arizona, New Jersey, Rhode Island, and Vermont—we adapted the KFF State Health Facts methodology to identify claims under their Section 1115 demonstrations (Chidambaram and Burns 2023). To identify institutional LTSS claims and classify the service by facility type, we used service type and benefit type on claims in the LT TAF file.

## Beneficiary characteristics

After identifying LTSS claims, we linked the claims to the eligibility file using beneficiaries' unique identification numbers to retain beneficiaries that met the inclusion criteria. To be included in the study population of HCBS or institutional LTSS users and expenditures, beneficiaries needed at least one month of Medicaid or Medicaid-expansion Children's Health Insurance Program (M-CHIP) enrollment and evidence of HCBS or institutional LTSS use in a given year.[9,10] Beneficiary characteristics were identified as follows:

- **Age.** We used beneficiaries' age as of December 31 of the calendar year to classify them into four age categories: 0 through 18 years, 19 through 64 years, 65 through 84 years, and 85 years and older.
- **Medicaid eligibility group.** Using a combination of age, sex, CHIP code, and Medicaid eligibility group code data elements in the TAF DE file, we classified beneficiaries into one of the following eligibility groups: aged, blind or disabled, new adults (VIII group), other adults (non-VIII group), children (non-M-CHIP), M-CHIP children, pregnancy, and missing/unknown.[11]
- **Dual eligibility status**. We determined whether a beneficiary was dually eligible for both Medicare and Medicaid using the dual eligible code data element in the TAF DE file that shows the beneficiary's most recent status. We classified beneficiaries as full-benefit dual eligibility status, partial-benefit dual eligibility status, or Medicaid-only.

- **Sex.** We identified beneficiary sex using the same two categories that the DE file uses: female or male.
- **Race and ethnicity.** The TAF data element for race and ethnicity is unusable or unreliable in many states. Therefore, we used the TAF REI companion file for more complete beneficiary race and ethnicity information for this analysis. The REI file supplements state-reported data by estimating race and ethnicity based on beneficiary information in the TAF DE file (first name, surname, self-reported race and ethnicity, and American Indian or Alaska Native certification); data from the TAF geocoded address companion file for beneficiaries; and geographic, race and ethnicity, and surname data from the Census Bureau. LTSS user counts and expenditures stratified by race and ethnicity should be interpreted as approximations because the calculations use both self-reported and imputed probabilities of a person being classified as a given race and ethnicity. In addition, total user counts that are calculated by summing the values of the different race and ethnicity amounts may not be equivalent to the true totals because they are approximations.
- **Geographic location.** We classified beneficiary ZIP codes as either rural or urban using the U.S. Department of Education National Center for Education Statistics (NCES) Education Demographic and Geographic Estimates (EDGE) locale classification indicators. We used each year's corresponding urban or rural locale assignment file from NCES EDGE.

### LTSS subpopulation groupings

We adapted the methodology from the CMS LTSS Users and Expenditures reports to identify seven LTSS subpopulation groupings (Stepanczuk et al. 2024b). We used beneficiary characteristics such as age, enrollment in Section 1915(c) waiver programs, chronic condition diagnoses, and service use to classify LTSS users into any of the following LTSS subpopulation groupings: (1) beneficiaries with I/DD or ASD; (2) beneficiaries younger than age 65 with potentially disabling conditions; (3) older adults (age 65 and older); (4) beneficiaries with mental illness, SED, or SUD; (5) beneficiaries with brain injuries; (6) beneficiaries with HIV/AIDS; and (7) other people who use LTSS (i.e., people in our study population that do not meet the criteria for any of the other six subpopulation groupings). Beneficiaries who met the criteria for more than one subpopulation were included in each of the applicable subpopulation groupings; therefore, subpopulation groupings are not mutually exclusive. For purposes of this issue brief, the subpopulation grouping-specific findings focus on the first six subpopulation groupings. For more detailed information on the methodology used to identify the LTSS subpopulation groupings, refer to Appendix B.

## Findings

Nationally, the number of Medicaid beneficiaries using HCBS increased from 2019 through 2021, while the number of institutional LTSS users decreased over that time period (Table 1). However, based on 2021 data, we found that there was variation in each state in the share of Medicaid beneficiaries that used HCBS or institutional LTSS (Figure 1). In most states, the share of HCBS users was larger than the share of institutional LTSS users. The characteristics of HCBS users generally differed from the characteristics of the overall Medicaid population; HCBS users were older, more likely to be in the blind or disabled eligibility group, and more likely to be dually eligible for Medicare and Medicaid (Table 2). HCBS users generally shared common user characteristics across LTSS subpopulation groupings, however there were some variations (Table 2). Also, we found that each subpopulation varied in the most used HCBS taxonomy category services, likely reflecting each subpopulation's unique needs (Figures 3–6).

### HCBS and institutional LTSS users from 2019 to 2021

From 2019 through 2021, the total number of Medicaid beneficiaries using HCBS increased, while the total number of institutional LTSS users decreased (Table 1). Nationally, the number of Medicaid beneficiaries increased from 91.6 million in 2019 to 97.7 million in 2021 (Table 1). In 2019, there were approximately 2.2 million, or 2.4 percent of Medicaid beneficiaries using HCBS, which increased to 2.5 million users, or 2.6 percent

of Medicaid beneficiaries, in 2021. Over the same time period, the number of institutional LTSS users decreased from 1.8 million in 2019 to 1.5 million in 2021.

**TABLE 1.** Total Medicaid Beneficiaries, HCBS Users, and Institutional LTSS Users, CYs 2019–2021

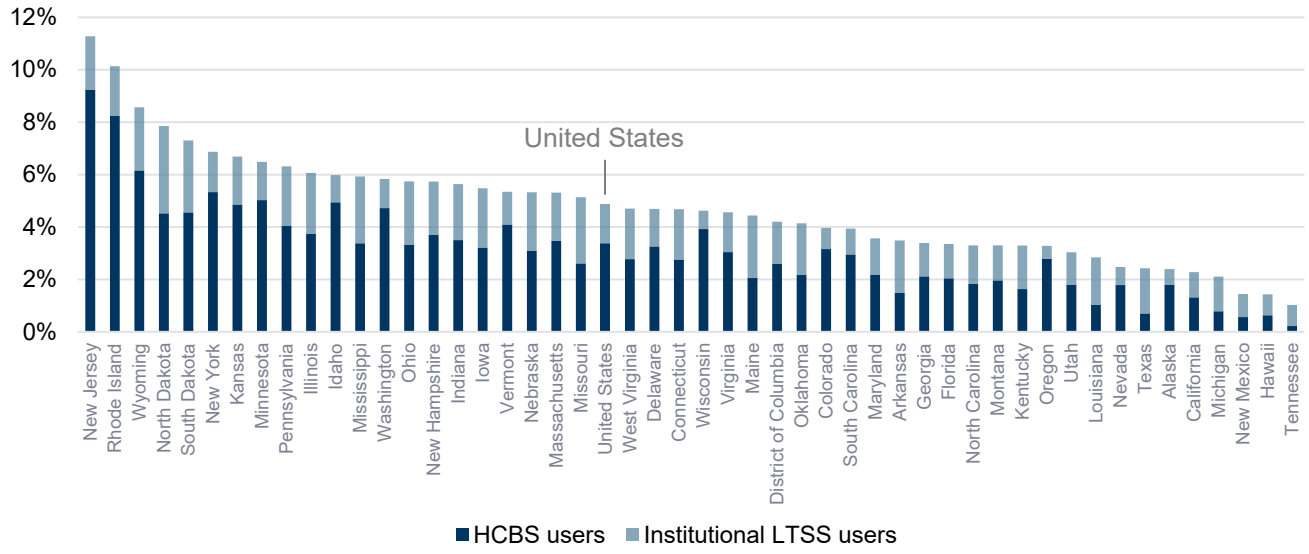
| Population | 2019 | | 2020 | | 2021 | |
|---|---|---|---|---|---|---|
| | Total (thousands) | % of total | Total (thousands) | % of total | Total (thousands) | % of total |
| **All Medicaid beneficiaries** | **91,559** | **100%** | **91,790** | **100%** | **97,668** | **100%** |
| HCBS users | **2,204** | 2.4 | 2,494 | 2.7 | 2,545 | 2.6 |
| Institutional LTSS users | **1,769** | 1.9 | 1,621 | 1.8 | 1,456 | 1.5 |

**Notes**: HCBS is home- and community-based services. LTSS is long-term services and supports. CY is calendar year. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. Medicaid beneficiaries who met the enrollment criteria and used both HCBS and institutional LTSS in a given year are counted in both groups.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

**State distribution of HCBS users and institutional LTSS users in 2021.** The share of Medicaid beneficiaries that used HCBS, institutional LTSS, or both varied by state in 2021 (Figure 1). The share of beneficiaries using HCBS across states ranged between less than one percent and nine percent. Compared to HCBS users, the share of institutional LTSS users across states was lower, which varied between less than one percent and three percent. Forty states had a higher share of HCBS users than institutional LTSS users. In 18 states, the share of HCBS users was greater than the national average, and in 27 states the share of institutional LTSS users was greater than the national average.

**FIGURE 1.** State Distribution of HCBS and Institutional LTSS Users as a Share of All Medicaid Beneficiaries, CY 2021




**Notes:** HCBS is home- and community-based services. LTSS is long-term services and supports. CY is calendar year. Data from Alabama and Arizona are excluded from this graph due to data reporting issues. Medicaid beneficiaries who met the enrollment criteria and used both HCBS and institutional LTSS in a given year are counted in both groups.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

## Medicaid beneficiary and HCBS user characteristics

The characteristics of HCBS users generally differed from the characteristics of the overall Medicaid population but remained relatively consistent from 2019 through 2021; therefore, the remainder of this issue brief will focus on data from 2021. Medicaid and M-CHIP covered 97.7 million beneficiaries in CY 2021 (Table 2). Most of the overall Medicaid population was younger than age 65 (90.4 percent), not dually eligible for Medicare and Medicaid (86.0 percent), and more likely to be in either a child-related eligibility group (i.e., children and M-CHIP children) (39.6 percent) or an adult-related eligibility group (i.e., new adult and other adult groups) (37.5 percent).

Compared to the overall Medicaid population, HCBS users were older, more likely to be in the blind or disabled eligibility group, more likely to be dually eligible for Medicare and Medicaid, and less likely to identify as Hispanic. Among HCBS users, 40.5 percent were 65 years and older, compared to 9.5 percent of the overall Medicaid population. However, beneficiaries between ages 19 and 64 comprised the largest age group among HCBS users (49.7 percent), a proportion similar to the overall Medicaid population (50.5 percent). The largest eligibility group among HCBS users was the blind or disabled eligibility group (50.1 percent), followed by beneficiaries in the aged eligibility group (40.1 percent). In contrast, children made up the largest eligibility group of Medicaid beneficiaries overall (34.5 percent), followed by the new adult group (VIII group) (23.5 percent). HCBS users were also less likely to identify as Hispanic (15.7 percent), compared to the overall Medicaid population (27.0 percent). The distribution of sex and geographic location among HCBS users generally aligned with those of the overall Medicaid population.

**TABLE 2.** Comparing Demographic Characteristics of Medicaid Beneficiaries and HCBS Users, CY 2021

| Demographic characteristics | All Medicaid beneficiaries | All HCBS users | I/DD or ASD | <65 with potentially disabling condition(s) | Older adults | Brain injuries | Mental illness, SED, or SUD | HIV/ AIDS |
|---|---|---|---|---|---|---|---|---|
| **Total (thousands)** | **97,668** | **2,545** | **782** | **555** | **1,029** | **31** | **1,030** | **27** |
| **Age** | | | | | | | | |
| 0–18 | 39.9% | 9.8% | 20.3% | 8.9% | – | 6.4% | 6.6% | 0.3% |
| 19–64 | 50.5 | 49.7 | 71.8 | 91.1 | – | 66.7 | 62.6 | 65.4 |
| 65–84 | 8.1 | 30.9 | 7.6 | – | 76.4% | 23.6 | 26.3 | 32.4 |
| 85 and older | 1.4 | 9.6 | 0.3 | – | 23.6 | 3.2 | 4.4 | 2.0 |
| **Sex** | | | | | | | | |
| Male | 45.0 | 44.6 | 60.0 | 49.5 | 31.0 | 54.7 | 44.8 | 50.1 |
| Female | 55.0 | 55.4 | 40.0 | 50.5 | 69.0 | 45.3 | 55.2 | 49.9 |
| **Eligibility** | | | | | | | | |
| Aged | 9.1 | 40.1 | 7.8 | – | 99.1 | 26.2 | 30.4 | 33.6 |
| Blind or disabled | 10.1 | 50.1 | 83.8 | 88.7 | 0.4 | 61.1 | 58.5 | 56.2 |
| New adults (VIII group)[1] | 23.5 | 4.7 | 2.1 | 7.1 | 0.5 | 8.0 | 6.1 | 8.4 |
| Other adults (non-VIII group) | 14.0 | 1.4 | 0.5 | 2.0 | – | 1.0 | 1.9 | 1.5 |
| Children | 34.5 | 2.9 | 4.6 | 1.6 | – | 2.8 | 2.5 | 0.1 |
| M-CHIP children[2] | 5.1 | 0.5 | 0.9 | 0.2 | – | 0.2 | 0.3 | – |
| Pregnancy | 1.8 | 0.0 | 0.0 | 0.0 | – | – | 0.0 | – |
| **Dually eligible status[3]** | | | | | | | | |
| Full-benefit | 10.4 | 63.5 | 47.8 | 50.8 | 92.5 | 63.1 | 60.9 | 61.2 |
| Partial-benefit | 3.7 | 1.1 | 0.4 | 0.7 | 1.5 | 0.6 | 0.9 | 1.1 |

| Demographic characteristics | All Medicaid beneficiaries | All HCBS users | I/DD or ASD | <65 with potentially disabling condition(s) | Older adults | Brain injuries | Mental illness, SED, or SUD | HIV/ AIDS |
|---|---|---|---|---|---|---|---|---|
| Medicaid-only | 86.0 | 35.4 | 51.8 | 48.5 | 5.9 | 36.3 | 38.2 | 37.8 |
| **Race and ethnicity[4]** | | | | | | | | |
| White, non-Hispanic | 43.1 | 52.3 | 62.8 | 53.9 | 47.9 | 62.9 | 59.1 | 23.2 |
| Black, non-Hispanic | 21.1 | 22.3 | 16.5 | 27.4 | 21.6 | 23.4 | 21.9 | 55.0 |
| Asian or Pacific Islander, non-Hispanic | 5.7 | 8.1 | 4.1 | 3.7 | 13.3 | 3.5 | 3.6 | 2.1 |
| AIAN, non-Hispanic | 1.3 | 0.8 | 0.8 | 0.9 | 0.7 | 1.0 | 0.9 | 0.6 |
| Multiracial, non-Hispanic | 1.7 | 0.8 | 1.0 | 1.0 | 0.5 | 0.8 | 0.9 | 0.4 |
| Hispanic, all races | 27.0 | 15.7 | 14.8 | 13.0 | 16.0 | 8.4 | 13.6 | 18.7 |
| **Geographic location[5]** | | | | | | | | |
| Urban | 79.7 | 83.4 | 81.3 | 80.4 | 84.8 | 80.9 | 82.2 | 92.5 |
| Rural | 19.1 | 15.8 | 18.3 | 19.1 | 14.7 | 18.6 | 16.8 | 7.2 |

**Notes:** HCBS is home- and community-based services. CY is calendar year. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. <65 is under 65 years old. "Potentially disabling conditions" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. Older adults are those age 65 and older. SED is serious emotional disturbance. SUD is substance use disorder. AIAN is American Indian and Alaska Native, non-Hispanic. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. The sum of users across the long-term services and supports subpopulation groupings is greater than the total number of HCBS users because beneficiaries are counted in each subpopulation grouping for which they which met the criteria. Beneficiaries with missing or unknown eligibility group, age, sex, race and ethnicity, or geographic location accounted for less than 2 percent of the population and are excluded from this table. Children and adults under age 65 who qualify for Medicaid on the basis of disability are included in the blind or disabled eligibility category. Individuals age 65 and older eligible through an aged, blind, or disabled pathway are included in the aged eligibility category.

– Dash indicates zero. 0.0 indicates a value less than 0.05 percent that rounds to zero.

[1] The new adult group includes those enrollees who are eligible under Section 1902(a)(10)(A)(i)(VIII) of the Social Security Act (the Act).

[2] Medicaid-expansion CHIP (M-CHIP) is CHIP-financed Medicaid coverage of targeted low-income children that meet the requirements of section 2103 of the Act.

[3] Full-benefit dually eligible beneficiaries receive the full range of Medicaid benefits offered in a given state, in addition to their Medicare benefits. Medicaid pays Medicare premiums and may also pay the cost-sharing for their Medicare services. When individuals receive Medicaid assistance with their Medicare premiums and cost-sharing but are not simultaneously enrolled in full Medicaid benefits, they are considered partial-benefit dually eligible beneficiaries.

[4] The TAF data element for race and ethnicity is unusable or unreliable in many states. Therefore, we used the TAF race and ethnicity imputation (REI) companion file for more complete beneficiary race and ethnicity information. For more information regarding the REI file, refer to Appendix B.

[5] Urban or rural location is classified based on beneficiary ZIP codes using the U.S. Department of Education National Center for Education Statistics Education Demographic and Geographic Estimates locale classification indicators.

**Source:** MACPAC, 2024, analysis of TAF data.

## Characteristics of LTSS subpopulation groupings

HCBS users generally shared common user characteristics across LTSS subpopulation groupings. For example, beneficiaries across most LTSS subpopulation groupings were primarily adults, eligible for HCBS through the blind or disabled pathway, identified as white, and resided in urban settings (Table 2). However, some variations exist in these trends by LTSS subpopulation grouping.

**Age group.** Across all subpopulation groupings, except for older adults, most beneficiaries were adults aged 19–64 years (Table 2). Age was used as the primary criteria for inclusion for two subpopulation groupings, older adults and beneficiaries under age 65 with potentially disabling conditions, which we observe in the age composition of each subpopulation. Older adults only include beneficiaries age 65 years and older and beneficiaries under age 65 with potentially disabling conditions only include beneficiaries under age 65. Beneficiaries with I/DD or ASD had the largest share of beneficiaries age 18 and younger (20.3 percent), and older adults had the largest share of beneficiaries age 85 and older (23.6 percent).

**Sex.** The distribution by sex was fairly similar across all subpopulation groupings, with a few slight variations. Older adults had the largest share of female HCBS users (69.0 percent) (Table 2). Beneficiaries with I/DD or ASD had the largest share of males (60.0 percent), followed by beneficiaries with brain injuries (54.7 percent).

**Eligibility.** Most beneficiaries were in the blind or disabled eligibility category across all subpopulation groupings except for the older adult subpopulation, which was almost exclusively in the aged eligibility group (age is used as part of the definition for the aged eligibility group) (Table 2). After older adults, beneficiaries with HIV/AIDS had the lowest share of HCBS users in the blind or disabled eligibility group (56.2 percent), compared to all other subpopulation groupings, which ranged from 58.5 percent to 88.7 percent of beneficiaries eligible via the blind or disabled pathway by subpopulation grouping. In addition, beneficiaries with I/DD or ASD had largest share of HCBS users in the children eligibility group (4.6 percent) compared to all other subpopulation groupings. Beneficiaries with HIV/AIDS, had the largest share of beneficiaries in an adult eligibility group (9.9 percent). Beneficiaries in M-CHIP and pregnancy-related eligibility groups accounted for the smallest share of users across all subpopulation groupings (less than one percent).

**Dually eligible status.** HCBS users with full-benefit dually eligible status were most prevalent in the older adult (92.5 percent) subpopulation, followed by the brain injuries (63.1 percent), HIV/AIDS (61.2 percent), and mental illness, SED, or SUD (60.9 percent) subpopulation groupings (Table 2). Beneficiaries eligible for Medicaid only (i.e., not dually eligible for Medicare and Medicaid) comprised more than half of beneficiaries with I/DD or ASD (51.8 percent). Beneficiaries with partial-benefit dually eligible status accounted for less than two percent of each subpopulation.

**Race and ethnicity.** Across all subpopulation groupings, most beneficiaries identified as white, non-Hispanic, with the exception of beneficiaries with HIV/AIDS, whose majority identified as Black, non-Hispanic (55.0 percent) (Table 2). Beneficiaries with brain injuries and beneficiaries with I/DD or ASD had the largest share of HCBS users who identified as white, non-Hispanic, with 62.9 percent and 62.8 percent, respectively. Beneficiaries with I/DD or ASD had the lowest share of HCBS users who identified as Black, non-Hispanic (16.5 percent). Compared to other subpopulation groupings, beneficiaries with HIV/AIDS and older adults had a higher share of HCBS users who identified as Hispanic, 18.7 percent and 16.0 percent, respectively. Beneficiaries who identified as Asian or Pacific Islander were most prevalent among older adults (13.3 percent) and accounted for approximately four percent or less of other subpopulation groupings. Beneficiaries who identified as American Indian and Alaska Native or multiracial, non-Hispanic, accounted for one percent or less of each subpopulation grouping.

**Geographic location.** Most beneficiaries across all subpopulation groupings resided in an urban area, ranging from 80.4 percent to 92.5 percent of beneficiaries in a given subpopulation grouping, and those who lived in a rural area ranged from 7.2 percent to 19.1 percent of their HCBS subpopulation grouping (Table 2). Beneficiaries with HIV/AIDS comprised the largest share of HCBS users that lived in an urban area (92.5 percent in urban

areas versus 7.2 percent lived in rural areas). Beneficiaries under age 65 with potentially disabling conditions had the largest share of users that lived in a rural area (19.1 percent) compared to all other subpopulation groupings.

## HCBS utilization and expenditures by taxonomy category

In 2021, the most commonly used HCBS taxonomy categories among all HCBS users were round-the-clock services (43.6 percent), home-based services (24.4 percent), and case management (23.4 percent) (Table 3). In addition to being the most commonly used service, round-the-clock services comprised the largest share of HCBS spending (45.0 percent). Case management was one of the most commonly used services across all HCBS users, but only accounted for 2.2 percent of total spending. These findings align with previous research, which found that case management was a widely used service but did not account for a large share of spending (Peebles and Bohl 2014).

**TABLE 3**. HCBS Users and Spending by HCBS Taxonomy Category, CY 2021

| HCBS taxonomy category | HCBS users | HCBS spending |
|---|---|---|
| **Total users (thousands) and spending (millions)** | **2,545** | **$82,450** |
| **Share of total** | | |
| Round-the-clock services | 43.6% | 45.0% |
| Home-based services | 24.4 | 16.6 |
| Case management | 23.4 | 2.2 |
| Nonmedical transportation | 16.1 | 2.5 |
| Equipment, technology, and modifications | 14.1 | 0.5 |
| Other health and therapeutic services | 13.1 | 5.6 |
| Day services | 10.8 | 5.5 |
| Other mental health and behavioral services | 8.1 | 6.4 |
| Caregiver support | 7.1 | 1.8 |
| Home-delivered meals | 7.0 | 0.4 |
| Nursing | 3.5 | 0.8 |
| Services supporting participant direction | 3.5 | 0.6 |
| Participant training | 3.2 | 1.2 |
| Supported employment | 2.3 | 0.9 |
| Community transition services | 0.2 | 0.0 |

**Notes:** HCBS is home- and community-based services. CY is calendar year. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. The sum of user and spending percentages across HCBS taxonomy categories will be greater than 100 percent because users and expenditures can be counted in more than one HCBS taxonomy category. Expenditures on a claim are attributed to each HCBS taxonomy category on the claim.

– Dash indicates zero. 0.0 indicates a value less than 0.05 percent that rounds to zero.

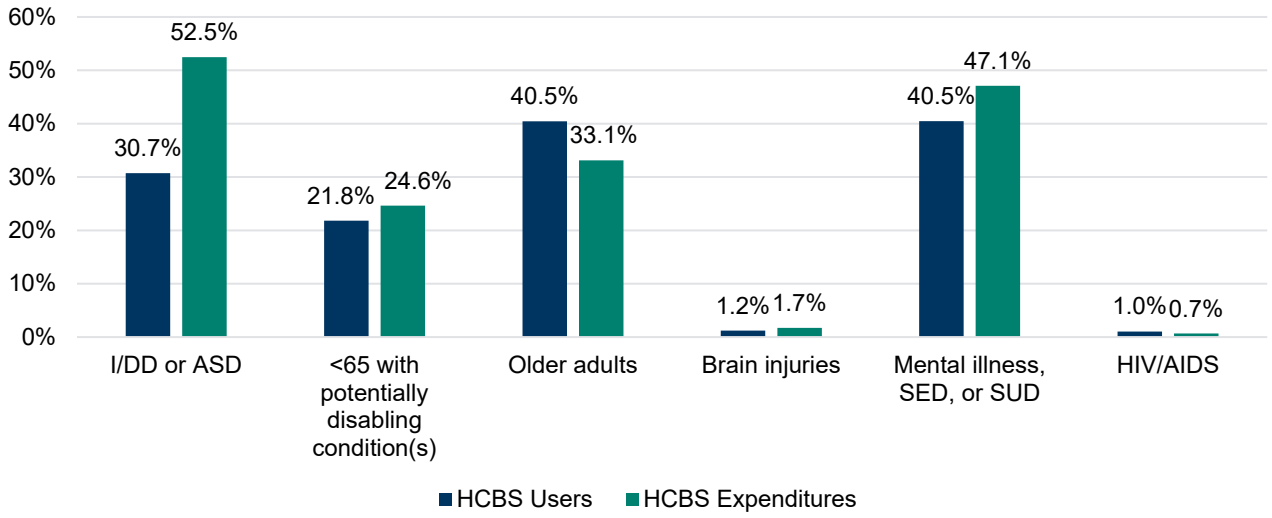
**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

## HCBS utilization and spending by subpopulation grouping

The distribution of HCBS users and spending varied by subpopulation grouping. The four largest LTSS subpopulation groupings among HCBS users were beneficiaries with mental illness, SED, or SUD and older adults (both with 40.5 percent), beneficiaries with I/DD or ASD (30.7 percent), and beneficiaries younger than age 65 with potentially disabling conditions (21.8 percent) (Figure 2). Despite comprising 30.7 percent of HCBS users, those with I/DD or ASD accounted for the largest share of spending at 52.5 percent of total HCBS spending. Beneficiaries with mental illness, SED, or SUD accounted for the second largest share of HCBS spending (47.1 percent) followed by older adults (33.1 percent), and beneficiaries under age 65 with potentially disabling

conditions (24.6 percent). Beneficiaries with HIV/AIDS and with brain injuries comprised the smallest share of HCBS users and spending. Beneficiaries with brain injuries accounted for approximately one percent of HCBS users and two percent of HCBS spending and beneficiaries with HIV/AIDS accounted for about one percent of HCBS users and spending.

**FIGURE 2.** Distribution of HCBS Users and Spending by LTSS Subpopulation, CY 2021



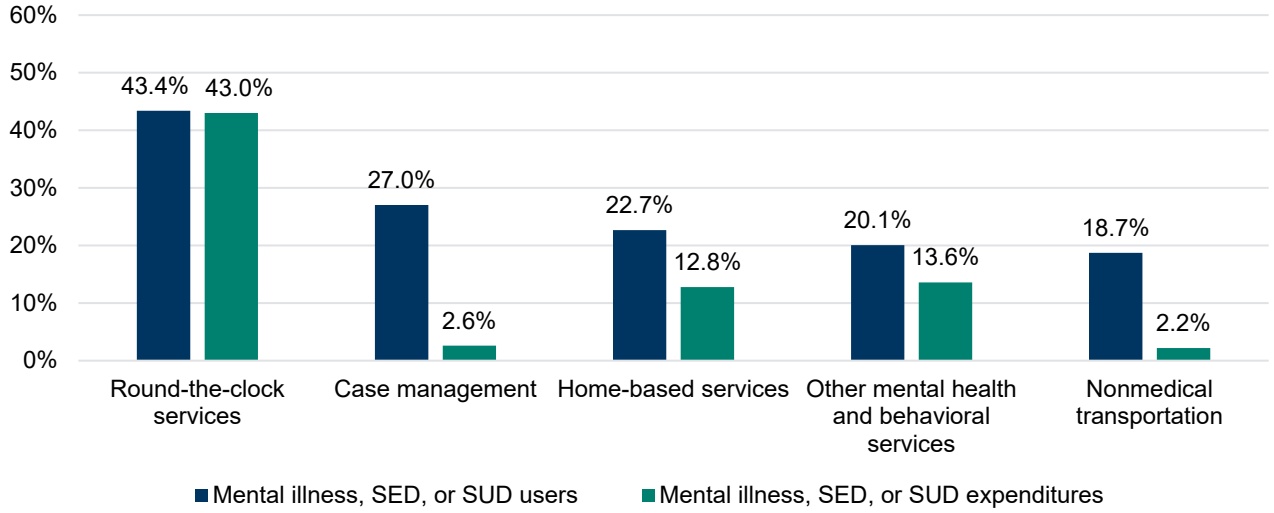

**Notes:** HCBS is home- and community-based services. LTSS is long-term services and supports. CY is calendar year. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. <65 is under 65 years old. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. SED is serious emotional disturbance. SUD is substance use disorder. This figure includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. The sum of percentages across the subpopulation groupings will total more than 100 because beneficiaries are counted in each subpopulation for which they which meet the criteria.

**Source:** MACPAC, 2024, analysis of TAF data.

Each subpopulation varied in the HCBS taxonomy category services used, likely reflecting each subpopulation's unique needs. Round-the-clock services and case management were among the most commonly used taxonomy across all subpopulation groupings (Figures 3–6). The remainder of this section highlights findings from the four largest subpopulation groupings for the five most commonly used taxonomy categories within each subpopulation.

**HCBS utilization and spending among beneficiaries with mental illness, SED, or SUD.** The most commonly used HCBS taxonomy among beneficiaries with mental illness, SED, or SUD was round-the-clock services (43.4 percent), which also accounted for the largest share of spending (43.0 percent) (Figure 3). Case management was the second most commonly used taxonomy (27.0 percent), but accounted for the smallest share of spending (2.6 percent). Compared to other subpopulation groupings, beneficiaries with mental illness, SED, or SUD used other mental health and behavioral services at a higher rate (20.1 percent).

**FIGURE 3.** Share of HCBS Utilization and Spending Among the Mental Illness, SED, or SUD Subpopulation by Taxonomy, CY 2021

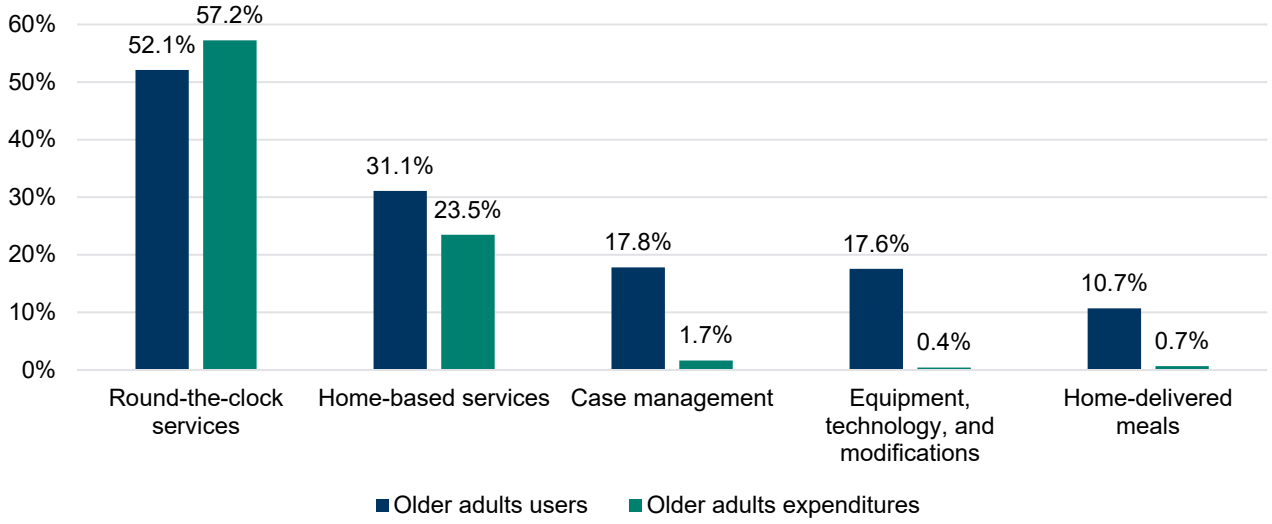



**Notes:** HCBS is home- and community-based services. SED is serious emotional disturbance. SUD is substance use disorder. CY is calendar year. This figure includes data from 49 states and the District of Columbia; Alabama's data are excluded due to data reporting issue, which impacted national trends. The sum of user and expenditure percentages across HCBS taxonomy categories will be greater than 100 because users and spending can be counted in more than one HCBS taxonomy category. Total expenditures on a claim are attributed to each HCBS taxonomy category that appear on the claim.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

**HCBS utilization and spending among older adults.** Just over half of older adults (52.1 percent) used round-the-clock services, which accounted for 57.2 percent of their HCBS spending (Figure 4). Compared to other subpopulation groupings, older adults used round-the-clock services at a higher rate. There were 31.1 percent of older adults that used home-based services, which accounted for 23.5 percent of their HCBS spending. Utilization of case management and equipment, technology, and modifications was similar among older adults, at 17.8 percent and 17.6 percent, respectively. Both service types accounted for a small share of spending: 1.7 percent for case management and 0.4 percent for equipment, technology, or modifications.

**FIGURE 4**. Share of HCBS Utilization and Spending Among Older Adults by Taxonomy, CY 2021

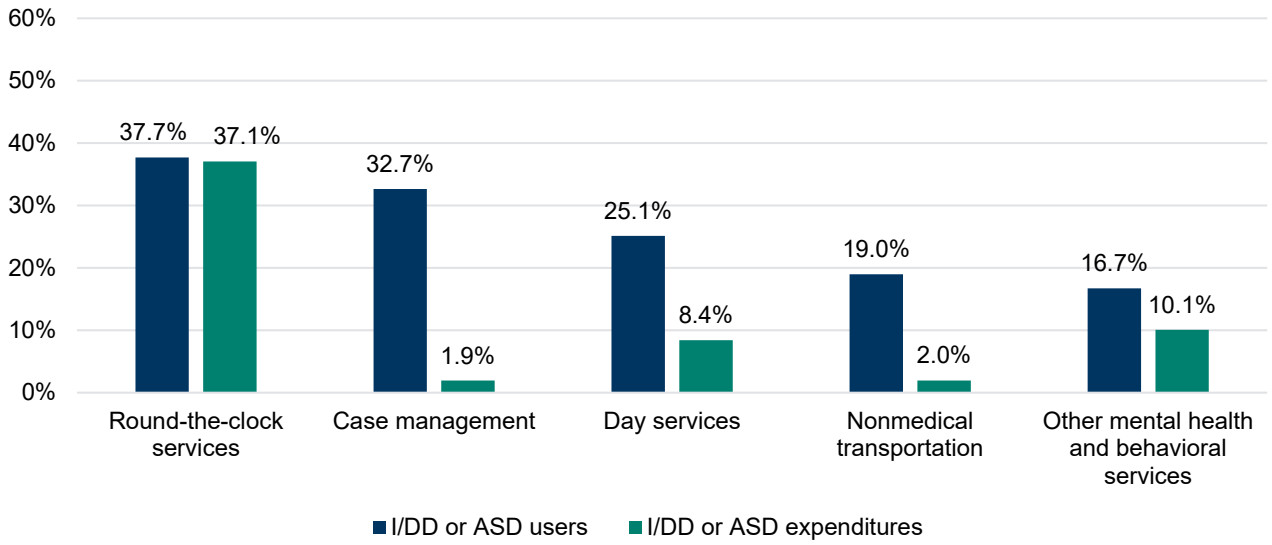



**Notes:** HCBS is home- and community-based services. CY is calendar year This figure includes data from 49 states and the District of Columbia; Alabama's data are excluded due to data reporting issue, which impacted national trends. The sum of user and expenditure percentages across HCBS taxonomy categories will be greater than 100 because users and spending can be counted in more than one HCBS taxonomy category. Total expenditures on a claim are attributed to each HCBS taxonomy category that appear on the claim.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

**HCBS utilization and spending among beneficiaries with I/DD or ASD.** Among beneficiaries with I/DD or ASD, 37.7 percent used round-the-clock services, which accounted for a similar share of their HCBS spending (37.1 percent) (Figure 5). Their use of case management and day services, 32.7 percent and 25.1 percent, respectively, was higher than any other subpopulation grouping. Additionally, beneficiaries with I/DD or ASD are the only subpopulation group to have day services as one of their top service utilization categories. Day services accounted for 8.4 percent of HCBS spending among beneficiaries with I/DD or ASD, and case management accounted for the smallest share (1.9 percent) of their HCBS spending. Other mental health and behavioral services accounted for 10.1 percent of HCBS spending, which is the second largest share after round-the-clock services.

**FIGURE 5.** Share of HCBS Utilization and Spending Among Beneficiaries with I/DD or ASD by Taxonomy, CY 2021

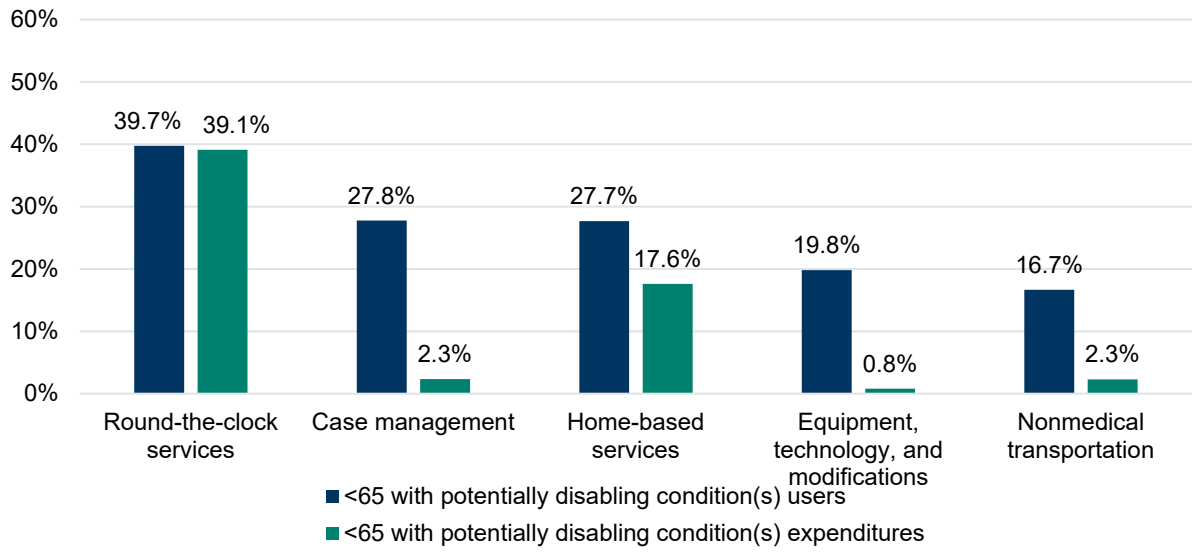



**Notes:** HCBS is home- and community-based services. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. CY is calendar year. This figure includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. The sum of user and expenditure percentages across HCBS taxonomy categories will be greater than 100 because users and spending can be counted in more than one HCBS taxonomy category. Total expenditures on a claim are attributed to each HCBS taxonomy category that appear on the claim.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

**HCBS utilization and spending among individuals under age 65 with potentially disabling conditions.** Round-the-clock services were used by 39.7 percent of individuals under age 65 with potentially disabling conditions, which accounted for a similar share of their HCBS spending (39.1 percent) (Figure 6). Case management and home-based services were the second most commonly used services and had a similar share of users, 27.8 percent and 27.7 percent, respectively. Almost 20 percent of individuals under age 65 with potentially disabling conditions used equipment, technology, and modifications, but those services accounted for less than one percent of spending.

**FIGURE 6.** Share of HCBS Utilization and Spending Among Individuals under Age 65 with Potentially Disabling Conditions by Taxonomy, CY 2021




**Notes:** HCBS is home- and community-based services. CY is calendar year. <65 is under 65 years old. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability. Because there is no disease severity or functional assessment data in the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. This figure includes data from 49 states and the District of Columbia; Alabama's data are excluded due to a data reporting issue, which impacted national trends. The sum of user and expenditure percentages across HCBS taxonomy categories will be greater than 100 because users and spending can be counted in more than one HCBS taxonomy category. Total expenditures on a claim are attributed to each HCBS taxonomy category that appear on the claim.

**Source:** MACPAC, 2024, analysis of TAF data.

## Conclusion

This analysis found that, nationally, the number of Medicaid beneficiaries using HCBS increased while the number of institutional LTSS users decreased from CYs 2019 to 2021. The data show that the share of Medicaid beneficiaries that used HCBS or institutional LTSS varied by state. In most states, the share of HCBS users was larger than the share of institutional LTSS users in CY 2021. Compared to the overall Medicaid population, HCBS users were older, more likely to be in the blind or disabled eligibility group, more likely to be dually eligible for Medicare and Medicaid, and less likely to identify as Hispanic. Across LTSS subpopulation groupings, HCBS users generally shared common user characteristics with some variations. Beneficiaries across most LTSS subpopulation groupings were primarily adults, eligible for Medicaid through the blind or disabled pathway, identified as white, and resided in urban settings. We found that each subpopulation grouping varied in their HCBS use and spending, including the HCBS taxonomy category services used, likely reflecting each subpopulation grouping's unique needs.

## Data limitations

TAF data quality varies by state. Some states have missing or inconsistent TAF data. For example, Alabama overreported Section 1915(c) users and expenditures in 2020 and 2021, which impacted national trends. In 2019 results, Alabama reported around 34,000 HCBS users, compared to around 780,000 in 2021. As a result, Alabama is excluded from this issue brief. Arizona did not have any claims flagged as HCBS despite the state delivering HCBS through a Section 1115 demonstration. TAF data do not include claims for the acute health care

services that dually eligible beneficiaries receive through Medicare; this lack of information may result in (1) an underestimate of the prevalence of chronic conditions and (2) under-identification of relevant LTSS subpopulation groupings based on such chronic conditions for dually eligible beneficiaries.

**States vary in how they bill for HCBS and how they define LTSS subpopulation groupings.** We used a version of the HCBS taxonomy that was originally developed for the MAX data system, the TAF predecessor. Although updates have been made to the code set, it is possible that some HCBS claims may not be classified into one of the taxonomy categories or may be classified into the incorrect HCBS taxonomy category. We refer to claims identified as being covered by a Section 1915 waiver or a Section 1115 demonstration but not as part of the HCBS taxonomy as "non-taxonomy" HCBS, which were included in the total HCBS user counts and expenditures throughout this brief, but were not included as a taxonomy category in figures stratified by HCBS taxonomy.

We used a standard methodology to identify LTSS subpopulation groupings across all states based on information available in TAF, a method that may not align with how each state defines its own target populations. States' internal data on LTSS users and expenditures for each subpopulation grouping might differ from our results, particularly if states have functional status or assessment data in their internal systems (and not in the TAF) that can be used to classify individuals.

## Endnotes

[1] The HCBS Section 1915(c) waiver technical guidance document uses the term “aged” and notes that although generally “aged” refers to individuals age 65 and older (aligning with § 1905(a)(iii) of the Social Security Act), states can identify a minimum age that is lower than 65 to align with state systems (CMS 2024).

[2] The total number of HCBS users varies based on the methodology used to identify HCBS users. Please see Methodological Approaches for Analyzing Use and Spending in Medicaid Long-Term Services and Supports: A Comparative Review, for more information (MACPAC 2024).

[3] These figures are based on data from 49 states and the District of Columbia. The analysis excluded Alabama due to a reporting issue that erroneously inflated the number of total HCBS users in the state in 2021. In the 2019 results, Alabama had around 34,000 HCBS users, compared to almost 780,000 in 2021. This reporting issue impacts national trends. Also, we did not identify any HCBS claims under Sections 1915 or 1115 HCBS authorities for Arizona, potentially resulting in an undercount of HCBS users.

[4] HCBS taxonomy categories include: case management; round-the-clock services; supported employment; day services; nursing; home-delivered meals; rent and food expenses for live-in caregiver; home-based services; caregiver support; other mental health and behavioral services; other health and therapeutic services; services supporting participant direction; participant training; equipment, technology, and modifications; nonmedical transportation; community transition services; other services; and unknown (Peebles and Bohl 2014).

[5] Because there is no disease severity or functional assessment data in the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), we must rely on diagnosis codes to identify possible disabilities for this LTSS subpopulation. We use the phrase “potentially disabling conditions” to indicate that the beneficiaries in the subpopulation have at least one condition that could be the basis of a disability.

[6] The Medicaid expenditures in this report are derived from claims data; as such, they comprise the state and federal share of LTSS expenditures. Institutional LTSS expenditure data do not include non-claims based payments such as disproportionate share hospital (DSH) payments to mental health facilities or non-DSH supplemental payments to nursing facilities.

[7] Medicaid Analytic eXtract (MAX) data contain Medicaid eligibility, service utilization, and payment information, and is the predecessor to the TAF.

[8] The analytic period includes data that cover the COVID-19 Public Health Emergency (PHE) in 2020, which had a major impact on the use of all health care services, including LTSS paid by Medicaid. We have not made any adjustments to the data to address changes in LTSS utilization and spending that may be attributable to the PHE.

[9] Medicaid-expansion CHIP (M-CHIP) is CHIP-financed Medicaid coverage of targeted low-income children that meet the requirements of section 2103 of the Social Security Act.

[10] We excluded State CHIP (S-CHIP) beneficiaries from our analysis because S-CHIP provides a more limited suite of coverage compared to Medicaid and M-CHIP.

[11] The new adult group includes those enrollees who are eligible under Section 1902(a)(10)(A)(i)(VIII) of the Social Security Act (the Act).

## References


Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2024. *Instructions, technical guide, and review criteria*. Baltimore, MD: CMS. https://wms-mmdl.cms.gov/WMS/faces/portal.jsp.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2023. *Medicaid long term services and supports annual expenditures report: Federal fiscal year 2020*. Baltimore, MD: CMS. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2020.pdf.

Centers for Medicare & Medicaid Services (CMS), U.S. Department of Health and Human Services. 2022. Application for a §1915(c) home and community-based services waiver. Baltimore, MD: CMS. https://www.medicaid.gov/medicaid/home-community-based-services/downloads/hcbs-waivers-application.pdf.

Chidambaram, P., and A. Burns. 2023. *How many people use Medicaid long-term services and supports and how much does Medicaid spend on those people?* Washington, DC: KFF.https://www.kff.org/report-section/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people-methods/.

Greener, E., A. Carpenter, and L. Nolan. 2023. *Identifying enrollees who use home and community-based services in the TAF*. Baltimore, MD: CMS. https://www.medicaid.gov/dq-atlas/downloads/supplemental/7061-Identifying-HCBS-in-TAF.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2024. *Methodological Approaches for Analyzing Use and Spending in Medicaid Long-Term Services and Supports: A Comparative Review*. August 2024. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2024/10/Methodological-Approaches-for-Analyzing-Use-and-Spending-in-Medicaid-Long-Term-Services-and-Supports-A-Comparative-Review.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2023. Chapter 4: Access to home- and community-based services. In *Report to Congress on Medicaid and CHIP*. June 2023. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2023/06/Chapter-4-Access-to-Home-and-Community-Based-Services.pdf.

Medicaid and CHIP Payment and Access Commission (MACPAC). 2022. Chapter 1: A New Medicaid Access Monitoring System. In *Report to Congress on Medicaid and CHIP*. June 2022. Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2022/06/Chapter-1-A-New-Medicaid-Access-Monitoring-System.pdf.

Murray, C., M. Eckstein, D. Lipson, and A. Wysocki. 2023. *Medicaid long term services and supports annual expenditures report: Federal fiscal year 2020*. Chicago, IL: Mathematica. https://www.medicaid.gov/media/164316.

Murray, C., A. Tourtellotte, D. Lipson, and A. Wysocki. 2021. *Medicaid long term services and supports annual expenditures report: Federal fiscal year 2019*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2019.pdf.

O'Malley Watts, M., M. Musumeci, and M. Ammula. 2022. *State policy choices about Medicaid home and community-based services amid the pandemic*. Washington, DC: KFF. https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-issue-brief/.

Peebles V. and A. Bohl. 2014. The HCBS taxonomy: a new language for classifying home- and community-based services. *Medicare & Medicaid Research Review* 4, no. 3: E1–E17. https://pmc.ncbi.nlm.nih.gov/articles/PMC4204915/pdf/mmrr2014-004-03-b01.pdf.

Peebles, V., M. Kim, A. Bohl, B. Morales, and D. Lipson. 2017. *HCBS claims analysis chartbook: Final report*. Report to the Medicaid and CHIP Payment and Access Commission. Chicago, IL: Mathematica Policy Research. https://www.macpac.gov/publication/hcbs-claims-analysis-chartbook-final-report/.

Ross, J., K. Liao, and A. Wysocki. 2021. *Medicaid section 1915(c) waiver programs annual expenditures and beneficiaries report, 2017–2018.* Chicago, IL: Mathematica. https://www.mathematica.org/publications/medicaid-section-1915c-waiver-programs-annual-expenditures-and-beneficiaries-report.

Rooney, J., C. Irvin, J. Self, et al. 2023. *Identifying and classifying Medicaid home and community-based services claims in the transformed Medicaid statistical information system, 2016-2020*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation (ASPE). https://aspe.hhs.gov/sites/default/files/documents/5ddae662bdcd7b04379e6f176a283441/identify-classify-hcbs-claims-tmsis-brief.pdf.

Stepanczuk, C., C. Murray, M. Eckstein, and A. Wysocki. 2024a. *Methodology for Identifying Medicaid Long-Term Services and Supports Expenditures and Users, 2019–2021*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-users-expenditures-method.pdf.

Stepanczuk, C., C. Murray, A. Carpenter, and A. Wysocki. 2024b. *Methodology for Identifying Medicaid Long-Term Services and Supports Expenditures and Users, 2022*. Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-users-expenditures-method-2022.pdf.

Wysocki, A., C. Murray, A. Kachalia, A. Carpenter, and C. Stepanczuk. 2024. *Trends in the Use of and Spending for Home and Community-Based Services as a Share of Total LTSS Use and Spending in Medicaid, 2019–2021.* Chicago, IL: Mathematica. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief.pdf.

# APPENDIX A: Detailed Tables

**TABLE A-1.** Utilization by HCBS Taxonomy Category and Subpopulation Grouping, CY 2021

| HCBS taxonomy category | All HCBS Users | I/DD or ASD | <65 with Potentially Disabling Conditions | Older adults | Brain injuries | Mental illness, SED, or SUD | HIV/AIDS |
|---|---|---|---|---|---|---|---|
| **Users (thousands)** | **2,545** | **782** | **555** | **1,029** | **31** | **1,030** | **27** |
| **Share of total HCBS users** | | | | | | | |
| Caregiver support | 7.1% | 14.3% | 7.6% | 2.6% | 4.3% | 4.8% | 1.2% |
| Case management | 23.4 | 32.7 | 27.8 | 17.8 | 24.4 | 27.0 | 15.7 |
| Community transition services | 0.2 | 0.1 | 0.2 | 0.1 | 0.3 | 0.3 | 0.2 |
| Day services | 10.8 | 25.1 | 10.0 | 5.5 | 8.9 | 11.8 | 2.5 |
| Equipment, technology, and modifications | 14.1 | 9.3 | 19.8 | 17.6 | 26.5 | 14.7 | 15.2 |
| Home-based services | 24.4 | 14.9 | 27.7 | 31.1 | 33.1 | 22.7 | 34.0 |
| Home-delivered meals | 7.0 | 1.0 | 8.5 | 10.7 | 6.7 | 8.3 | 11.5 |
| Nonmedical transportation | 16.1 | 19.0 | 16.7 | 10.7 | 13.2 | 18.7 | 14.6 |
| Nursing | 3.5 | 3.2 | 6.5 | 3.5 | 2.5 | 4.0 | 2.2 |
| Other health and therapeutic services | 13.1 | 13.9 | 15.2 | 10.1 | 13.5 | 13.6 | 6.4 |
| Other mental health and behavioral services | 8.1 | 16.7 | 7.3 | 2.7 | 13.9 | 20.1 | 2.3 |
| Participant training | 3.2 | 5.9 | 4.5 | 1.2 | 6.1 | 3.9 | 1.2 |
| Round-the-clock services | 43.6 | 37.7 | 39.7 | 52.1 | 39.1 | 43.4 | 43.4 |
| Services supporting participant direction | 3.5 | 7.0 | 4.6 | 1.3 | 4.5 | 3.8 | 0.7 |
| Supported employment | 2.3 | 6.3 | 1.5 | 0.2 | 2.4 | 2.9 | 0.4 |

**Notes:** HCBS is home- and community-based services. CY is calendar year. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. <65 is under 65 years old. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the TAF, we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. SED is serious emotional disturbance. SUD is substance use disorder. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to data reporting issue, which impacted national trends. The sum of users across the LTSS subpopulation groupings is greater than the total number of HCBS users because beneficiaries are counted in each subpopulation grouping for which they which met the criteria. The sum of user percentages across HCBS taxonomy categories will be greater than 100 because users and expenditures can be counted in more than one HCBS taxonomy category.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System analytic files data.

**TABLE A-2.** Spending by HCBS Taxonomy Category and Subpopulation Grouping, CY 2021

| HCBS taxonomy category | All HCBS Users | I/DD or ASD | <65 with potentially disabling condition(s) | Older adults | Brain injuries | Mental illness, SED, or SUD | HIV/AIDS |
|---|---|---|---|---|---|---|---|
| **Total HCBS expenditures (millions)** | **$82,450** | **$43,253** | **$20,315** | **$27,325** | **$1,424** | **$38,843** | **$548** |
| **Share of total HCBS expenditures** | | | | | | | |
| Caregiver support | 1.8% | 2.4% | 1.7% | 0.6% | 1.1% | 1.1% | 0.4% |
| Case management | 2.2 | 1.9 | 2.3 | 1.7 | 1.7 | 2.6 | 3.0 |
| Community transition services | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Day services | 5.5 | 8.4 | 5.4 | 2.5 | 3.4 | 5.2 | 1.4 |
| Equipment, technology, and modifications | 0.5 | 0.3 | 0.8 | 0.4 | 0.8 | 0.4 | 0.4 |
| Home-based services | 16.6 | 6.9 | 17.6 | 23.5 | 16.4 | 12.8 | 34.5 |
| Home-delivered meals | 0.4 | 0.0 | 0.4 | 0.7 | 0.3 | 0.4 | 1.3 |
| Nonmedical transportation | 2.5 | 2.0 | 2.3 | 2.4 | 1.4 | 2.2 | 1.4 |
| Nursing | 0.8 | 0.8 | 2.2 | 0.3 | 1.0 | 0.4 | 0.3 |
| Other health and therapeutic services | 5.6 | 5.0 | 6.9 | 4.0 | 6.2 | 5.5 | 3.3 |
| Other mental health and behavioral services | 6.4 | 10.1 | 7.1 | 2.7 | 7.0 | 13.6 | 1.5 |
| Participant training | 1.2 | 1.5 | 1.3 | 0.4 | 5.7 | 1.3 | 0.7 |
| Round-the-clock services | 45.0 | 37.1 | 39.1 | 57.2 | 57.2 | 43.0 | 50.3 |
| Services supporting participant direction | 0.6 | 0.9 | 0.6 | 0.1 | 0.8 | 0.5 | 0.1 |
| Supported employment | 0.9 | 1.5 | 0.6 | 0.2 | 1.2 | 0.9 | 0.3 |

**Notes:** HCBS is home- and community-based services. CY is calendar year. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. <65 is under 65 years old. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the TAF, we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. SED is serious emotional disturbance. SUD is substance use disorder. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to data reporting issue, which impacted national trends. The sum of expenditures across the LTSS subpopulation groupings is greater than total HCBS expenditures because beneficiaries are counted in each subpopulation grouping for which they which met the criteria. The sum of expenditure percentages across HCBS taxonomy categories will be greater than 100 because expenditures can be counted in more than one HCBS taxonomy category. Total expenditures on a claim are attributed to each HCBS taxonomy category that appear on the claim.

**Source:** MACPAC, 2024, analysis of Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF) data.

**TABLE A-3.** Spending per User by HCBS Taxonomy Category and Subpopulation Grouping, CY 2021

| HCBS taxonomy category | All HCBS Users | I/DD or ASD | <65 with Potentially Disabling Conditions | Older adults | Brain injuries | Mental illness, SED, or SUD | HIV/AIDS |
|---|---|---|---|---|---|---|---|
| **All HCBS** | **$32,402** | **$55,339** | **$36,605** | **$26,544** | **$46,299** | **$37,707** | **$20,593** |
| Caregiver support | $8,259 | $9,291 | $8,369 | $6,061 | $11,506 | $8,480 | $6,499 |
| Case management | 2,999 | 3,290 | 3,076 | 2,464 | 3,240 | 3,639 | 3,972 |
| Community transition services | 2,116 | 2,796 | 2,497 | 1,626 | 2,797 | 2,082 | 2,876 |
| Day services | 16,307 | 18,523 | 19,847 | 12,120 | 17,677 | 16,681 | 12,015 |
| Equipment, technology, and modifications | 1,040 | 1,929 | 1,489 | 661 | 1,342 | 1,026 | 523 |
| Home-based services | 22,044 | 25,808 | 23,287 | 20,031 | 22,988 | 21,270 | 20,923 |
| Home-delivered meals | 1,739 | 2,019 | 1,827 | 1,700 | 2,000 | 1,714 | 2,346 |
| Nonmedical transportation | 5,050 | 5,687 | 5,005 | 6,081 | 4,851 | 4,403 | 1,975 |
| Nursing | 7,255 | 14,380 | 12,201 | 1,956 | 17,881 | 4,155 | 2,860 |
| Other health and therapeutic services | 13,821 | 19,787 | 16,655 | 10,617 | 21,141 | 15,300 | 10,778 |
| Other mental health and behavioral services | 25,503 | 33,365 | 35,810 | 26,710 | 23,329 | 25,503 | 13,450 |
| Participant training | 11,564 | 14,470 | 10,243 | 9,279 | 42,890 | 12,700 | 11,578 |
| Round-the-clock services | 33,495 | 54,379 | 36,006 | 29,157 | 67,740 | 37,363 | 23,835 |
| Services supporting participant direction | 5,399 | 6,877 | 5,010 | 1,863 | 8,067 | 4,525 | 2,957 |
| Supported employment | 12,224 | 12,923 | 14,090 | 17,382 | 24,044 | 12,330 | 15,205 |

**Notes:** HCBS is home- and community-based services. CY is calendar year. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. <65 is under 65 years old. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the Transformed Medicaid Statistical Information System (T-MSIS) analytic files (TAF), we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. SED is serious emotional disturbance. SUD is substance use disorder. This table includes data from 49 states and the District of Columbia; Alabama's data are excluded due to data reporting issue, which impacted national trends. The sum of expenditures across the LTSS subpopulation groupings is greater than total HCBS expenditures because beneficiaries are counted in each subpopulation grouping for which they which met the criteria.

**Source:** MACPAC, 2024, analysis of TAF data.

# APPENDIX B: Methods

## Long-term services and supports subpopulation groupings

We adapted the methodology from the Centers for Medicare & Medicaid Services (CMS) Long-Term Services and Supports (LTSS) Users and Expenditures reports to identify seven LTSS subpopulation groupings (Stepanczuk et al. 2024b). We used characteristics such as age, enrollment in Section 1915(c) waiver programs, chronic condition flags, and service use to classify LTSS users into any subpopulation for which they qualify (Table B-1). For two of the subpopulation groupings—older adults (age 65 and older) and beneficiaries with autism spectrum disorder (ASD) or intellectual disabilities or developmental disabilities (I/DD)—we use the same approach as the CMS reports. For another two subpopulation groupings, we modified the methodology: we removed having a traumatic brain injury diagnosis from the beneficiaries younger than age 65 with potentially disabling conditions subpopulation definition as we have a separate subpopulation for beneficiaries with brain injuries. We included other mental health and behavioral services from the Assistant Secretary for Planning and Evaluation Home- and Community-Based Services Module in the beneficiaries with mental illness, serious emotional disturbance (SED), or substance use disorder (SUD) subpopulation definition. We also added two new subpopulation groupings that are not included in the CMS reports: beneficiaries with brain injuries and beneficiaries with HIV/AIDS. The final subpopulation—other beneficiaries who use LTSS—includes beneficiaries in our sample that do not meet the criteria for any of the other six subpopulation groupings; this subpopulation was excluded from the figures throughout this memo.

**TABLE B-1.** Relevant Criteria for LTSS Subpopulation Identification

| Population | Age | Waiver program enrollment from TAF eligibility file | Claims-based chronic conditions | Claims-based service use |
|---|---|---|---|---|
| Older adults | X | | | |
| Beneficiaries younger than age 65 with potentially disabling conditions | X | X | X | |
| Beneficiaries with I/DD or ASD | | X | X | X |
| Beneficiaries with mental illness, SED, or SUD | | X | X | X |
| Beneficiaries with brain injuries | | X | X | |
| Beneficiaries with HIV/AIDS | | X | X | |

**Notes:** LTSS is long-term services and supports. TAF is the Transformed Medicaid Statistical Information System (T-MSIS) Analytic File. "Potentially disabling condition(s)" refers to beneficiaries with the presence of diagnosis codes that indicate a possible disability; because there is no disease severity or functional assessment data in the TAF, we must rely on diagnosis codes to indicate that the beneficiaries in the subpopulation grouping have at least one condition that could be the basis of a disability. I/DD is intellectual or developmental disabilities. ASD is autism spectrum disorder. SED is serious emotional disturbance. SUD is substance use disorder.

**Source:** Stepanczuk et al. 2024b.