

# Medicaid Home- and Community-Based Services: Characteristics and Spending of High-Cost Users

Medicaid enrollees increasingly are receiving long-term services and supports (LTSS) in the home and community. In 2016, for the fourth consecutive year, more than half of Medicaid spending for LTSS was for home- and community-based services (HCBS) rather than institutional care (Eiken et al. 2018). This shift is the result of a variety of factors, including efforts by federal and state policymakers to rebalance Medicaid LTSS spending towards HCBS in order to curb spending growth and meet beneficiary preferences to live in the community. Medicaid spending on HCBS users remains disproportionately high relative to their share of enrollment. In 2013, the approximately 4 percent of Medicaid enrollees who used HCBS accounted for 23.9 percent of Medicaid fee-for-service (FFS) spending on all services (\$97.8 billion of \$409.3 billion) (MACPAC 2017).<sup>1</sup>

HCBS users have diverse needs, and thus vary in the types of HCBS they use. To date, however, analyses of service use and spending associated with HCBS users have not taken a detailed look at the types of HCBS used and the individual characteristics of users. This fact sheet presents the results of an analysis that describes, in greater detail than has been done before, the characteristics and service use of Medicaid enrollees who used HCBS in 44 states in 2012, and analyzes Medicaid spending for these HCBS users.<sup>2</sup> We focused particularly on high-cost users, defined as the 3 percent of HCBS users with the highest spending on HCBS in each state. These high-cost users accounted for nearly one-third of Medicaid spending on HCBS in our analysis (\$17.8 of \$58.1 billion).<sup>3</sup>

Most HCBS users, and particularly those who are high-cost users, were age 19 to 64 and qualified for Medicaid-covered HCBS due to a disability. Intellectual disorders and related conditions (such as Down syndrome) as well as neurological disorders (such as cerebral palsy and epilepsy) were the most common diagnoses reported on claims data for high-cost users. This population has high care needs; 57.1 percent of Medicaid spending for high-cost users was for around-the-clock care.

Details on the methodology used in this analysis can be found in Appendix A. The complete results are available in the MACPAC-commissioned report by Mathematica Policy Research, *HCBS claims analysis chartbook: Final report* (Peebles et al. 2017).

## Who are HCBS users?

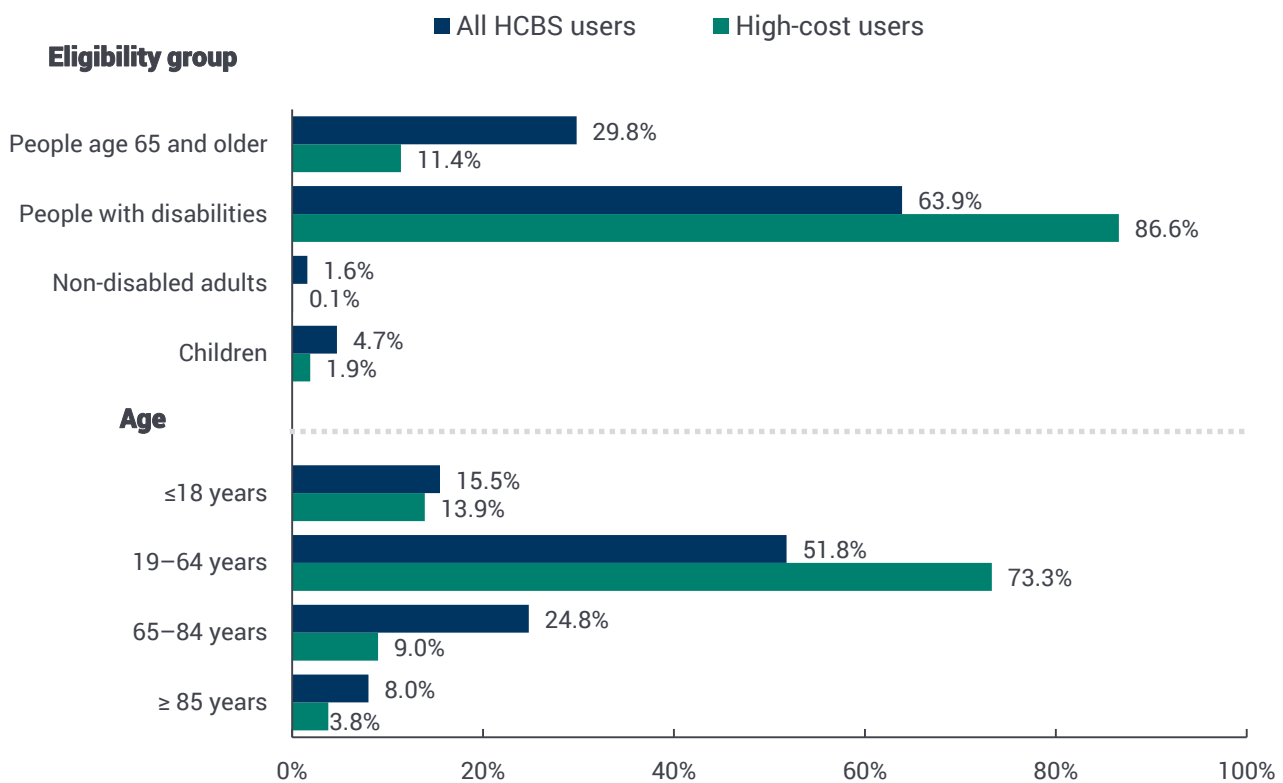
In 2012, about 5.9 million individuals used Medicaid-covered HCBS, and 174,220 individuals met our definition of being a high-cost user. Compared to all HCBS users, a higher proportion of high-cost users were age 19 to 64 and qualified for Medicaid-covered HCBS based on a disability. Their HCBS needs were persistent; in 2012, most high-cost users (92.4 percent) used HCBS services for 10 to 12 months of the year, and about three in four had been characterized as high-cost users in the prior year.<sup>4</sup>



## Demographic characteristics

- Nearly 2 in 3 HCBS users (63.9 percent) and nearly 9 in 10 high-cost users (86.6 percent) were eligible for Medicaid-covered HCBS due to disability. High-cost users were less likely than all HCBS users (11.4 percent vs. 29.8 percent) to be eligible due to age (Figure 3).<sup>5</sup>
- Nearly three in four (73.3 percent) high-cost users were between the ages of 19 and 64.
- Compared to all HCBS users, a greater proportion of high-cost users were male (56.7 percent vs. 42.5 percent).
- High-cost users were more likely to be white and of non-Hispanic ethnicity compared to all HCBS users (62.9 percent vs. 49.9 percent).

**FIGURE 1.** Medicaid Eligibility and Age of All HCBS Users Compared to High-Cost Users, 2012



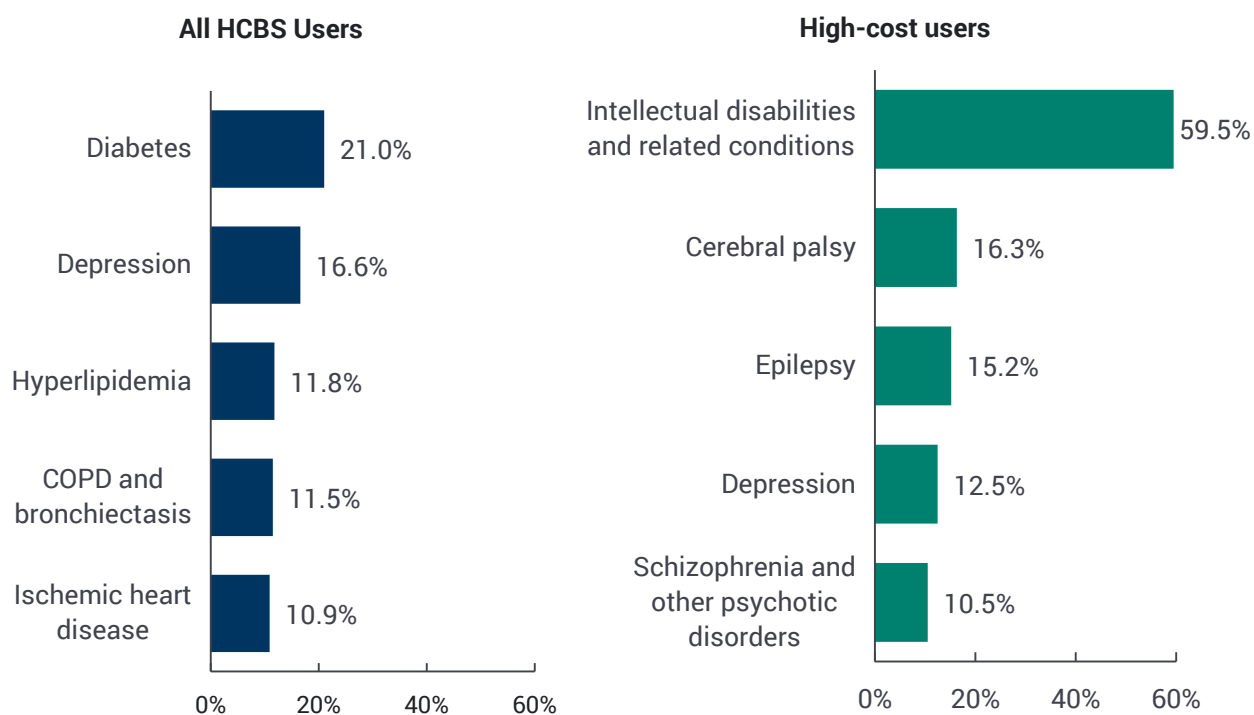
**Notes:** HCBS are home- and community-based services. FFS is fee for service. Eligibility group refers to the basis of eligibility among individuals with Medicaid FFS HCBS claims. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. We also excluded high-cost HCBS users who (a) lived fewer than three months of the year and (b) were outliers based on spending. **Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eExtract.



## Medical conditions

About 60 percent of high-cost users had been diagnosed with intellectual disabilities and related conditions, and 16.3 percent had been diagnosed with cerebral palsy (Figure 4). These developmental and neurological conditions are generally associated with functional limitations that require HCBS. The most common conditions among all HCBS users were diabetes (21 percent) and depression (16.6 percent). Most of the commonly reported conditions for all HCBS users are conditions associated with aging, such as hyperlipidemia (i.e., high cholesterol) and ischemic heart disease. Claims data do not provide information on functional limitations, such as mobility issues that limit performance of bathing, toileting and other activities of daily living, which drive beneficiaries' use of HCBS. Furthermore, many individuals may experience multiple conditions that influence their need for HCBS.

**FIGURE 2.** Five Most Commonly Reported Conditions for All HCBS Users and High-Cost Users, 2012



**Notes:** HCBS are home- and community-based services. COPD is chronic obstructive pulmonary disease. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. The top five most commonly reported conditions were identified from the top twenty conditions in each state across 2010-2012. Conditions that did not occur in at least two states in at least two years were removed.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eExtract.



## Persistence of high-cost HCBS spending

High-cost users include individuals with physical, mental, and cognitive conditions whose need for care persist over extended periods of time and who experience similar spending per year. In 2012, 76.6 percent of high-cost users also had been in the high-cost group in 2011.

Beneficiaries who were high-cost users for at least two consecutive years had a similar demographic profile as high-cost users overall. For example, in 2011–2012, 67 percent of the persistently high-cost group had intellectual disabilities compared to 59 percent of high-cost users in 2012. Among persistently high-cost users, 17 percent had a cerebral palsy diagnosis and 15 percent reported epilepsy, which were similar to figures for the overall high-cost population.

## Medicaid spending for HCBS users

Total Medicaid spending for high-cost HCBS users was largely driven by HCBS, particularly services covered under Section 1915(c) waivers (Box 1). In 2012, national per capita spending on HCBS for high-cost users exceeded \$100,000.

### **BOX 1.** Medicaid Coverage of Home- and Community-Based Services

States can choose to cover home- and community-based services (HCBS) under their state plan or through Section 1915(c) waiver authorities. HCBS waivers permit states to restrict and expand coverage for LTSS in ways not permitted under their state plans, including flexibility in providing benefits to specific groups and caps on enrollment.

#### **State plan services**

Some HCBS, such as home health care, are mandatory state plan services, while other services such as personal care may be offered as a state option. State plan services must be made available to all Medicaid enrollees, contingent on medical necessity. Thus, state plan services are typically limited in scope compared to HCBS delivered through waivers.

#### **Section 1915(c) HCBS waivers**

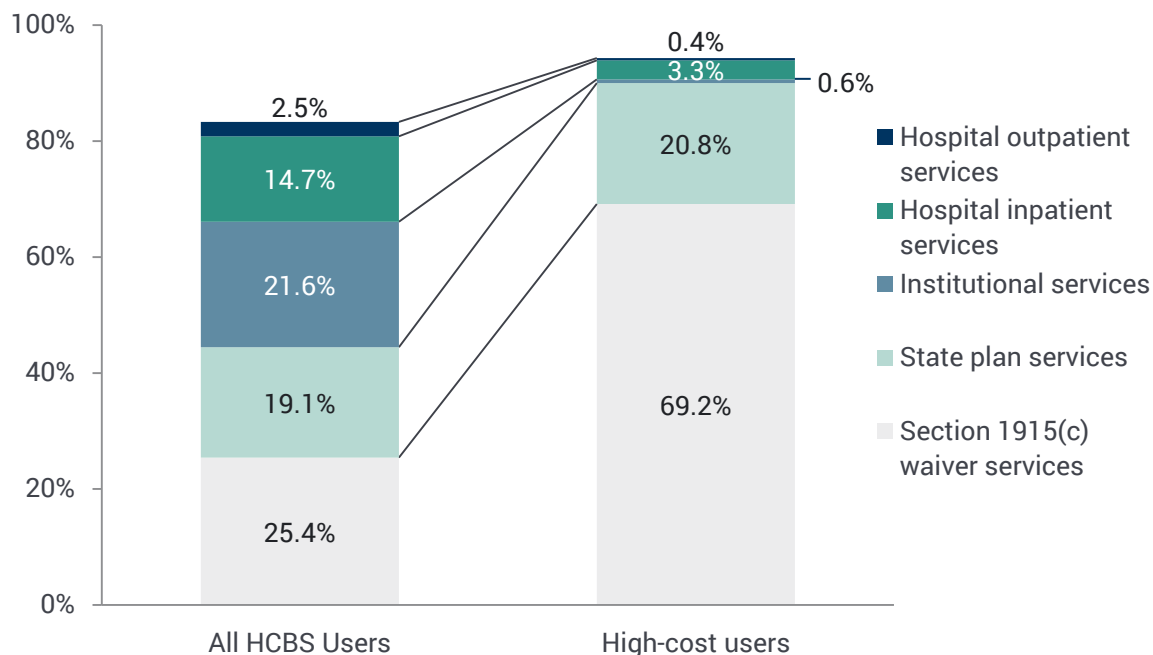
Under Section 1915(c) waiver authority, HCBS are restricted to people who meet the criteria for an institutional level of care. States can cap the total number of HCBS participants and also restrict eligibility to certain populations, such as individuals with intellectual or developmental disabilities with behavioral health conditions, individuals with brain injuries, the aged and disabled, technology-dependent individuals, and other groups. Although this fact sheet focuses on HCBS provided through fee for service, states may also combine Section 1915(c) waivers with Medicaid managed care authorities to cover HCBS through managed long-term services and supports (MLTSS) programs.



## Medicaid spending on services for high-cost HCBS users

Institutional services comprised less than 1 percent of overall spending for high-cost users in 2012, compared to 21.6 percent for all HCBS users (Figure 3). HCBS covered under state plan and Section 1915(c) waivers accounted for 90.6 percent of overall Medicaid spending for high-cost users in 2012, compared to 66 percent for all HCBS users.

**FIGURE 3.** Share of Medicaid FFS Spending by Service Type for All HCBS Users and High-Cost Users, 2012



**Notes:** LTSS are long-term services and supports. HCBS is home- and community-based services. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. Spending data are annualized. The sum of the shares of spending do not total 100 percent, total non-LTSS expenditures and total non-hospital services are based on MAX type-of-service codes which can be cross categorized with LTSS categories; therefore, we do not report all type-of-service categories or overall expenditures. Non-hospital services cannot be summed and therefore are not shown in this figure.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eXtract.

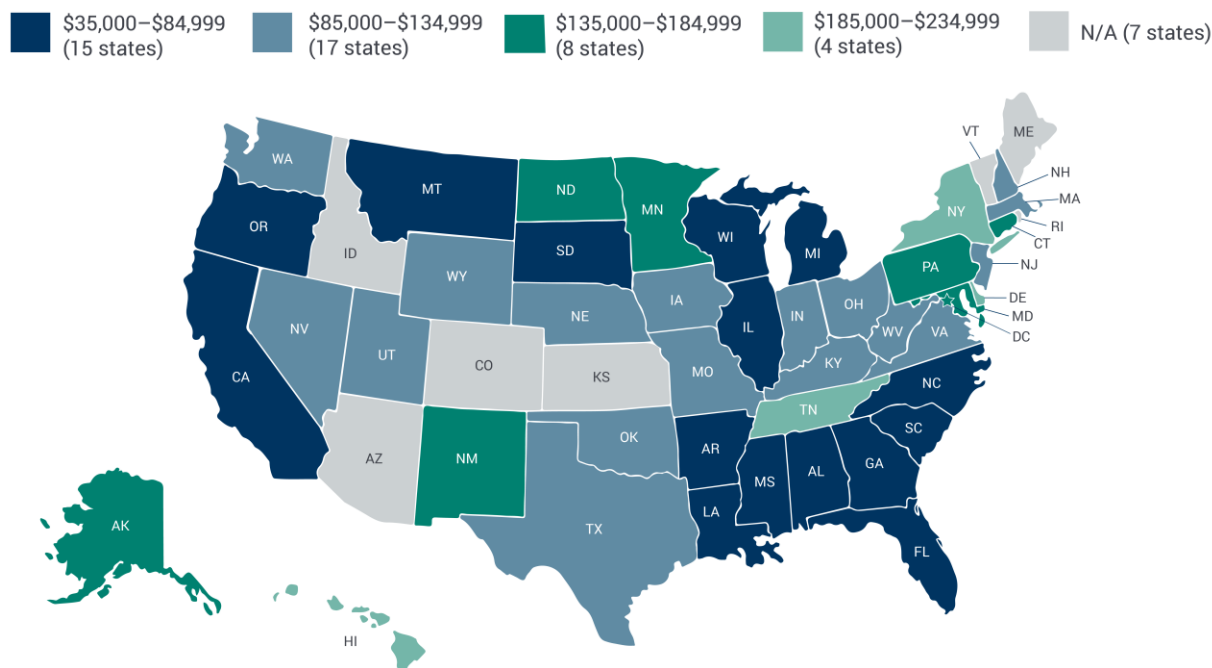
## Average spending on high-cost users' HCBS

On average, HCBS spending per high-cost enrollee was more than 10 times that for all HCBS users (\$102,091 compared to \$9,925). However, many enrollees who used HCBS had relatively low spending. Median spending for all HCBS users was \$978; median spending for high-cost users was \$84,198.



States varied widely in average spending per high-cost user, from \$36,335 in Mississippi to \$234,003 in Tennessee (Figure 4). State variation reflects multiple factors, including how each state delivers HCBS and differences in the populations enrolled in those state’s FFS HCBS programs.<sup>6</sup>

**FIGURE 4.** Average Medicaid Spending on HCBS per High-Cost HCBS User, by State, 2012



**Notes:** HCBS is home- and community-based services. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through various authorities such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. Spending data are annualized.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eXtract.

## HCBS use and associated spending

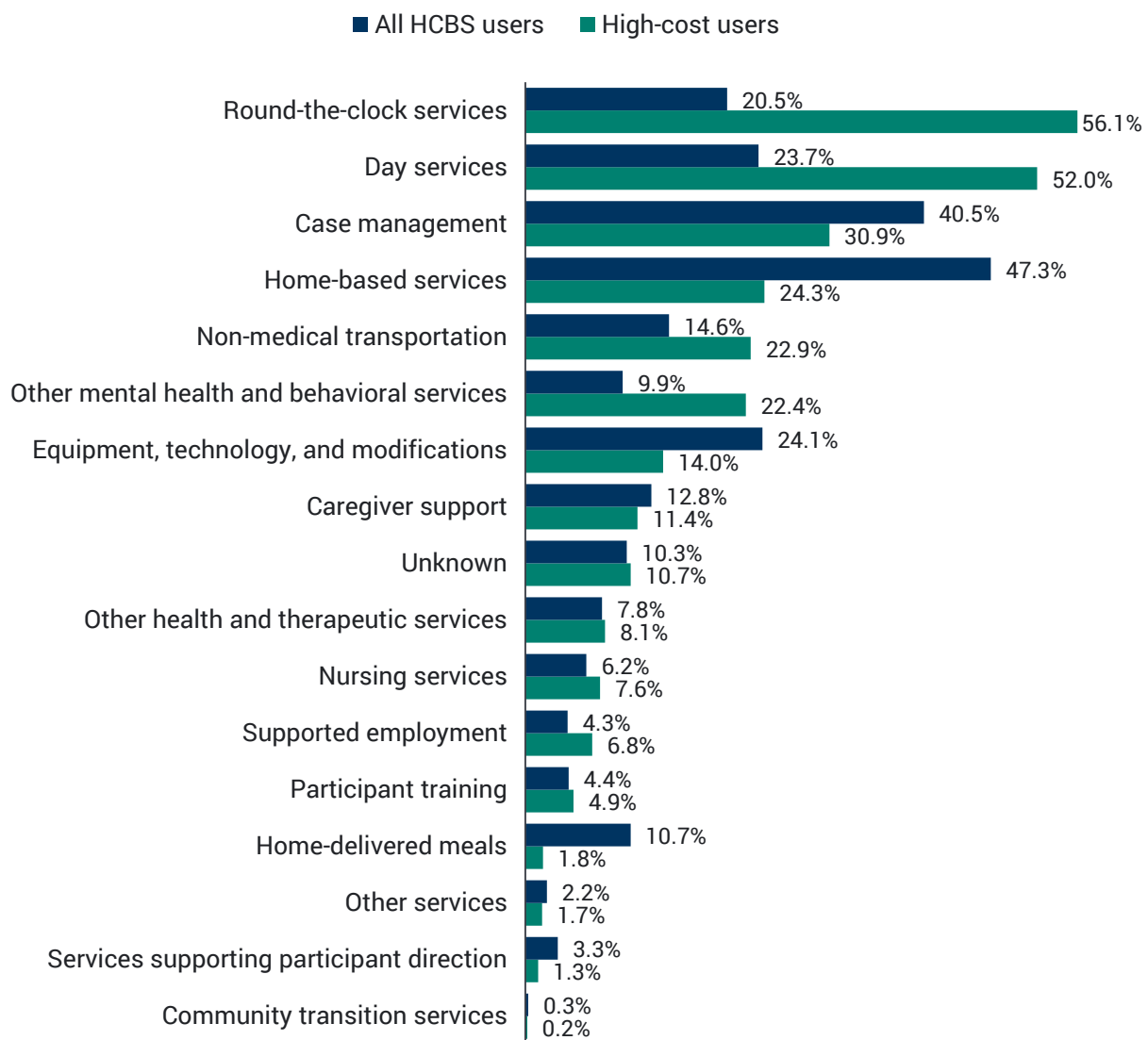
As noted above, we were able to examine the use of specific HCBS at a more granular level than previously possible. To do so, our analysis applied the HCBS taxonomy classification system to Medicaid claims data to identify specific HCBS use under Section 1915(c) waiver services. Thus, the analysis described below excludes beneficiaries’ use of state plan services and spending for those services. State plan services are typically more limited in scope than those provided under Section 1915(c) waivers.<sup>7</sup>



## High-cost users' HCBS use

Over half (56.1 percent) of high-cost users who used Section 1915(c) waiver services used around-the-clock services (such as mental health services, in-home habilitation support, and 24-hour care provided in residential settings), compared to about 21 percent of all HCBS users (Figure 5). When compared to all HCBS users, high-cost users were more than twice as likely to use day services (such as day habilitation, prevocational services, and adult day care centers) and other mental health and behavioral services, and less likely to use services in 8 of the 18 HCBS taxonomy service categories.

**FIGURE 5.** Share of All HCBS Users and High-Cost Users with Claims for Section 1915(c) Waiver Services, 2012





**FIGURE 5.** (continued)

**Notes:** HCBS is home- and community-based services. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. HCBS taxonomy applies to only Section 1915(c) services in the Medicaid Analytic eXtract data. Unknown includes HCBS claims that did not have enough information to be classified into a more specific taxonomy category. Community transition services do not include services under the Money Follows the Person demonstration. States reported those services to the Centers for Medicare & Medicaid Services separately from Section 1915(c) waiver spending. Excluded from this figure is the category of rent and food expenses for live-in caregiver, which was reported by only one state (Minnesota), for 10 HCBS users.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eXtract.

## Average Medicaid spending on HCBS categories

More than 80 percent of HCBS spending for high-cost users was for round-the-clock services, day services, and home-based services (such as habilitation services provided by home health aides, homemakers, and others) (Table 1). Average spending was highest for round-the-clock services, at \$93,635 for high-cost HCBS users and \$50,411 for all HCBS users. Average spending for high-cost users exceeded all HCBS users in every category; however, the difference in spending between the two groups varied significantly by HCBS type. For example, average spending for home-delivered meals was about 13 percent greater for high-cost users than for all HCBS users. By contrast, average spending for high-cost users was over 400 percent greater than that of all HCBS users for nursing services and for services supporting self-direction.

**TABLE 1.** Use of and State Spending on Section 1915(c) Waiver Services for High-Cost Users, by HCBS Category, 2012

HCBS category	Number of states reporting	Percentage of total Medicaid FFS high-cost HCBS spending	Section 1915(c) waiver services spending	
			Average spending	
			All HCBS users	High-cost users
All	44	100.0%	\$26,083	\$91,919
Round-the-clock services	39	57.1	50,411	93,635
Home-based services	42	12.8	13,368	48,510
Day services	43	12.5	14,579	22,134
Other mental health and behavioral services	37	3.5	7,833	14,293
Nursing services	35	2.2	5,162	26,806
Case management	35	2.1	2,306	6,274
Participant training	23	1.9	16,891	36,182





**TABLE 1.** (continued)

HCBS category	Number of states reporting	Percentage of total Medicaid FFS high-cost HCBS spending	Section 1915(c) waiver services spending	
			Average spending	
			All HCBS users	High-cost users
Non-medical transportation	33	1.0%	\$2,612	\$4,052
Caregiver support	43	1.0	4,369	7,762
Supported employment	35	0.9	8,190	12,135
Equipment, technology, and modifications	43	0.4	957	2,260
Services supporting participant direction	13	0.3	4,441	24,205
Other health and therapeutic services	35	0.3	1,964	3,137
Other services	15	0.1	1,556	3,409
Community transition services	15	<0.05	5,927	21,859
Home delivered meals	26	<0.05	1,564	1,762
Unknown	33	3.8	11,203	32,888

**Notes:** HCBS is home- and community-based services. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual or developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. Spending data are annualized. HCBS taxonomy applies to only Section 1915(c) services in Medicaid Analytic eXtract data. Unknown includes HCBS claims that did not have enough information to be classified into a more specific taxonomy category. Community transition services do not include services under the Money Follows the Person demonstration. Excluded from this table is the category of rent and food expenses for live-in caregiver, which was reported by only one state (Minnesota), for 10 HCBS users.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eXtract.

The share of total HCBS spending attributable to specific HCBS categories varied by state. In most states, however, at least half of spending on HCBS for high-cost users was for round-the-clock services, or day services.<sup>8</sup>

- In 26 states, at least half of the total HCBS spending for high-cost users was for round-the-clock services. Spending on round-the-clock services ranged from 0 percent in Arkansas to about 90 percent in Massachusetts.
- In seven other states, 60 percent or more of total HCBS spending for the high-cost group was for home-based services.
- In a few states, the highest spending category was for other services. For example, participant training accounted for 71 percent of spending in Virginia, and nursing accounted for 67 percent of spending in South Carolina.



## Endnotes

<sup>1</sup> The share of Medicaid spending attributed to HCBS users from MACPAC's *MACStats: Medicaid and CHIP data book* varies compared to the analysis in this fact sheet, in part due to differences in how HCBS users were defined (MACPAC 2017). For example, Mathematica Policy Research uses additional HCBS-related claims in identifying HCBS users, such as private duty nursing and durable medical equipment, to identify HCBS users.

<sup>2</sup> The HCBS taxonomy was developed by Truven Health Analytics and Mathematica Policy Research under contract with the Centers for Medicare & Medicaid Services. The taxonomy maps states' HCBS procedure codes to 60 service types, which are then grouped into 18 taxonomy categories (Peebles and Bohl 2013).

<sup>3</sup> In this fact sheet, "all HCBS users" refers to our total sample of HCBS users after exclusions. In Mathematica's report, these individuals are referred to as "total HCBS population".

<sup>4</sup> Most users had Section 1915(c) waiver and state plan service claims for 10 to 12 months of 2012. Among high-cost HCBS users, 8 in 10 had used waiver services, and about 1 in 2 used state plan services for the same duration.

<sup>5</sup> Medicaid users in this analysis met income requirements for Medicaid eligibility. The users were then grouped based on categorical eligibility requirements.

<sup>6</sup> For example, Tennessee's HCBS FFS spending was primarily for services provided to individuals with intellectual or developmental disabilities (ID/DD) who were not included in the state's managed long-term services and supports (MLTSS) program. Since 2012, Tennessee has implemented MLTSS for individuals with ID/DD who became eligible as of July 1, 2016. Beneficiaries who were eligible prior to that date can continue to receive their LTSS through FFS (TN HCFA 2018).

<sup>7</sup> The HCBS taxonomy uses MAX claims data and only applies to Section 1915(c) waiver services, not state plan services. The taxonomy groups over 60 unique types of services into 18 categories. Round-the-clock services include residential habilitation and mental health services provided in group living, shared living, and in-home settings. Day services include prevocational services, day habilitation services, partial hospitalization, and others. Home-based services include habilitation services and services provided by home health aides, homemakers, and companions, as well as personal care, and other services. Caregiver support includes respite provided in or outside of the home, as well as caregiver counseling or training. Community transition services do not include services under the Money Follows the Person demonstration. States reported those services to CMS separately from Section 1915(c) waiver spending. Unknown includes HCBS claims that did not have information to be classified into a taxonomy category (Peebles and Bohl 2013).

<sup>8</sup> See Exhibit HC. 8 in Mathematica Policy Research's full report for state-level results (Peebles et al. 2017).

## References

Eiken, S., K. Sredl, B. Burwell, and A. Amos. 2018. *Medicaid expenditures for long-term services and supports in FY 2016*. Cambridge, MA: IBM Watson Health. <https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpenditures2016.pdf>.



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## APPENDIX A: Methodology

In 2017, MACPAC contracted with Mathematica Policy Research to review fee-for-service (FFS) claims data in the Medicaid Analytic eXtract (MAX) using the home- and community-based services (HCBS) taxonomy—a classification system developed for the Centers for Medicare & Medicaid Services and applied to Medicaid claims data (Peebles and Bohl 2013). The taxonomy allows for the assessment of state-level variation across 18 HCBS categories. This fact sheet uses 2012 data from 44 states to examine the characteristics and spending of home- and community-based services (HCBS) users who had at least one FFS Section 1915(c) waiver or state plan claim. The analyses included states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long term services and supports (MLTSS) programs, such as beneficiaries with intellectual or developmental disabilities. The results for such states (i.e., Tennessee, Michigan, and Hawaii) are not comparable to those from states in which FFS spending covers all HCBS users. Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded either because data were not available or the state only provides HCBS through MLTSS.

Our analysis focused on spending and characteristics of high-cost users, defined as those with spending in the top 3 percent of HCBS FFS spending in the states included in the analysis. We annualized spending data so that they represent Medicaid payment amounts for 12 months (with adjustments made for beneficiaries who died during the year). The spending figures presented in this fact sheet should not be interpreted as actual Medicaid spending, and are not comparable to the results of HCBS analyses in MACPAC's *MACStats: Medicaid and CHIP data book* due to differences in our inclusion and exclusion criteria for beneficiaries and defined HCBS types (MACPAC 2017).

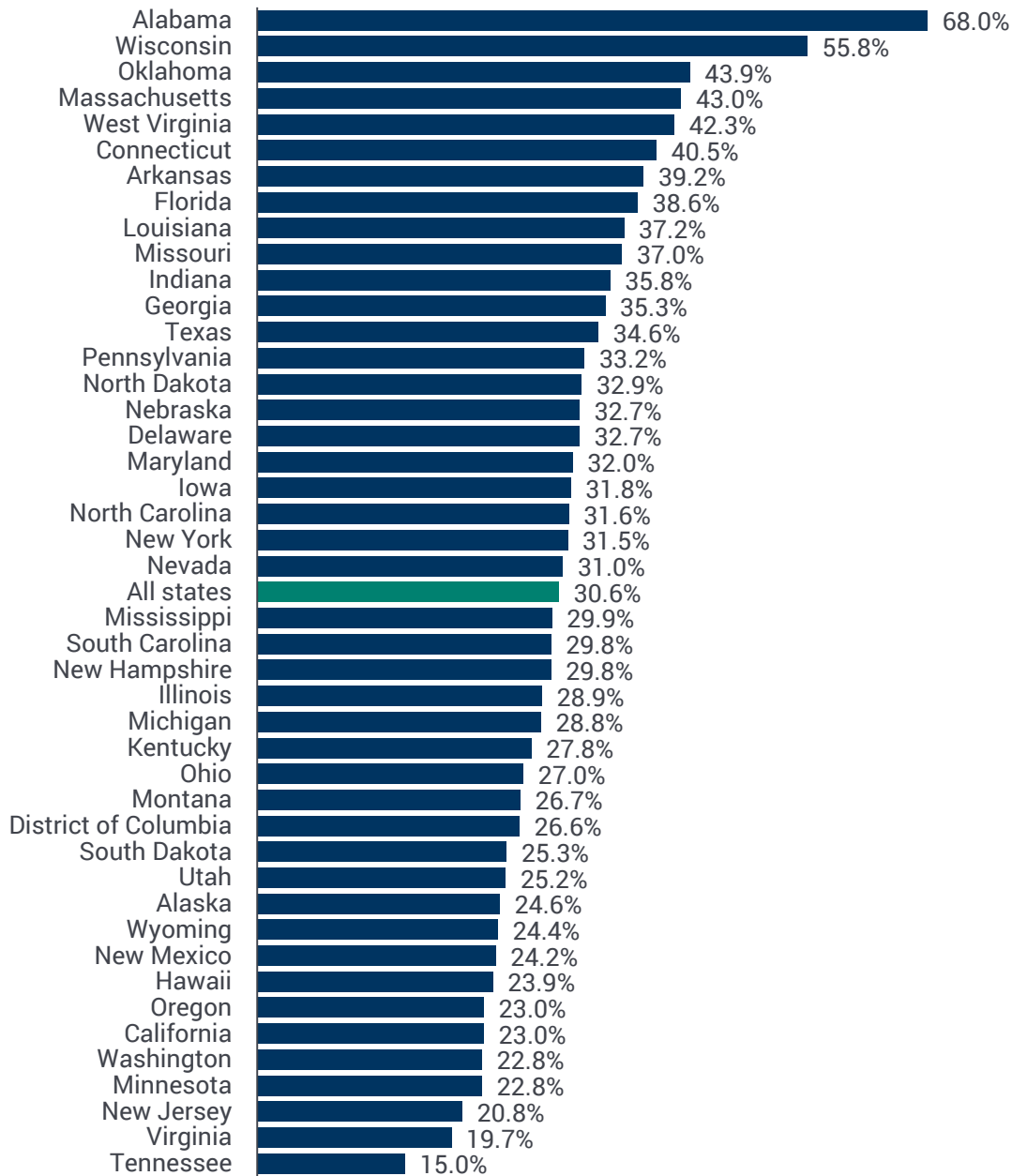
We excluded from the sample of high-cost HCBS users those who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS use in categories that could explain such high spending (for example, round-the-clock services). This was done to acknowledge that annualizing spending produced some outliers.

For more information on the study methodology, see the MACPAC-commissioned report by Mathematica Policy Research, *HCBS claims analysis chartbook: Final report* (Peebles et al. 2017).



## APPENDIX B. HCBS Expenditures Attributed To High-Cost Users

FIGURE B-1. Share of Total HCBS Expenditures Attributed To High-Cost Users, 2012



**FIGURE B-1.** (continued)

**Notes:** HCBS are home- and community-based services. FFS is fee for service. The analyses include all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as Section 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed long-term services and supports programs, such as beneficiaries with intellectual/developmental disabilities. In 2012, 44 states were analyzed; Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont were excluded. Due to variation in state adoption of managed long-term services and supports, HCBS policies and different authorities that may be present in each state, the results are not comparable across states. High-cost users are defined as HCBS users with expenditures in the top 3 percent of our analytic sample, by state. We also excluded high-cost HCBS users who (a) lived fewer than three months of the year and (b) were outliers based on spending. Spending data are annualized.

**Source:** Mathematica Policy Research, 2017, analysis for MACPAC on home- and community-based services use from the Medicaid Analytic eExtract.

