

# REPORT

HCBS CLAIMS ANALYSIS CHARTBOOK:

FINAL REPORT

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## EXECUTIVE SUMMARY

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Home- and community-based services (HCBS) allow older adults and people with disabilities to live in their home or a community-based residence by providing them with a diverse set of services and supports. Over the last 20 years, states have sought to increase access to Medicaid-paid HCBS in order to accommodate beneficiary preferences to live at home or in the community and to reduce overall long-term services and support (LTSS) spending by substituting less costly HCBS for more expensive care in nursing homes and other long-term care institutions.

The purpose of this study is to identify patterns of use and spending on specific types of HCBS for two groups of fee-for-service (FFS) Medicaid beneficiaries: (1) all HCBS users, regardless of the amount of services or spending associated with them, and (2) high-cost HCBS users. The study addresses three key research questions:

1. What are the characteristics of FFS Medicaid beneficiaries who use HCBS, for example, age, gender, race/ethnicity, dual eligibility, basis of Medicaid eligibility, and major health conditions?
2. What are their HCBS use patterns, as defined by the service categories in the HCBS taxonomy, overall and for each LTSS population group? Which services are most and least frequently used? How do the patterns vary by state and over time?
3. How much is spent on HCBS in total and by type of HCBS, as defined by service categories in the HCBS taxonomy? How is total HCBS spending distributed across 1915(c) waivers, HCBS state plan benefits, managed care, and other Medicaid authorities, if it is possible to distinguish them? How does spending vary by each LTSS population group? How do spending patterns vary by state and over time?

For this analysis, we used Medicaid Analytic eXtract (MAX) files, which contain extensive information about the characteristics of Medicaid beneficiaries and the number and cost of services they use during a calendar year, standardized across states. We examined FFS claims and spending from 2010 to 2013, which were the most recent data available at the time of this study. We defined HCBS users as Medicaid beneficiaries with at least one FFS 1915(c) waiver service claim or one state plan service claim with a valid FFS community-based long-term care flag during the study years. Based on availability of MAX data for our target population, the analysis for 2010 to 2012 included 44 states and the analysis for 2013 included 25 states.

### Key Findings

- From 2010 to 2012, the 44 states in the analytic sample accounted for approximately 6 million individual HCBS users each year. The HCBS claims in the MAX data from these 44 states accounted for roughly \$58.1 billion (approximately 85 percent) of annual total HCBS expenditures reported in CMS-64 data (Eiken et al. 2017). Results were typically consistent across years; therefore, our analysis presented in this report mostly focused on 2012 (the

year with the most recent and the majority of states represented). Only 25 states had 2013 MAX data available at the time of our analysis.

- On average, 1915(c) waiver services (as opposed to state plan services) accounted for the majority of HCBS FFS expenditures in 2012. Of those HCBS users using 1915(c) waiver services, average per participant spending on HCBS 1915(c) waiver services was roughly \$26,000 per year.
- In all four study years, the most frequent demographic and eligibility characteristics of HCBS users were as follows: Medicaid eligibility based on blindness/disability (64 to 65 percent), not dually eligible for Medicare (40 to 44 percent), ages 19 to 64 years (52 to 53 percent), female (58 percent), and white non-Hispanic (50 to 52 percent).
- In addition to LTSS needs, the HCBS user population had a high prevalence of chronic conditions, and the five most commonly reported conditions were: diabetes, depression, hyperlipidemia, chronic obstructive pulmonary disease (COPD), and ischemic heart disease. In 2012, average costs per HCBS user with any health conditions was \$22,324, but three conditions had average costs over \$50,000 per HCBS user: intellectual disabilities and related conditions, mobility impairments, and epilepsy.
- According to the HCBS taxonomy, a wide variety of HCBS services were used in each state. All 44 states reported 1915(c) waiver expenditures for day services; caregiver support; and equipment, technology, and modifications, with the most frequently used being home-based services (47.5 percent of 1915(c) waiver users) and case management (40.5 percent of 1915(c) waiver users). Although a wide range of HCBS services were used across the 18 HCBS taxonomy categories, round-the-clock services, home-based services, and day services comprised 77.2 percent of total Medicaid FFS expenditures for 1915(c) waiver users.
- We identify high-cost HCBS users as HCBS users in the top 3.0 percentile of HCBS FFS spending in their state. Although the high-cost HCBS user population represents 3 percent of the total HCBS user population, they account for 30.6 percent of overall HCBS spending and 41.2 percent of 1915(c) waiver spending.
- The high-cost HCBS user population had a similar enrollment, demographic, and chronic condition profile compared with the total HCBS population, but in greater proportions. Compared with the total HCBS population, a greater proportion of high-cost HCBS users qualified for Medicaid based on a disability (86.6 vs. 63.9 percent), were between the ages of 19 and 64 (73.3 vs. 51.8 percent), were male (56.7 vs. 42.5 percent), or were of white, non-Hispanic race/ethnicity (62.9 vs. 49.9 percent). The high-cost HCBS user group is more than three times as likely as the total HCBS population to have claims with diagnosis code related to autism, epilepsy, intellectual disabilities, or other developmental delays.
- Because of the differences in the distribution of user characteristics in the high-cost HCBS population relative to the total HCBS population, the types of HCBS services used also differed between the two groups. Round-the-clock services, home-based services, and day



services comprised about 80 percent of total Medicaid FFS expenditures for high-cost HCBS waiver users in 2012; the majority (57.1 percent) of expenditures were for round-the-clock services. Compared to the total HCBS population, high-cost HCBS users were more than twice as likely to use round-the-clock services, day services, and other mental health and behavioral services. On the other hand, compared with the total HCBS population, high-cost HCBS users were less likely to use 8 of the 18 HCBS taxonomy category services, such as home delivered meals, services supporting participant direction, and equipment, technology, and modifications.

- For 27 of 44 states, round-the-clock services were used by at least half of the high-cost HCBS users and was the most commonly used taxonomy category. In the majority of states, high-cost HCBS users were more likely than the total HCBS user population to use round-the-clock and nursing services. However, in the majority of states, high-cost users were often less likely to use many categories of service, including case management, supported employment, day services, home-delivered measures, home-based services, caregiver support, and equipment, technology, and modifications.
- For high-cost HCBS users, total LTSS spending (including HCBS and institutional services) comprised 90.6 percent of their total Medicaid expenditures, compared to 66.1 percent for all HCBS users. Less than one percent of total LTSS expenditures were spent on institutional services for the high-cost user population, meaning they received virtually all services in home and community-based settings.
- Roughly 75 percent of high-cost HCBS users are also defined as consistently high-cost HCBS users (users with expenditures in the top 3.0 percent of our analytic sample, by state, for two consecutive study years). Similar to the high-cost group, the consistently high-cost group was also more likely to be Medicaid-eligible based on disability, below the age of 65, male, or of white, non-Hispanic race/ethnicity.

Results specific to HCBS categories are based on the application of the HCBS taxonomy to the MAX claims data. However, the HCBS taxonomy is only applied to FFS 1915(c) waiver claims, which means that state plan, and more importantly, managed care claims, are not included. As more reliable data are made available, future research should expand these analyses to state plan and managed care services, as HCBS programs continue to evolve to meet the growing needs of Medicaid beneficiaries.

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## I. INTRODUCTION

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### A. Background

Home- and community-based services (HCBS) allow older adults and people with disabilities to live in their home or a community-based residence by providing them with a diverse set of services and supports, such as round-the-clock residential habilitation, personal assistance, case management, adult day programs, and supported employment services. Over the last 20 years, states have sought to increase access to HCBS in order to accommodate beneficiary preferences to live at home or in the community and to reduce overall long-term services and support (LTSS) spending by substituting less costly HCBS for more expensive care in nursing homes and other long-term care institutions. State progress is evident: aggregate national Medicaid expenditures on HCBS in federal fiscal year 2013 exceeded spending for institutional care for the first time (Eiken et al. 2016).

State Medicaid programs cover HCBS through a variety of programs, including state plan services and waiver authorities, notably 1915(c) HCBS waivers. **State plan services** include personal care, home health care, private duty nursing care, and residential care, and they are made available to all eligible participants as medically necessary (see Section II.B for a full list of state plan services included in the analysis). Some services, like home health care, must be covered by all states while other services, like personal care services, are optional (25 states currently do so, and must be made available to all eligible beneficiaries based on medical necessity), although states can determine the amount, scope, and duration of these benefits based on their HCBS user population and available resources (Ng et al. 2016).

On the other hand, 1915(c) HCBS **waiver services** are restricted to people who meet institutional level of care criteria and, unlike state plan services, they allow states to cap the total number of HCBS participants. These populations include aged and disabled, physically disabled, intellectually or developmentally disabled (IDD), and people with mental illness or serious emotional disturbance (see Section II.B for a full list of populations covered by 1915(c) waiver authorities). To exercise their waiver authorities, states must meet federal cost neutrality requirements to not exceed state budgetary restrictions (Ng et al. 2016). As a result, states may use various eligibility and financial strategies to limit access to 1915(c) waiver services. These strategies include requiring eligible HCBS users to meet institutional level of care criteria, setting financial eligibility standards, capping total expenditures allowed for services, capping total number of HCBS users for services, and maintaining waiting lists for services (Ng et al. 2016). Similar to state plan services, states cover different waiver services based on their HCBS user populations.

Some states cover HCBS through both options. For example, limited personal care assistance may be covered as a state plan benefit, and more extensive personal care hours may be provided under 1915(c) waiver programs for individuals who qualify.

States may also use section 1115 demonstration waivers to provide HCBS to some or all of their eligible HCBS users and/or to provide a combination of state plan and waiver options (MACPAC 2014). Some states, such as Arizona, Rhode Island, and Vermont, cover all of their HCBS through 1115 waivers. Other states, such as Delaware and Tennessee, cover HCBS

through 1915(c) waivers for certain populations (i.e., people with IDD) and 1115 waivers for the remaining populations.

In order to address difficulties reporting on the variation in HCBS use and spending, researchers developed the HCBS taxonomy, a uniform classification system composed of 18 service categories including over 60 specific services.<sup>1</sup> For example, researchers have used the taxonomy to analyze utilization and spending of 1915(c) waiver services by HCBS categories, in aggregate and across states (Peebles and Bohl 2014).

To date, however, studies of HCBS utilization and spending patterns have been limited to HCBS waiver programs and to one-year cross-sectional analyses. Patterns of HCBS use and spending by categories in the taxonomy have not been the subject of study for HCBS delivered through state plan services or through new program authorities.<sup>2</sup> In addition, even though annual reports on national and state HCBS expenditures have examined HCBS spending for major subgroups of HCBS waiver participants (such as older adults and people under age 65 with physical disabilities, people with intellectual and developmental disabilities [IDD], and people with serious mental illness or serious emotional disturbance), only a few studies have examined HCBS spending by user characteristics, such as dual eligibility, age, gender, race, and ethnicity. Existing data about the characteristics of high-cost HCBS users are also inadequate to provide states with information needed to target more cost-effective delivery models to this population.

## **B. Objectives and research questions**

The Medicaid and CHIP Payment and Access Commission (MACPAC) commissioned Mathematica to study HCBS use and spending patterns over time, across states, by specific HCBS user subgroups, and among individuals with high HCBS costs and/or use. It also sought to examine the share of total Medicaid spending attributable to HCBS among high-cost HCBS users. The results may help policymakers and program managers identify whether greater use of certain types of services and supports, such as supported employment or caregiver support, are associated with lower costs per HCBS user, lower use of institutional care, and other important health, financial, and clinical outcomes of interest. The results might also inform debate on policy options that can provide more cost-effective LTSS to the growing number of people who need it.

The purpose of this study is to identify patterns of use and spending on specific types of HCBS for two groups of fee-for-service (FFS) Medicaid HCBS users: (1) all HCBS users, regardless of the amount of services or spending associated with them, and (2) high-cost HCBS users. The study addresses three key research questions:

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<sup>1</sup> States began using the taxonomy to report HCBS waiver claims in the Medicaid Statistical Information System (MSIS) in 2010.

<sup>2</sup> In 2014, HCBS spending on programs that were operating under new authorities (Community First Choice, section 1915(i), section 1915(j), Health Homes, and the Money Follows the Person [MFP] demonstration) represented 16.4 percent of all HCBS spending, a substantial increase from 4.4 percent in 2010 (Eiken et al. 2016).

1. What are the characteristics of FFS Medicaid beneficiaries who use HCBS, for example age, gender, race/ethnicity, dual eligibility, basis of Medicaid eligibility, and major health conditions?
2. What are their HCBS use patterns, as defined by the service categories in the HCBS taxonomy, overall and for each LTSS population group? Which services are most and least frequently used? How do the patterns vary by state and over time?
3. How much is spent on HCBS in total and by type of HCBS, as defined by the service categories in the HCBS taxonomy? How is total HCBS spending distributed across 1915(c) waivers, HCBS state plan benefits, managed care (if available), and other Medicaid authorities (if it is possible to distinguish them)? How does spending vary by each LTSS population group? How do spending patterns vary by state and over time?

### **C. Roadmap to the report**

Following this introduction, Section II briefly describes the data and methods used to construct the analytic files and the HCBS users and spending excluded from the analysis. A more detailed methodology appears in Appendix A. In Section III, we present results on total HCBS spending across states and over time. In Section IV, we present results similar to those in Section III but with a focus on high-cost HCBS users. We highlight areas where the results from the high-cost analysis differ from those of the total population analysis. Finally, in Section V, we discuss the conclusions from this analysis.

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## II. METHODS

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### A. Data sources

For this analysis, we used Medicaid Analytic eXtract (MAX) files, which contain extensive information about the characteristics of Medicaid beneficiaries and the number and cost of services they use during a calendar year, standardized across states. The years covered in this analysis span from 2010 through 2013, which represent the most recent years available in MAX at the time of this analysis, and therefore, include the largest share of states (for comparison, just 11 states had data available in 2014 MAX files at the time of our analysis).

We used the Personal Summary (PS), Other Therapy (OT), Long-Term Care (LT), and Inpatient (IP) MAX files to identify beneficiaries eligible to be included in our final analytic sample. The MAX PS file contains information on demographic characteristics; program and managed care plan enrollment, including 1915(c) waiver enrollment; and total Medicaid FFS expenditures by service type for all Medicaid beneficiaries. The OT file contains claim-level information on 1915(c) waiver services and HCBS state plan services, and it sorts HCBS by the 18 HCBS taxonomy categories for all 1915(c) waiver claims in the file (Peebles and Bohl 2014). The MAX LT file includes claims for institutional long-term care admissions, and the MAX IP file contains claims for inpatient hospital services, including diagnoses, procedures, and service beginning and end dates.

In addition to using the MAX files, we compared the total HCBS expenditures to LTSS spending reported by Truven Health Analytics (now part of the IBM Watson Health Business) based on CMS-64 expenditure reports, which states submit on a quarterly basis to the Centers for Medicare & Medicaid Services (CMS) to claim federal Medicaid matching funds (Eiken et al. 2017).

### B. HCBS users included in the analysis

HCBS users analyzed for this study include beneficiaries with at least one FFS 1915(c) waiver service claim or one state plan service claim with a valid FFS community-based long-term care flag during the study years. Our analysis examined only FFS claims and spending. The 1915(c) waivers included those for numerous target groups: aged and disabled, aged, physically disabled, people with brain injuries, people with HIV/AIDS, intellectually disabled/developmentally disabled, people with mental illness/serious emotional disturbance, technology dependent/medically fragile, individuals with autism/autism spectrum disorder, and unspecified or unknown populations. HCBS state plan services included personal care, private duty nursing, adult day care, home health care, residential care, rehabilitation for aged or disabled enrollees, targeted case management for aged or disabled enrollees, transportation, hospice, or durable medical equipment. Details on the creation of analytic files appear in Appendix A.

### C. Exclusions

This study did not examine HCBS spending for HCBS users enrolled in managed LTSS (MLTSS) plans because MAX files generally contain incomplete or inaccurate payment data for encounter claims. For example, MAX payment fields for HCBS provided through a managed care plan are frequently missing (i.e., encounter claims are assigned \$0 for claim payment). This

study also excluded seven states. Five states—Colorado, Idaho, Kansas, Maine, and Rhode Island—were excluded because of incomplete MAX files for at least one of the study years. We excluded Arizona from the analysis because it operated MLTSS (1) statewide, (2) for all LTSS users, and (3) in all four study years (no other state met all three of these criteria). We also excluded Vermont because it does not operate any 1915(c) waivers. As noted above, some states, such as Tennessee, Michigan, and Hawaii, provide HCBS through several program types and authorities for different populations, for example, MLTSS for older adults and people with physical disabilities and HCBS 1915(c) waivers for people with intellectual or developmental disabilities. Although we did not exclude such states from the analysis, their FFS HCBS expenditures are not representative of the entire HCBS population, so their results are not comparable to results from states in which FFS spending covers all HCBS users. In summary, 2010 to 2012 analysis included 44 states, and 2013 analysis included 25 states.

We also excluded beneficiaries with missing or undefined demographic information, those whose date of death occurred before the study year, and those whose claims did not indicate that they were true HCBS users, such as (1) 1915(c) waiver enrollees with no 1915(c) waiver or state plan service claims during the year; (2) HCBS users with 12 months of concurrent 1915(c) waiver claims and institutional care claims in a given year; (3) HCBS users with 12 months of state plan service claims limited to transportation, hospice care, or durable medical equipment services and no other types of HCBS during a given study year<sup>3</sup>; and (4) any other HCBS users without FFS HCBS expenditures.

Appendix A presents more detail on specific data elements extracted from MAX, the data quality checks we conducted, and limitations of the data sources and analytic approach.

#### **D. Analytic approach**

To explore the main research questions for this project, we analyzed the data by examining the distribution of HCBS users and expenditures by subgroups across states and over time, and exploring correlation coefficients between HCBS taxonomy categories to understand which services are most frequently combined. We also examined trends over a three-year period (2010-2012) to determine if notable changes occurred in the distribution of users and expenditures. To present more detailed state- and service-level data, we used information from 2012 because it is the most recent year with the most number of states (44) represented. In contrast, only 25 states had 2013 MAX data available at the time of our analysis.

Any utilization and spending analysis by specific types of HCBS, organized by the categories in the HCBS taxonomy, did not include state plan services because the taxonomy is applied only to 1915(c) waiver claims. Unlike waiver services, which are assumed to be HCBS, state plan services are not limited to beneficiaries who use LTSS. For example, home health services may be provided on a post-acute care basis for a limited period of time. We did not distinguish whether or not state plan services were used as HCBS because it would require more

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<sup>3</sup> Beneficiaries who use these three types of service and do not use any other type of HCBS frequently reside in institutions. The analytic sample includes beneficiaries who use any of these three services along with any other type of HCBS.



analytic resources than allowed for this project. As a result, we did not apply the HCBS taxonomy to state plan services (Wenzlow, Peebles, and Kuncaitis 2011).

### **E. Methods for the high-cost user analysis**

To study the characteristics of HCBS users with high HCBS spending, we identified high-cost HCBS users by dividing the total population into spending percentiles. To choose an appropriate cutoff to identify “high-cost” users, we analyzed summary statistics and graphical representations of HCBS users in the top one, two, three, five, and ten percent (percentile) of total 2012 HCBS costs for each state. Based on this analysis, we chose a cutoff of three percent because it balanced the need for a sufficiently large sample of HCBS users and users with sufficiently large expenditures. We defined total HCBS spending as the sum of annualized total 1915(c) waiver and state plan service expenditures.

After restricting the high-cost population to users in the top three percent of state HCBS costs, we further excluded HCBS users who (a) lived fewer than three months of the year (January-March) and (b) had spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded HCBS users who lived fewer than three months because their costs are deceptively high due to the methods we used to annualize costs for partial-year users. In particular, expenditures for users who died in January or February are overinflated because most of them had high costs early in the year (right before their death), which would not have been representative of the costs for the remainder of the year had they survived. We also excluded HCBS users who had greater than \$1 million in HCBS spending but did not use any high-cost waiver service categories; although these beneficiaries used HCBS services per the set of services types included in our definition, we believe these large HCBS payments were most likely for service contracts (for example, lump-sum payments for transportation services), or they were billing anomalies. Based on these two additional criteria, we excluded an additional 1,483 HCBS users (less than 1 percent of HCBS users initially identified by the 3 percent cutoff).<sup>4</sup> A total of 1,482 users, primarily from California, Florida, New York, and Texas, were excluded because they lived fewer than three months in 2012. This group accounted for \$342,844,861 of HCBS expenditures (approximately 1.9 percent of the original high-cost HCBS expenditures, and 0.6 percent of total population HCBS expenditures). One HCBS user in New York was excluded because the user reported almost \$10 million in annualized expenditures in 2010.

We compared spending, utilization, and characteristics of the high-cost HCBS user group to the total population. The comparisons focused on the proportion of spending concentrated in the high-cost HCBS group, as well as on differences in the distribution of high-cost HCBS users characteristics (for example, age or chronic conditions). No statistical analyses were performed; all observations were based on summary statistics.

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<sup>4</sup> Although we excluded these users from our high-cost analysis, they were included in the total population analysis because their expenditures were still part of the total HCBS costs that the relevant states incurred. In other words, we believe these were HCBS users, but the reason their HCBS expenditures were large did not match our target population. Their expenditures represented less than 1 percent of overall expenditures in 2012, and therefore should not have impacted the results of the total population analysis.

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### III. FINDINGS ON TOTAL HCBS USERS AND SPENDING

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#### A. Total HCBS users and spending in the analytic sample

- From 2010 to 2012, the 44 states in the analytic sample accounted for approximately 6 million individual HCBS users each year (Exhibit III.1).
- In 2012, approximately 1.3 million HCBS users had 1915(c) waiver claims in the 44 study states, which accounts for 86.8 percent of the 1.5 million HCBS users in all 50 states and the District of Columbia reported as receiving 1915(c) waiver services, according to CMS-372 data for the same year (Eiken 2016).
- In 2012, the 44 study states reported \$58.1 billion on Medicaid HCBS claims, which is 83.5 percent of total HCBS expenditures by all states (\$69.5 billion) as reported in CMS-64 data (Eiken et al 2017). These shares were similar in 2011 (86.5 percent) and 2010 (86.8 percent) (Eiken et al 2014).
- Federal and state Medicaid spending on HCBS remained relatively unchanged in the three-year period from 2010 to 2012; spending increased modestly from \$57.7 billion in 2010 to \$58.1 billion in 2012.<sup>5</sup> In 2013, when MAX data were available for only 25 states, \$42.2 billion was spent on about 3.8 million HCBS users.<sup>6</sup>
- 1915(c) waiver expenditures accounted for a slightly larger share (54 to 58 percent in each year) of total HCBS expenditures relative to spending on state plan services.

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<sup>5</sup> The 2010–2012 analysis includes FFS spending on HCBS in 44 states. We excluded Colorado, Idaho, Kansas, Maine, and Rhode Island from the analysis because of incomplete MAX data in 2010–2013. We excluded Arizona from the analysis because of an insufficient number of FFS claims in 2010–2013 (fewer than 3 to 4 percent of all claims). We excluded Vermont because of data reliability issues with the MAX data.

<sup>6</sup> At the time of our analysis, 2013 MAX data were available and deemed reliable for the following states: Arkansas, California, Connecticut, Georgia, Hawaii, Indiana, Iowa, Louisiana, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, New Jersey, New York, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Utah, Washington, West Virginia, and Wyoming.

**Exhibit III.1. Total HCBS users and spending, 2010 to 2013<sup>a</sup>**

Year	2010	2011	2012	2013
<b>Total number of HCBS users<sup>a</sup></b>	6,129,339	6,114,377	5,856,105	3,821,531
With 1915(c) waiver enrollment	5,050,524	5,002,100	4,701,153	3,059,836
With 1915(c) waiver claims	1,183,671	1,238,518	1,282,782	842,775
With state plan service claims	5,723,903	5,681,512	5,384,955	3,599,562
<b>Total MAX HCBS expenditures (\$)</b>	\$57,679,278,732	\$58,553,428,145	\$58,119,663,724	\$42,167,996,679
1915(c) waivers	\$31,139,592,157	\$32,544,734,083	\$33,211,885,524	\$24,542,441,446
State plan services	\$26,539,686,575	\$26,008,694,062	\$24,907,778,199	\$17,625,555,233
<b>Total CMS-64 HCBS expenditures (\$)</b>	\$61,491,308,583	\$62,010,029,569	\$63,689,024,548	\$48,314,860,032
1915(c) waivers	\$35,611,834,944	\$36,279,854,385	\$37,658,728,215	\$27,020,198,049
State plan services	\$25,879,473,639	\$25,730,175,184	\$26,030,296,333	\$21,294,661,983

Source: Mathematica analysis of 2010–2013 MAX PS, and OT files; Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013; Truven Health Analytics.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup>HCBS users in the analytic sample include beneficiaries with at least one HCBS-related claim (either a 1915(c) waiver claim or state plan service claim) with positive Medicaid expenditures.

We examined the share of 1915(c) HCBS waiver and state plan expenditures as reported in MAX to total HCBS expenditures reported in CMS-64 reports for the same set of 44 states in the 2010–2012 sample and the 25 states in the 2013 sample.

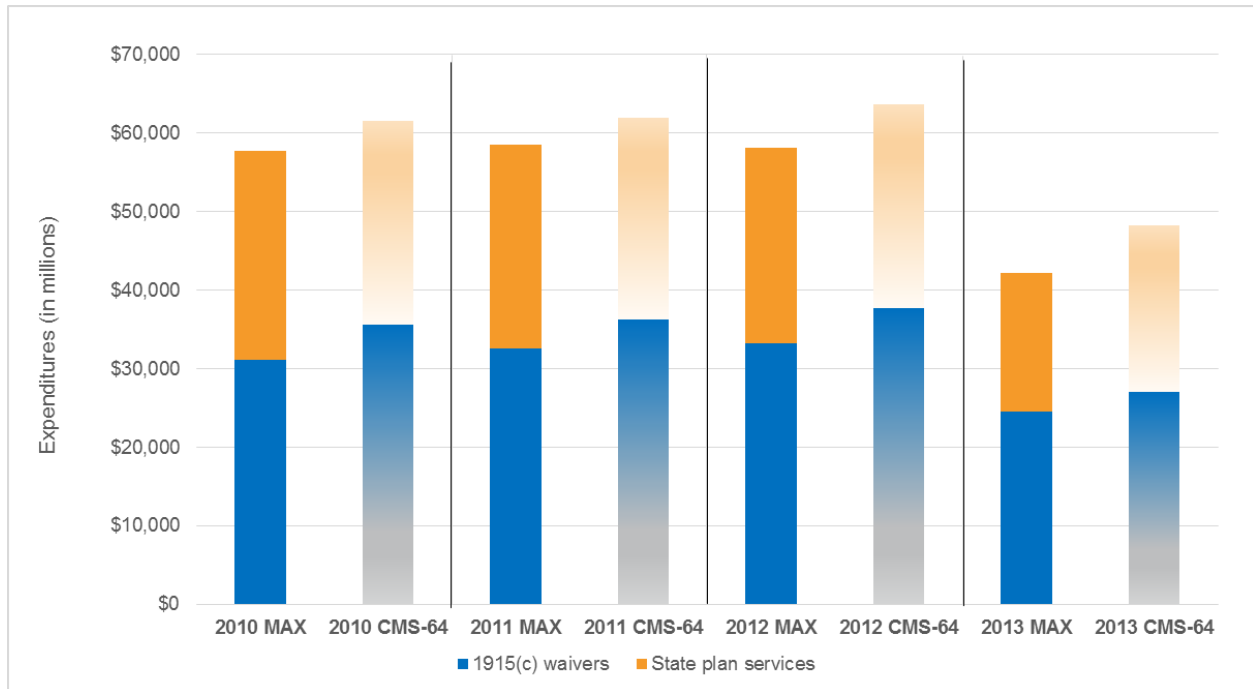
- In both 2010 and 2011, HCBS claims spending as reported in MAX comprised about 94 percent of total HCBS expenditures for waiver and state plan services reported in CMS-64 data for the same set of 44 states (Exhibit III.2).
- In 2012, HCBS claims spending as reported in MAX files comprised 91.3 percent of total HCBS spending for the same set of 44 states according to CMS-64 reports.
- In 2013, HCBS claims spending in MAX files comprised 87.3 percent of total HCBS spending for the same set of 25 states according to CMS-64 reports.

1915(c) waiver and HCBS state plan expenditures in MAX differ from expenditures reported in CMS-64 for three reasons. First, MAX data are derived from adjudicated claims submitted to the state by providers for each service rendered and do not include payments made outside of claims. CMS-64 data are generated from all Medicaid expenditures submitted to CMS by states through the Medicaid Budget and Expenditure System (MBES) to draw down federal matching funds and include lump-sum payments, such as capitation payments, disproportionate share hospital payments and supplemental payments made to providers, and possibly participant-directed cash payments.<sup>7</sup> Second, CMS-64 data are reported by fiscal year as opposed to MAX data that are reported by calendar year. Lastly, expenditures for HCBS state plan services may differ because of different definitions of HCBS used by each data source.

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<sup>7</sup> Annual Medicaid LTSS expenditure reports rely primarily on CMS-64 data and obtain additional information directly from states operating MLTSS programs to estimate the amount of capitation payments to MLTSS plans for HCBS versus institutional care. However, overall MLTSS expenditures are conservative estimates due to challenges in collecting MLTSS data (see Appendix A, Eiken et al. 2016). In addition, expenditures on personal care services reported on CMS-64 forms are frequently incorrect (GAO, 2017).

**Exhibit III.2. HCBS expenditures, MAX and CMS-64, 2010 to 2013**



Source: Mathematica analysis of 2010–2013 MAX PS, and OT files; Medicaid expenditures for LTSS in FY 2013; Truven Health Analytics.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**B. State variation in HCBS users and spending**

- The number of HCBS users in 2012 averaged 133,093 per state, ranging from 4,035 in Hawaii to 814,384 in California. Nineteen of the 44 states had more than 100,000 HCBS users, and four of these states (California, Florida, New York, and Texas) had over 300,000 HCBS users (Exhibit III.3). These 4 states comprised 35.7 percent of all HCBS users in our sample.
- State spending on HCBS waiver services averaged \$754.8 million in 2012, ranging from \$43.4 million in Montana to nearly \$5.7 billion in New York. State plan service expenditures in 2012 averaged \$566 million, ranging from \$1.6 million in Hawaii to \$6.3 billion in California. The average waiver and state plan expenditures across states was \$1.3 billion, ranging from \$99.1 million in Hawaii to nearly \$10.7 billion in New York.

**Exhibit III.3. HCBS users and expenditures, by state, 2012**

State	Total HCBS expenditures			Total number of HCBS users
	1915(c) waivers	HCBS state plan services	Total 1915(c) waivers and state plan services	
All states	\$33,211,885,524	\$24,907,778,199	\$58,119,663,724	5,856,105
Alabama	\$368,500,439	\$191,776,101	\$560,276,540	237,145
Alaska	\$217,702,827	\$170,402,116	\$388,104,943	18,966
Arkansas	\$218,637,439	\$257,657,687	\$476,295,126	100,854
California	\$2,334,035,860	\$6,275,488,210	\$8,609,524,070	814,384
Connecticut	\$971,584,881	\$406,416,489	\$1,378,001,370	106,078
Delaware	\$97,309,294	\$25,101,694	\$122,410,988	6,928
District of Columbia	\$185,733,908	\$293,360,005	\$479,093,913	28,640
Florida	\$1,080,949,631	\$863,985,405	\$1,944,935,036	340,514
Georgia	\$839,239,062	\$309,248,186	\$1,148,487,247	207,309
Hawaii	\$97,550,143	\$1,578,425	\$99,128,568	4,035
Illinois	\$1,402,845,781	\$408,095,496	\$1,810,941,277	294,316
Indiana	\$599,584,906	\$471,813,896	\$1,071,398,801	124,105
Iowa	\$520,645,998	\$224,256,051	\$744,902,049	87,901
Kentucky	\$442,513,427	\$79,124,903	\$521,638,330	49,110
Louisiana	\$526,464,008	\$445,494,118	\$971,958,126	152,029
Maryland	\$744,473,652	\$446,143,822	\$1,190,617,474	88,749
Massachusetts	\$906,887,756	\$889,009,435	\$1,795,897,191	219,822
Michigan	\$119,444,910	\$643,525,046	\$762,969,956	164,855
Minnesota	\$1,691,035,072	\$776,425,659	\$2,467,460,731	130,261
Mississippi	\$222,980,962	\$114,381,233	\$337,362,196	93,502
Missouri	\$560,634,036	\$817,758,516	\$1,378,392,551	172,097
Montana	\$43,384,733	\$80,922,701	\$124,307,434	19,882
Nebraska	\$252,853,774	\$81,792,929	\$334,646,703	35,729
Nevada	\$93,173,873	\$175,584,656	\$268,758,529	29,591
New Hampshire	\$256,719,814	\$43,095,063	\$299,814,877	22,222
New Jersey	\$868,574,691	\$230,711,196	\$1,099,285,887	69,796
New Mexico	\$282,833,258	\$9,428,572	\$292,261,830	15,274
New York	\$5,682,100,453	\$4,996,777,005	\$10,678,877,458	533,351
North Carolina	\$662,402,678	\$863,600,662	\$1,526,003,340	218,155
North Dakota	\$146,983,083	\$33,701,025	\$180,684,108	13,944

Total HCBS expenditures				
State	1915(c) waivers	HCBS state plan services	Total 1915(c) waivers and state plan services	Total number of HCBS users
Ohio	\$1,920,460,730	\$1,020,739,813	\$2,941,200,543	230,182
Oklahoma	\$454,631,436	\$114,965,183	\$569,596,619	84,933
Oregon	\$410,792,957	\$135,874,860	\$546,667,816	57,634
Pennsylvania	\$2,682,110,385	\$181,698,769	\$2,863,809,154	203,291
South Carolina	\$191,607,661	\$343,099,319	\$534,706,979	78,753
South Dakota	\$112,029,732	\$22,241,145	\$134,270,878	14,472
Tennessee	\$508,759,651	\$85,622,888	\$594,382,538	12,806
Texas	\$1,768,543,522	\$1,503,545,859	\$3,272,089,382	402,508
Utah	\$166,962,349	\$78,864,477	\$245,826,826	21,207
Virginia	\$1,099,722,492	\$87,107,847	\$1,186,830,339	64,181
Washington	\$786,924,042	\$420,789,963	\$1,207,714,005	108,083
West Virginia	\$420,846,628	\$152,816,705	\$573,663,332	70,646
Wisconsin	\$137,166,752	\$111,871,137	\$249,037,888	99,126
Wyoming	\$113,546,840	\$21,883,935	\$135,430,775	8,739

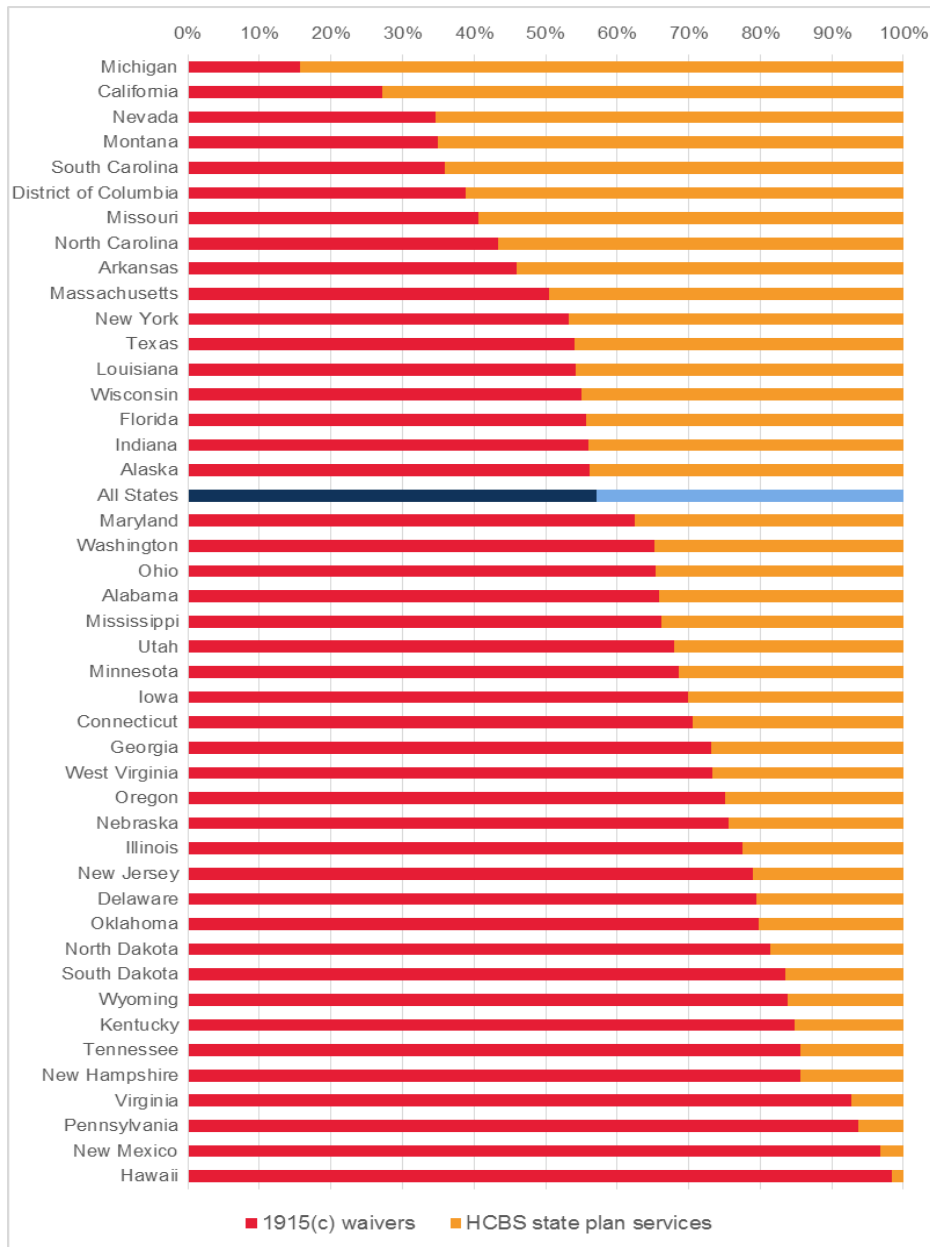
Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.



**Exhibit III.4. Share of HCBS expenditures spent on 1915(c) waivers and state plan services, by state in 2012**



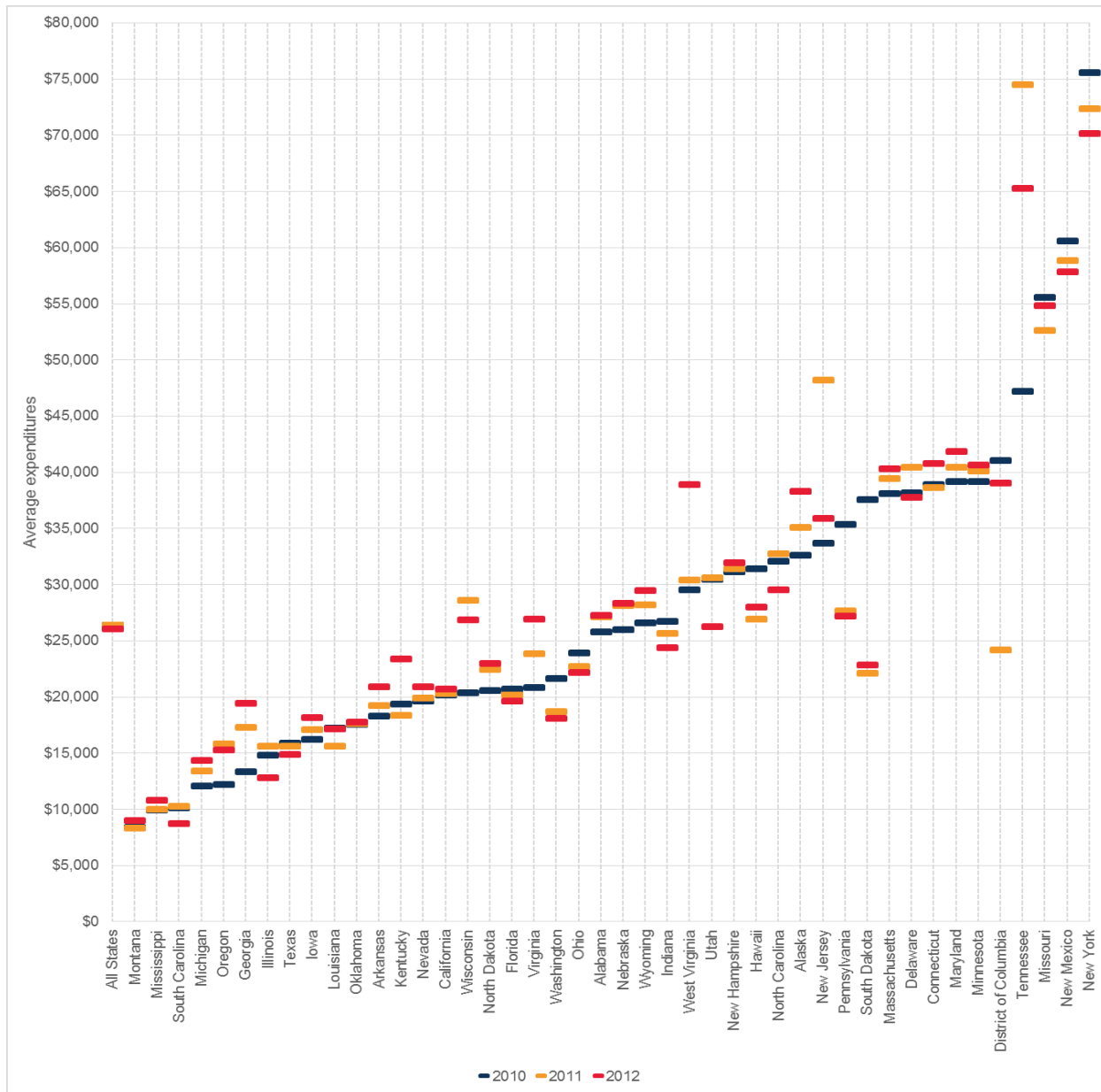
Source: Mathematica analysis of 2012 MAX, PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- In 2012, 35 of 44 states reported 50 percent or more of total HCBS expenditures on 1915(c) waiver services. The pattern was consistent in the other study years (2010, 2011, and 2013).
- On average, states spent 57.1 percent of total HCBS FFS dollars on 1915(c) waiver services in 2012, ranging from 15.7 percent in Michigan to 98.4 percent in Hawaii (Exhibit III.4). The differences reflect the flexibility afforded to states under federal law to provide HCBS through different federal authorities (state plan services or waivers) and different delivery arrangements (FFS or MLTSS) and to different populations of HCBS users.
- Average per participant spending on HCBS 1915(c) waiver services was \$26,444 in 2010, \$26,419 in 2011, and \$26,083 in 2012, across the 44 states in our analysis.
- With a few exceptions, most states reported consistent average waiver expenditures each year. The changes in South Dakota may be attributed to data issues, as CMS-64 data only shows modest changes in total HCBS (around 2 percent) between years. For the District of Columbia and New Jersey, where the per participant spending amounts in 2011 differed markedly from the preceding and subsequent years, the changes also appear to be attributable to data quality problems rather than to policy changes (Exhibit III.5).
  - In South Dakota, average 1915(c) waiver expenditures per participant declined from \$38,000 in 2010 to \$22,000 in 2011 and rose slightly to \$23,000 in 2012.
  - In New Jersey, average 1915(c) waiver expenditures per participant was almost \$34,000 in 2010, rising steeply to \$48,000 in 2011, and then declining to \$36,000 in 2012.
  - In the District of Columbia, average 1915(c) waiver expenditures per participant was \$41,000 in 2010, dropping precipitously to \$24,000 in 2011 and then rising sharply to \$39,000 in 2012.
- Average per participant spending on HCBS state plan services was \$4,330 in 2010, \$4,254 in 2011, and \$4,253 in 2012 (Exhibit III.6).
- Similar to average waiver expenditures, most states had consistent average state plan expenditures each year. Two exceptions were Tennessee with a \$5,800 increase from 2011 to 2012 and District of Columbia with nearly \$5,000 increase from 2011 to 2012. The increase in Tennessee should be interpreted with caution as Tennessee expenditures are not representative of all HCBS users in the state because of the statewide MLTSS.

**Exhibit III.5. Average FFS 1915(c) expenditures per 1915(c) waiver service user across states, 2010 to 2012**

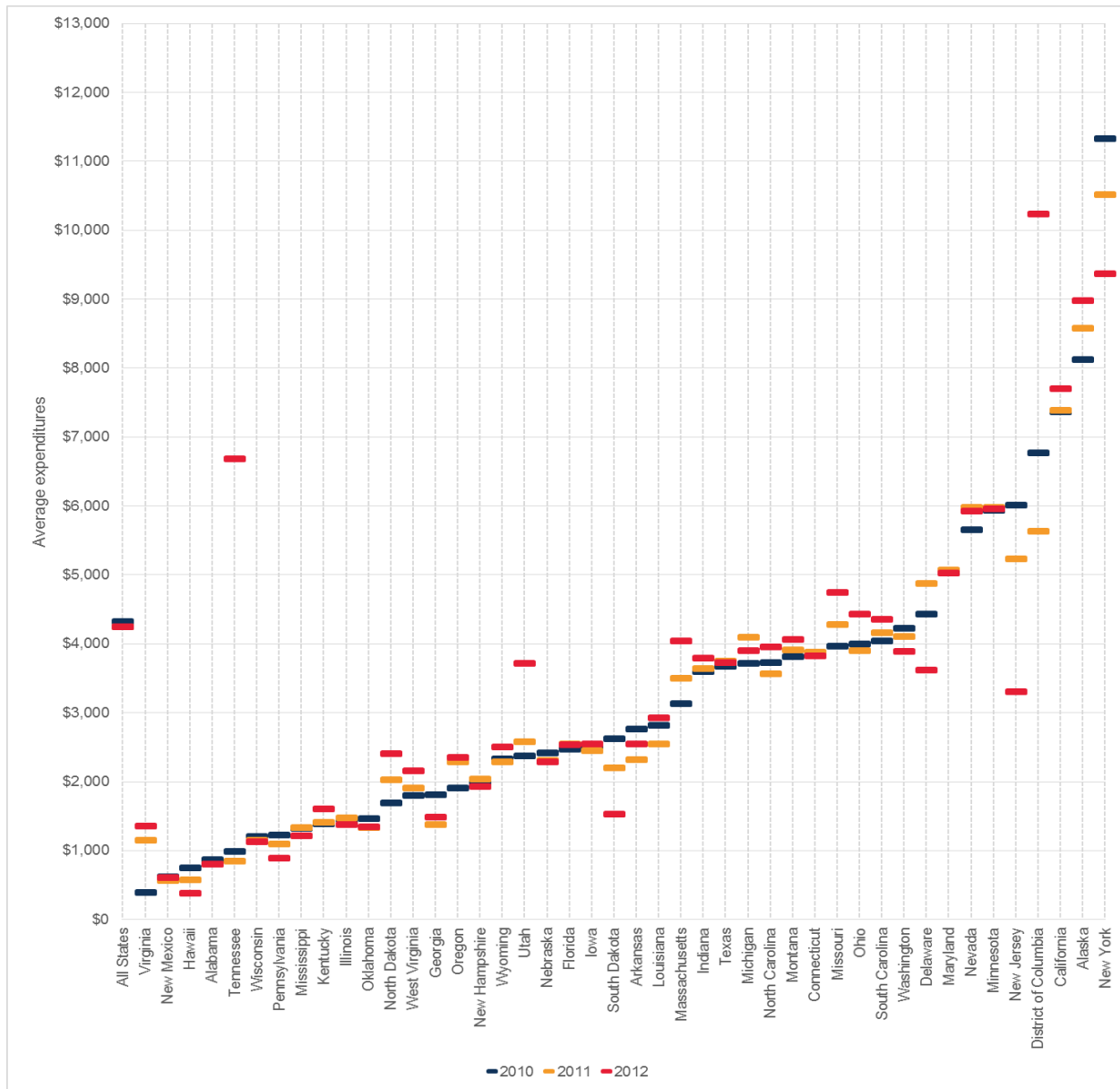


Source: Mathematica analysis of 2010–2012 MAX PS, and OT files.

Notes: The 2010–2012 analyses included 44 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Exhibit III.6. Average FFS state plan service expenditures per state plan service user across states, 2010 to 2012**



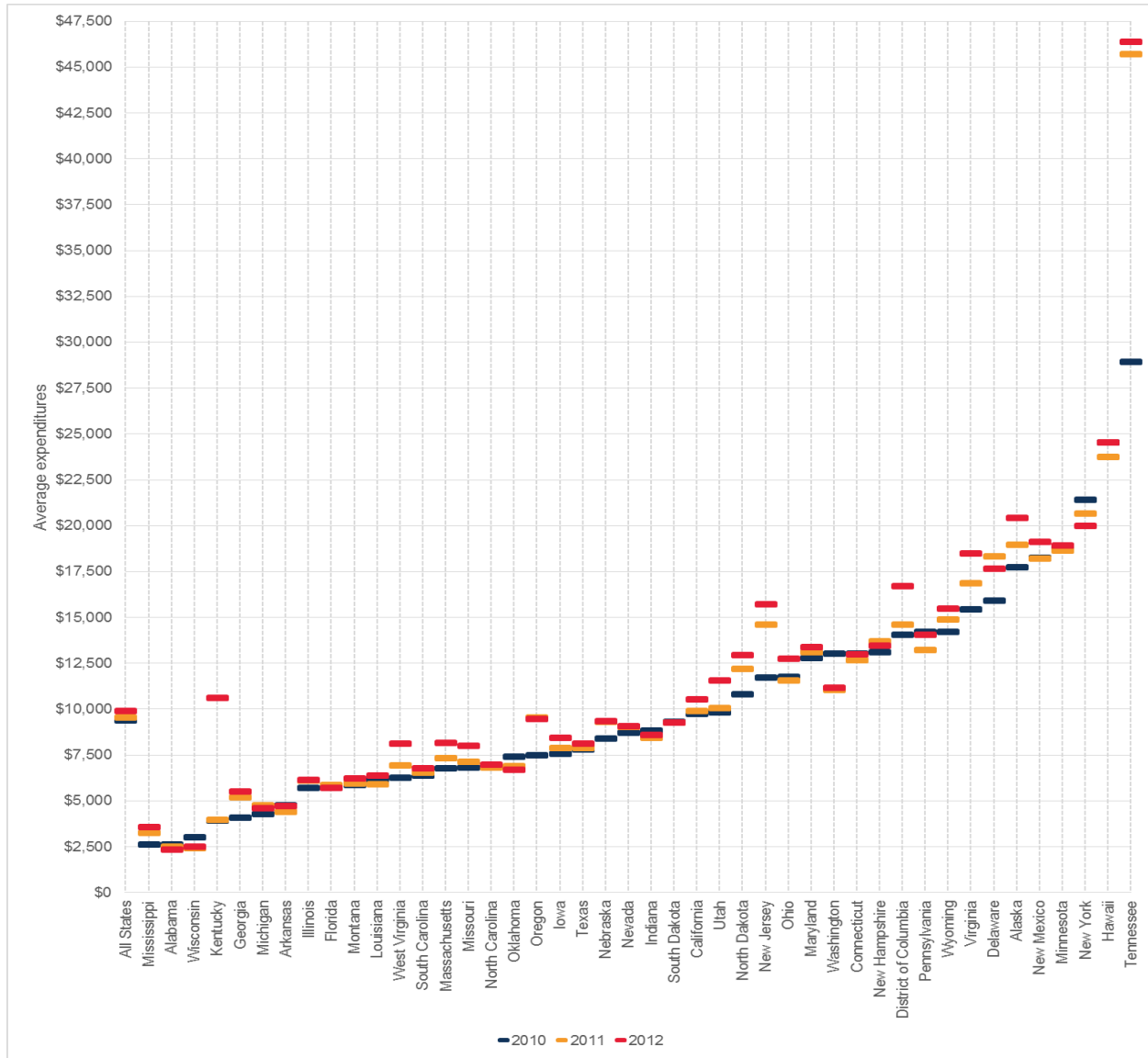
Source: Mathematica analysis of 2010–2012 MAX PS, and OT files.

Notes: The 2010–2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- Across 44 states, average spending per participant on total FFS HCBS expenditures (both waiver and state plan) was \$9,410 in 2010, \$9,576 in 2011, and \$9,925 in 2012 (Exhibit III.7).
- Tennessee's total HCBS expenditures per HCBS user also increased from 2010 to 2011 (\$29,000 to \$46,000). As noted, Tennessee's state plan expenditure was much higher than that in other states because the state restricted expenditures to people with intellectual or developmental disabilities, a group with high average spending per participant. It excludes HCBS spending for all other HCBS user groups, such as older adults and people under age 65 with physical disabilities who are served through statewide managed care programs in the state; in addition, the MAX data do not include HCBS expenditures for MLTSS enrollees.

**Exhibit III.7. Average total FFS HCBS expenditures per HCBS user across states, 2010 to 2012**



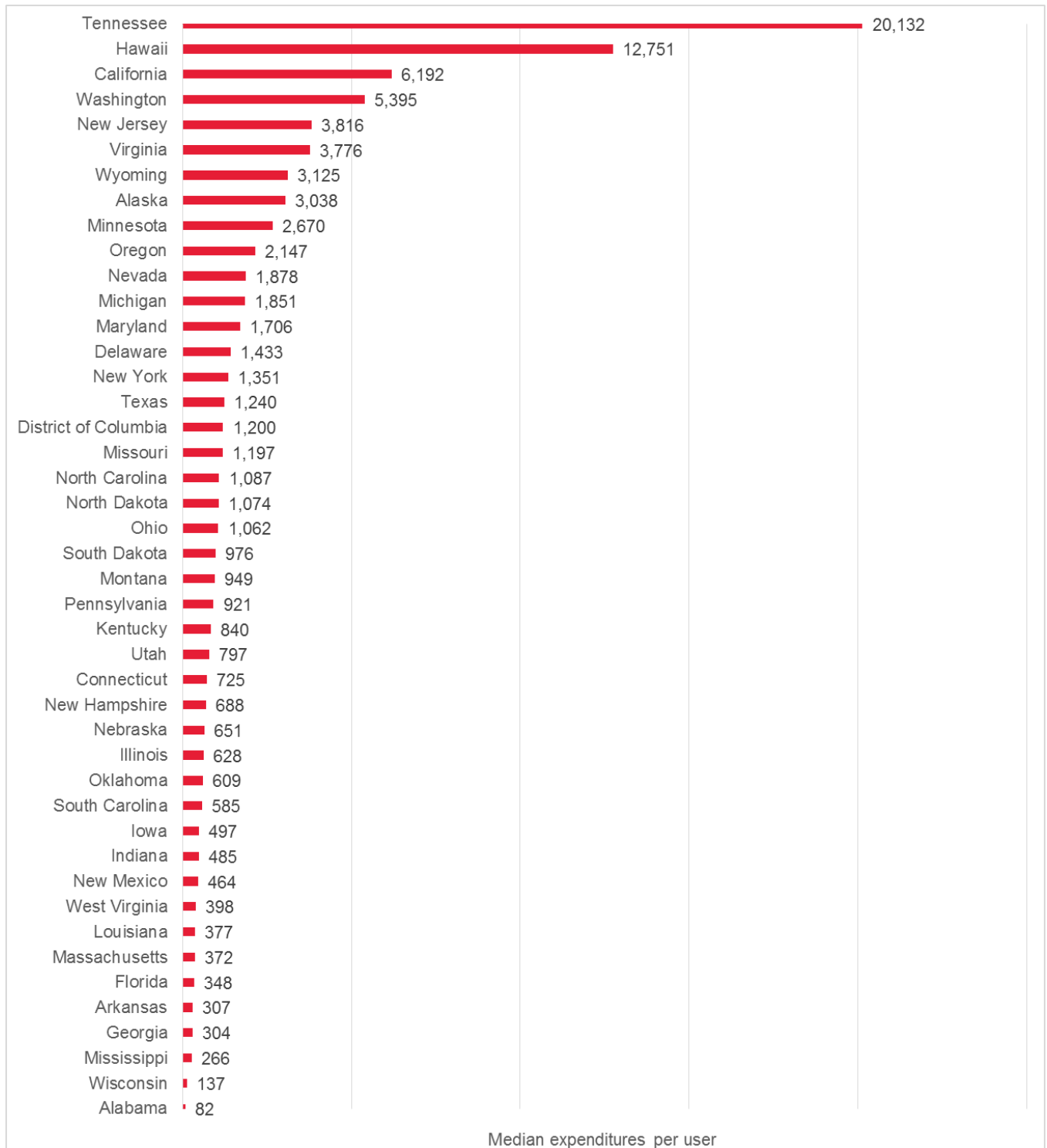
Source: Mathematica analysis of 2010–2012 MAX, PS, and OT files.

Notes: The 2010–2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- In 2012, the median FFS Medicaid HCBS expenditures per HCBS user ranged from under \$100 in Alabama to \$20,132 in Tennessee (Exhibit III.8).
- Twenty-three states report a median FFS HCBS expenditure less than \$1,000.
- FFS spending in Hawaii and Tennessee was much higher than in other states because it is restricted to expenditures for people with intellectual or developmental disabilities, a group with high average spending per participant. It excludes HCBS spending for all other HCBS user groups, such as older adults and people under age 65 with physical disabilities who are served through statewide managed care programs in both states; the MAX data do not include HCBS expenditures for MLTSS enrollees.

**Exhibit III.8. Median Medicaid HCBS expenditures per HCBS user, by state, 2012**



Source: Mathematica analysis of 2012 MAX PS files.

Notes: HCBS represents both fee-for-service (FFS) 1915(c) waiver and state plan benefit services.



2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

### **C. Non-LTSS spending for HCBS Users**

In addition to analyzing LTSS spending, we analyzed non-LTSS expenditure data for HCBS users. Non-LTSS expenditures were identified in MAX by the type-of-service code and include hospital, physician, nurse practitioner, other practitioner, laboratory and X-ray, dental, and prescription drug services.

- Across years, inpatient hospital services accounted for most of the hospital spending (85 to 86 percent across years). Outpatient hospital services represented roughly 14 percent of hospital spending.
- Prescription drugs made up the largest share of non-hospital services. In addition to the expenditures for prescription drugs paid by Medicaid, Medicare typically covers a large share of prescription drug claims for the HCBS dual-eligible population; our analysis does not include Medicare prescription services.

### Exhibit III.9. Percentage of total FFS Medicaid expenditures for LTSS and non-LTSS for all HCBS users, by year

	2010	2011	2012	2013
Number of states included	44	44	44	25
Total number of HCBS users	6,149,431	6,114,377	5,856,105	3,821,531
Total Medicaid expenditures <sup>a</sup>	100.0%	100.0%	100.0%	100.0%
<b>Total LTSS expenditures<sup>b</sup></b>	<b>63.3%</b>	<b>63.4%</b>	<b>66.1%</b>	<b>69.6%</b>
1915(c) HCBS waiver services	35.8%	37.2%	38.4%	39.0%
State plan HCBS services	30.5%	29.7%	28.8%	28.0%
Institutional services	33.7%	33.2%	32.7%	33.0%
<b>Total non-LTSS expenditures<sup>c,d</sup></b>				
Total hospital services	32.7%	33.3%	32.9%	32.0%
Inpatient services	86.1%	86.0%	85.6%	84.6%
Outpatient services	13.9%	14.0%	14.4%	15.4%
Total nonhospital services <sup>d</sup>				
Physician services	10.6%	10.0%	9.3%	8.1%
Nurse practitioner services	0.2%	0.2%	0.2%	0.2%
Other practitioner services	0.6%	1.1%	1.2%	1.5%
Laboratory and x-ray services	6.3%	6.0%	5.7%	5.1%
Dental services	1.4%	1.3%	1.3%	1.0%
Prescription drugs	26.2%	25.5%	21.6%	18.2%

Source: Mathematica analysis of 2010–2013 MAX PS, OT, IP, and LT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> Total Medicaid FFS expenditures do not equal the sum of total LTSS expenditures and total non-LTSS expenditures because of overlaps in the definitions of the LTSS and non-LTSS service payment variables available in the MAX data.

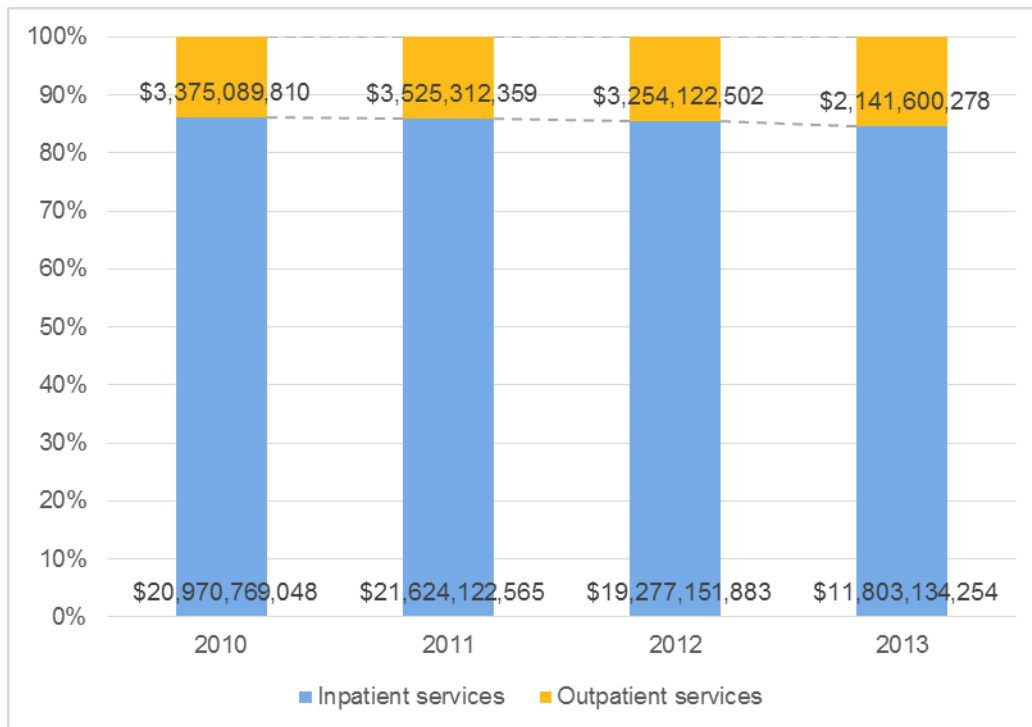
<sup>b</sup> Total LTSS expenditures are reported as a percent of total Medicaid expenditures. Sub-categories are reported as a percent of total LTSS expenditures.

<sup>c</sup> Total non-LTSS expenditures are reported as a percent of total Medicaid expenditures. Sub-categories are reported as a percent of total non-LTSS expenditures.

<sup>d</sup> Total non-LTSS expenditures and total nonhospital 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 and we do not report overall expenditures.

- Expenditures for inpatient services remained consistent from 2010 to 2012, with the 44 study states reporting \$19.3 to \$21.6 billion (Exhibit III.10).
- Expenditures for both inpatient and outpatient services declined in 2013 (because of a smaller number of study states); however, the percentage of overall hospital services remained consistent with that of previous years.

**Exhibit III.10. Inpatient and outpatient hospital service expenditures for all HCBS users, by year**



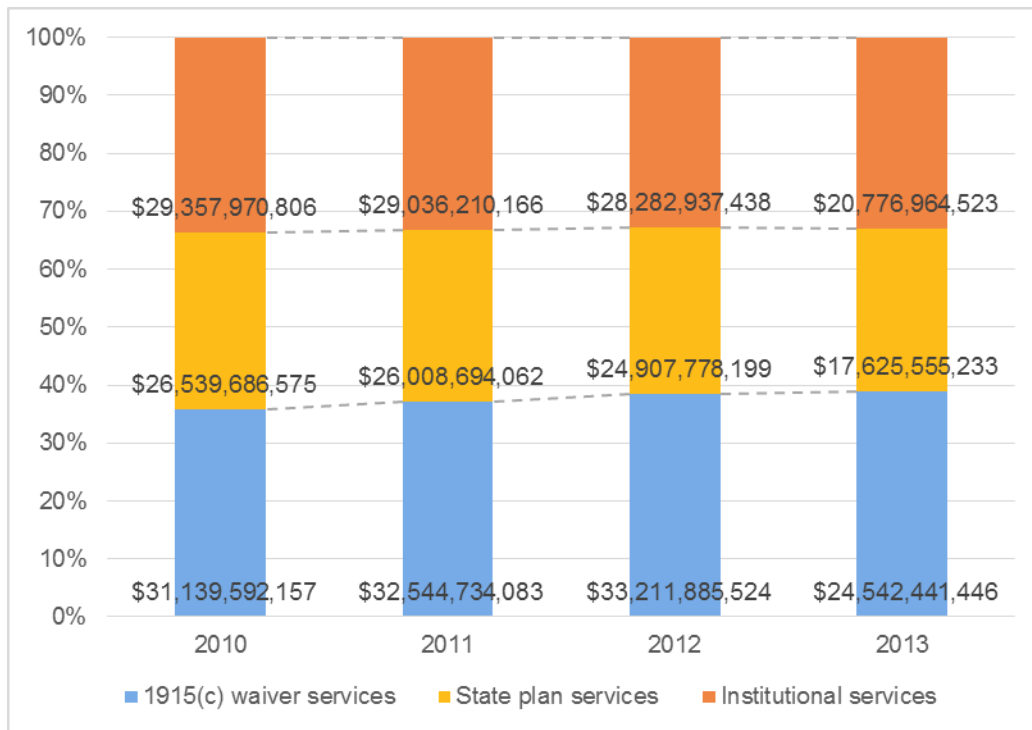
Source: Mathematica analysis of 2010–2013 MAX PS, OT, IP, and LT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- From 2010 to 2013, the study states reported consistent breakdowns of LTSS by 1915(c) waiver, state plan, and institutional long-term care services (Exhibit III.11).

**Exhibit III.11. LTSS expenditures for all HCBS users, by year**



Source: Mathematica analysis of 2010–2013 PS, OT, IP, and LT files.

Notes: The 2010-2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**D. HCBS user demographics**

In all four study years, the largest proportion of HCBS users in the sample was eligible for Medicaid based on blindness/disability (64 to 65 percent), not dually eligible for Medicare (40 to 44 percent), ages 19 to 64 years (52 to 53 percent), female (58 percent), and white non-Hispanic (50 to 52 percent) (Exhibit III.12).

In 2013, the proportion of people with certain characteristics—such as children, Medicaid-only beneficiaries, age (0 to 18 years)— are slightly different than in other years because a few large states, such as Florida, Illinois, and Texas, were not included in the 2013 analysis as a consequence of incomplete MAX files.

**Exhibit III.12. Percentage of HCBS users in subpopulation, by year**

	2010	2011	2012	2013
<b>Total number of HCBS users</b>	<b>6,149,431</b>	<b>6,134,947</b>	<b>5,877,367</b>	<b>3,841,806</b>
<b>Medicaid eligibility</b>				
Aged	29.4%	29.6%	29.8%	31.3%
Blind/disabled	65.2%	64.7%	63.9%	64.3%
Adults	1.5%	1.5%	1.6%	1.6%
Children	3.8%	4.1%	4.7%	2.7%
<b>Dual status</b>				
Full dual	36.7%	33.0%	32.9%	33.2%
Partial dual	19.0%	23.3%	24.4%	26.6%
Medicaid-only	44.3%	43.6%	42.7%	40.2%
<b>Age</b>				
0 to 18 years	14.6%	14.9%	15.5%	12.6%
19 to 64 years	52.7%	52.5%	51.8%	53.0%
65 to 84	24.9%	24.8%	24.8%	26.0%
85 years and older	7.8%	7.8%	8.0%	8.5%
<b>Gender</b>				
Female	58.3%	57.9%	57.5%	57.5%
Male	41.7%	42.1%	42.5%	42.5%
<b>Race/ethnicity</b>				
White, non-Hispanic	50.5%	50.1%	49.9%	52.0%
Black, non-Hispanic	23.0%	22.8%	22.7%	20.0%
Hispanic	11.6%	11.2%	11.2%	11.3%
Other nonwhite, non-Hispanic	14.9%	15.9%	16.2%	16.7%

Source: Mathematica analysis of 2010–2013 MAX PS, OT, IP, and LT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- In 2012, average Medicaid FFS expenditures per HCBS user were highest for individuals eligible for Medicaid based on blindness/disability (\$23,939), not dually eligible for Medicare (\$25,004), age 85 and older (\$28,015), male (\$25,653), and white non-Hispanic (\$24,807) (Exhibit III.13).
- When only accounting for average LTSS total expenditures per HCBS user, individuals with the highest average LTSS expenditures per user included those who were eligible for Medicaid based on age, full dual-eligibles, 85 and older, male, and white non-Hispanic.
- For each subpopulation, average waiver expenditures always exceeded average state plan expenditures. Even though our sample was limited to HCBS users, we found a sizeable amount of institutional expenditures, which may be due to transfers or hospitalization.

**Exhibit III.13. Average FFS Medicaid expenditures for long-term services and supports (LTSS) for all states in 2012, by subpopulation**

	Average LTSS expenditures					
	Average Medicaid FFS expenditures	LTSS total	1915(c) waiver and state plan services	1915(c) waivers	State plan services	Institutional LTSS <sup>a</sup>
<b>All HCBS users</b>	<b>22,324</b>	<b>14,754</b>	<b>9,925</b>	<b>26,083</b>	<b>4,253</b>	<b>4,830</b>
<b>Medicaid eligibility</b>						
Aged	20,312	17,891	8,471	14,727	5,162	9,420
Blind/disabled	23,939	14,339	11,216	33,385	4,027	3,123
Adults	18,753	2,763	2,415	9,798	1,893	348
Children	14,377	4,607	4,168	7,019	2,375	440
<b>Dual status</b>						
Full dual	19,692	17,331	11,669	29,199	4,442	5,662
Partial dual	21,188	18,259	10,144	23,397	4,305	8,115
Medicaid-only	25,004	10,766	8,454	24,877	4,078	2,312
<b>Age</b>						
0 to 18 years	19,547	8,583	7,482	12,262	4,930	1,102
19 to 64 years	24,623	14,763	11,397	37,040	3,284	3,366
65 to 84	17,422	14,883	7,922	15,521	4,600	6,961
85 years and older	28,015	26,230	11,321	13,451	8,150	14,909
<b>Gender</b>						
Female	20,605	13,913	8,983	22,411	4,369	4,930
Male	24,653	15,893	11,200	30,478	4,097	4,694
<b>Race/ethnicity</b>						
White, non-Hispanic	24,807	17,814	11,596	29,924	4,070	6,218
Black, non-Hispanic	20,301	12,072	8,170	21,720	3,772	3,902
Hispanic	18,616	11,045	8,317	17,355	5,230	2,729
Other nonwhite, non-Hispanic	20,117	11,703	8,375	22,076	4,815	3,328

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> Institutional LTSS includes the following MAX type of service codes: 02 = Mental hospital services for the aged, 04 = Inpatient psychiatric facility for individuals under the age of 21, 05 = Intermediate care facility for individuals with intellectual disabilities, and 07 = Nursing facility services – all other.



We used the Chronic Condition Warehouse (CCW) coding system to analyze differences in spending and services received by HCBS users with different chronic conditions and diagnoses.<sup>8</sup>

- In 2012, average costs per HCBS user with any health conditions were \$22,324, but three conditions had average costs over \$50,000 per HCBS user (or more than double the average): (1) intellectual disabilities and related conditions, (2) mobility impairments<sup>9</sup>, and (3) epilepsy (Exhibit III.14). These three conditions also reported average costs over \$50,000 per HCBS user in 2010 and 2011.
- In 2012, the five most common conditions were diabetes, depression, hyperlipidemia, and chronic obstructive pulmonary disease (COPD), and ischemic heart disease: 21.0 percent of all HCBS users had diabetes, 16.6 percent had depression, 11.8 percent had hyperlipidemia, 11.5 percent had COPD, and 10.9 percent had ischemic heart disease.
- In 2012, total Medicaid FFS expenditures for the top 10 most expensive chronic conditions totaled over \$204.0 billion (data not shown).

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<sup>8</sup> Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year. Our analysis presents spending per user for each chronic condition, rather than a user with multiple conditions. Additional information can be found here: <https://www.ccwdata.org/web/guest/condition-categories>.

<sup>9</sup> Mobility impairments include ICD-9 codes related to spinocerebellar disease, hemiplegia, paralysis of all four limbs, paraplegia, paralysis unspecified, late effects of cerebrovascular disease. The full list of ICD-9 and ICD-10 codes can be found here: <https://www.ccwdata.org/documents/10280/19140001/oth-cond-algo-mobility.pdf>.

**Exhibit III.14. Average Medicaid FFS expenditures per HCBS user and total number of HCBS users, by chronic condition, 2012 (in order of most costly conditions)**

	Average Medicaid FFS expenditures per beneficiary	Total number of HCBS users	Rank (based on the total number of HCBS users)
<b>All HCBS users</b>	\$22,324	5,856,105	--
<b>Chronic Health Conditions</b>			
Intellectual disabilities and related conditions	\$56,635	551,202	7
Mobility impairments	\$51,342	188,212	22
Epilepsy	\$50,026	256,109	17
Chronic kidney disease (CKD)	\$38,640	502,368	9
Alzheimer's disease and related disorders or senile dementia	\$38,462	433,271	12
Stroke/transient ischemic attack	\$36,277	226,401	18
Peripheral vascular disease (PVD)	\$34,893	225,565	19
Autism spectrum disorders	\$34,834	145,838	24
Hypothyroidism	\$34,304	259,344	16
Chronic heart failure (CHF)	\$33,711	487,018	10
Cancer	\$33,692	221,804	20
Other developmental delays	\$33,545	178,710	23
Sensory impairments	\$33,392	204,346	21
Schizophrenia and other psychotic disorders	\$32,290	458,248	11
ADHD, conduct disorders, hyperkinetic syndrome	\$30,009	259,927	15
Bipolar disorder	\$27,854	405,193	13
Learning disabilities	\$27,617	115,211	25
Chronic obstructive pulmonary disease and bronchiectasis	\$27,032	671,885	4
Anxiety disorders	\$26,862	520,001	8
Depression	\$26,358	970,642	2
Ischemic heart disease (IHD)	\$25,666	636,057	5
Hyperlipidemia	\$25,228	688,602	3
Fibromyalgia, chronic pain, and fatigue	\$25,209	317,503	14
Diabetes	\$22,769	1,232,385	1
Post-traumatic stress disorder (PTSD)	\$22,684	98,558	26
Rheumatoid arthritis/osteoarthritis	\$20,341	598,455	6

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states and the 2013 analysis included 25 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

This table presents the 26 most common conditions that were reported among all HCBS users. To identify these 26 conditions we looked at the top 20 conditions in each state across all years, and then removed any conditions that did not occur in at least 2 states in at least 2 years (for example, deleted conditions that only appeared in one state or in one year). Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

- Average LTSS expenditures per HCBS user ranged from \$8,220 (fibromyalgia, chronic pain and fatigue) to \$49,281 (intellectual disabilities and related conditions) in 2012 (Exhibit III.15).
- In 2012, average 1915(c) waiver and state plan services ranged from \$5,785 (fibromyalgia, chronic pain and fatigue) to \$40,675 (intellectual disabilities and related conditions).
- In 2012, average 1915(c) waiver expenditures per HCBS user varied from \$14,556 (fibromyalgia, chronic pain and fatigue) to \$51,464 (intellectual disabilities and related conditions). Four other conditions reported waiver expenditures per user between \$40,000 and \$50,000: ADHD, bipolar, epilepsy, and schizophrenia and other psychotic disorders.
- Average state plan expenditures per HCBS user varied from \$3,002 (bipolar disorder) to \$9,685 (mobility impairments). Average 1915(c) waiver expenditures per user exceeded average state plan expenditures per user for every chronic condition, possibly because of limits on the amount duration and scope of state plan benefits, or because waiver services are more expansive and more expensive.
- Average institutional LTSS expenditures ranged from \$1,140 (learning to disabilities) to \$21,694 (Alzheimer's disease and related disorders or senile dementia). Three other conditions have average institutional LTSS costs per user between \$10,000 and \$20,000: mobile impairments, peripheral vascular disease, and sensory impairments.

**Exhibit III.15. Average FFS Medicaid expenditures for long-term services and supports (LTSS) for all states in 2012, by chronic condition**

	Average Medicaid FFS expenditures	Average LTSS expenditures				
		LTSS total	1915(c) waiver and state plan services	1915(c) waivers	State plan services	Institutional LTSS
All HCBS users	22,324	14,754	9,925	26,083	4,253	4,830
ADHD, Conduct Disorders, Hyperkinetic Syndrome	30,009	19,509	15,149	48,049	3,015	4,360
Alzheimer's Disease and Related Disorders or Senile Dementia	38,462	33,311	11,617	16,375	6,897	21,694
Anxiety Disorders	26,862	13,633	8,795	34,904	3,248	4,838
Autism Spectrum Disorders	34,834	27,115	24,536	35,374	5,627	2,579
Bipolar Disorder	27,854	15,301	10,285	43,801	3,002	5,016
Cancer	33,692	12,843	7,965	18,382	5,293	4,879
Chronic Heart Failure (CHF)	33,711	17,973	8,828	15,531	5,775	9,145
Chronic Kidney Disease (CKD)	38,640	17,038	8,506	18,548	5,326	8,532
Chronic Obstructive Pulmonary Disease (COPD) and Bronchiectasis	27,032	13,696	7,454	16,370	4,620	6,242
Depression	26,358	14,679	8,069	29,372	3,504	6,610
Diabetes	22,769	13,293	7,469	19,765	4,066	5,824
Epilepsy	50,026	32,335	22,362	43,747	7,894	9,973
Fibromyalgia, Chronic Pain and Fatigue	25,209	8,220	5,785	14,556	3,907	2,436
Hyperlipidemia	25,228	13,873	8,714	28,963	3,771	5,159
Hypothyroidism	34,304	21,632	11,845	35,473	4,187	9,787
Ischemic Heart Disease (IHD)	25,666	14,182	7,152	15,043	4,858	7,030
Intellectual Disabilities and Related Conditions	56,635	49,281	40,675	51,464	5,979	8,606
Learning Disabilities	27,617	16,459	15,320	32,580	7,721	1,140
Mobility Impairments	51,342	33,336	18,220	28,545	9,685	15,116
Other Developmental Delays	33,545	20,541	19,070	21,752	7,141	1,472
Peripheral Vascular Disease (PVD)	34,893	23,792	10,277	25,564	5,853	13,515
Post-traumatic Stress Disorder (PTSD)	22,684	9,714	7,503	32,337	3,318	2,210
Rheumatoid Arthritis/ Osteoarthritis	20,341	12,085	7,631	16,793	4,528	4,454
Schizophrenia and Other Psychotic Disorders	32,290	19,752	11,125	43,466	4,182	8,627
Sensory Impairments	33,392	24,852	14,326	38,743	5,627	10,526
Stroke/Transient Ischemic Attack	36,277	20,036	10,254	17,652	5,868	9,781

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

This table presents the 26 most common conditions that were reported among all HCBS users. To identify these 26 conditions we looked at the top 20 conditions in each state across all years, and then removed any conditions that did not occur in at least 2 states in at least 2 years (for example, deleted conditions that only appeared in one state or in one year). Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

- We also analyzed changes in the total number of users and the average Medicaid FFS expenditures per user for each chronic condition from 2011 to 2012.
- The number of HCBS users for several conditions remained constant across the two years, although the number of users for a few conditions saw sizeable reductions. From 2011 to 2012, the number of HCBS users with ischemic heart disease dropped by 8.8 percent (61,000 beneficiaries); the number of HCBS users with hyperlipidemia dropped by 8.0 percent (60,000 beneficiaries); and the number of HCBS users with diabetes dropped by 6.9 percent (90,000 beneficiaries) (Exhibit III.16).
- The largest increase in the number of HCBS users with chronic conditions came under the heading of other developmental delays, increasing by 22.2 percent (32,455 beneficiaries) from 2011 to 2012. However, average Medicaid expenditures for this group saw the largest decrease among all conditions from 2011 to 2012 (12.6 percent).

**Exhibit III.16. Average Medicaid FFS expenditures per HCBS user<sup>a</sup> and total number of HCBS users, by chronic condition, 2011 and 2012**

Chronic health conditions	2011		2012		2012–2011 Difference	
	Total number of HCBS users	Average Medicaid FFS expenditures	Total number of HCBS users	Average Medicaid FFS expenditures	Total number of HCBS users	Average Medicaid FFS expenditures
<b>All HCBS users</b>	<b>6,114,377</b>	<b>\$22,589</b>	<b>5,856,105</b>	<b>\$22,324</b>	<b>-258,272</b>	<b>\$-265</b>
Intellectual disabilities and related conditions	554,154	\$56,972	551,202	\$56,635	-2,952	\$-337
Mobility impairments	192,441	\$52,082	188,212	\$51,342	-4,229	\$-740
Epilepsy	255,542	\$50,368	256,109	\$50,026	567	\$-342
Chronic kidney disease	515,307	\$40,515	502,368	\$38,640	-12,939	\$-1,875
Alzheimer's disease and related disorders or senile dementia	442,434	\$39,337	433,271	\$38,462	-9,163	\$-875
Stroke/transient ischemic attack	238,459	\$37,825	226,401	\$36,277	-12,058	\$-1,548
Peripheral vascular disease (PVD)	240,749	\$35,881	225,565	\$34,893	-15,184	\$-988
Autism spectrum disorders	124,239	\$35,414	145,838	\$34,834	21,599	\$-580
Hypothyroidism	272,071	\$34,384	259,344	\$34,304	-12,727	\$-80
Chronic heart failure (CHF)	525,960	\$34,888	487,018	\$33,711	-38,942	\$-1,177
Cancer	234,693	\$34,425	221,804	\$33,692	-12,889	\$-733
Other developmental delays	146,255	\$38,381	178,710	\$33,545	32,455	\$-4,836
Sensory impairments	211,506	\$33,568	204,346	\$33,392	-7,160	\$-176
Schizophrenia and other psychotic disorders	481,859	\$32,558	458,248	\$32,290	-23,611	\$-268
ADHD, conduct disorders, hyperkinetic syndrome	258,462	\$29,790	259,927	\$30,009	1,465	\$219
Bipolar disorder	415,944	\$28,197	405,193	\$27,854	-10,751	\$-343
Learning disabilities	101,008	\$30,313	115,211	\$27,617	14,203	\$-2,696
Chronic obstructive pulmonary disease and bronchiectasis (COPD)	713,339	\$27,839	671,885	\$27,032	-41,454	\$-807
Anxiety disorders	496,725	\$27,462	520,001	\$26,862	23,276	\$-600
Depression	1,019,946	\$26,790	970,642	\$26,358	-49,304	\$-432
Ischemic heart disease (IHD)	697,736	\$26,444	636,057	\$25,666	-61,679	\$-778
Hyperlipidemia	748,834	\$25,115	688,602	\$25,228	-60,232	\$113
Fibromyalgia, chronic pain, and fatigue	312,490	\$25,965	317,503	\$25,209	5,013	\$-756
Diabetes	1,323,061	\$23,347	1,232,385	\$22,769	-90,676	\$-578
Post-traumatic stress disorder (PTSD)	91,652	\$23,468	98,558	\$22,684	6,906	\$-784
Rheumatoid arthritis/osteoarthritis	628,482	\$21,155	598,455	\$20,341	-30,027	\$-814

Source: Mathematica analysis of 2010–2012 MAX PS and OT files.

Notes: The 2011–2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

This table presents the 26 most common conditions that were reported among all HCBS users. To identify these 26 conditions we looked at the top 20 conditions in each state across all years, and then removed any conditions that did not occur in at least 2 states in at least 2 years (for example, deleted conditions that only appeared in one state or in one year). Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

<sup>a</sup>The average Medicaid FFS expenditures is calculated from the total Medicaid FFS payment amount variable (TOT\_MD\_CD\_PYMT\_AMT) in the MAX PS file.

- Across all four study years, six conditions were ranked most common among all HCBS users: diabetes, depression, hyperlipidemia, COPD and bronchiectasis, ischemic heart disease, and rheumatoid arthritis/osteoarthritis (Exhibit III.17). Across the four study years, diabetes consistently ranked as the most common condition. Depression ranked second for each year; hyperlipidemia, third; and COPD, fourth. Ischemic heart disease and rheumatoid arthritis/osteoarthritis ranked as either fifth or sixth in each year.
- In 2012, the same six conditions were found in 81.9 percent of all HCBS users.
- Medicaid FFS expenditures for beneficiaries with the top six conditions totaled over \$117.7 billion, or 90.0 percent of the \$130.7 billion in total spending in 2012. The six conditions also accounted for 76.0 percent of all LTSS expenditures (51.9 percent of 1915(c) waiver spending, 79.9 percent of state plan service spending, and almost 100 percent of institutional LTSS spending). However, the six conditions were not the most expensive in terms FFS Medicaid spending per HCBS user (Exhibit III.18).
- The six conditions with the highest average Medicaid expenditures among all HCBS users in 2012 were intellectual disabilities and related conditions, mobility impairments, epilepsy, chronic kidney disease, Alzheimer's disease and related disorders or senile dementia, and stroke/transient ischemic attack (Exhibit III.18).
- In 2012, the average total LTSS expenditures for HCBS users with intellectual disabilities and related conditions (\$49,281) were more than three times the average total LTSS expenditures for all HCBS users (\$14,754). Average waiver expenditures for this population were about double the average waiver expenditures for all users (\$22,324).
- Individuals with mobility impairments had average Medicaid waiver expenditures similar to those of the total population, although state plan services and institutional LTSS services were much higher than the average for all users.



**Exhibit III.17. Total and average Medicaid FFS expenditures and LTSS expenditures, for the top six most common chronic conditions, 2012**

	Diabetes	Depression	Hyperlipidemia	COPD and bronchiectasis	Ischemic heart disease	Rheumatoid arthritis/ osteoarthritis	Total HCBS users
<b>Total number of beneficiaries</b>	<b>1,232,385</b>	<b>970,642</b>	<b>688,602</b>	<b>671,885</b>	<b>636,057</b>	<b>598,455</b>	<b>5,856,105</b>
Total Medicaid FFS expenditure	\$28,059,859,705	\$25,583,935,690	\$17,371,927,955	\$18,162,635,577	\$16,325,145,386	\$12,172,998,760	\$130,733,119,649
Average Medicaid FFS expenditures per user	\$22,769	\$26,358	\$25,228	\$27,032	\$25,666	\$20,341	\$22,324
<b>Total LTSS expenditure</b>	<b>\$16,382,045,934</b>	<b>\$14,248,525,787</b>	<b>\$9,553,174,028</b>	<b>\$9,201,840,879</b>	<b>\$9,020,610,783</b>	<b>\$7,232,339,569</b>	<b>\$86,402,601,161</b>
All HCBS services	\$9,204,526,982	\$7,832,187,080	\$6,000,761,426	\$5,007,930,006	\$4,549,136,929	\$4,566,541,238	\$58,119,663,724
1915(c) waivers	\$4,193,234,148	\$4,430,938,957	\$3,403,855,235	\$1,904,021,243	\$1,458,899,810	\$1,856,502,672	\$33,211,885,524
State plan services	\$5,011,292,835	\$3,401,248,123	\$2,596,906,191	\$3,103,908,762	\$3,090,237,119	\$2,710,038,565	\$24,907,778,199
Institutional LTSS	\$7,177,518,952	\$6,416,338,707	\$3,552,412,602	\$4,193,910,873	\$4,471,473,854	\$2,665,798,331	\$28,282,937,438
<b>Average LTSS expenditure</b>	<b>\$13,293</b>	<b>\$14,679</b>	<b>\$13,873</b>	<b>\$13,696</b>	<b>\$14,182</b>	<b>\$12,085</b>	<b>\$14,754</b>
All HCBS services	\$7,469	\$8,069	\$8,714	\$7,454	\$7,152	\$7,631	\$9,925
1915(c) waivers	\$19,765	\$29,372	\$28,963	\$16,370	\$15,043	\$16,793	\$26,083
State plan services	\$4,066	\$3,504	\$3,771	\$4,620	\$4,858	\$4,528	\$4,253
Institutional LTSS	\$5,824	\$6,610	\$5,159	\$6,242	\$7,030	\$4,454	\$4,830

Source: Mathematica analysis of 2012 MAX PS and OT files.

Notes: 2012 analyses included 44 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

**Exhibit III.18. Total and average Medicaid FFS expenditures and LTSS expenditures, for the top six conditions with the most expensive average Medicaid expenditures, 2012**

	Intellectual disabilities and related conditions	Mobility impairments	Epilepsy	Chronic kidney disease	Alzheimer’s disease and related disorders or senile dementia	Stroke/transient ischemic attack	Total HCBS users
<b>Total number of beneficiaries</b>	<b>551,202</b>	<b>188,212</b>	<b>256,109</b>	<b>502,368</b>	<b>433,271</b>	<b>226,401</b>	<b>5,856,105</b>
Total Medicaid FFS expenditures	\$31,217,517,424	\$9,663,245,777	\$12,812,081,730	\$19,411,267,868	\$16,664,583,998	\$8,213,038,444	\$130,733,119,649
Average Medicaid FFS expenditure	\$56,635	\$51,342	\$50,026	\$38,640	\$38,462	\$36,277	\$22,324
<b>Total LTSS expenditure</b>	<b>\$27,164,053,679</b>	<b>\$6,274,322,226</b>	<b>\$8,281,196,756</b>	<b>\$8,559,269,622</b>	<b>\$14,432,736,221</b>	<b>\$4,536,152,836</b>	<b>\$86,402,601,161</b>
All HCBS services	\$22,420,260,873	\$3,429,291,611	\$5,727,043,372	\$4,273,044,309	\$5,033,294,584	\$2,321,613,878	\$58,119,663,724
1915(c) waivers	\$19,124,482,981	\$1,606,466,296	\$3,705,256,421	\$1,597,314,078	\$2,045,090,870	\$993,107,588	\$33,211,885,524
State plan services	\$3,295,777,892	\$1,822,825,315	\$2,021,786,951	\$2,675,730,230	\$2,988,203,713	\$1,328,506,291	\$24,907,778,199
Institutional LTSS	\$4,743,792,806	\$2,845,030,614	\$2,554,153,384	\$4,286,225,314	\$9,399,441,638	\$2,214,538,958	\$28,282,937,438
<b>Average LTSS total expenditure</b>	<b>\$49,281</b>	<b>\$33,336</b>	<b>\$32,335</b>	<b>\$38,640</b>	<b>\$33,311</b>	<b>\$20,036</b>	<b>\$14,754</b>
All HCBS services	\$40,675	\$18,220	\$22,362	\$8,506	\$11,617	\$10,254	\$9,925
1915(c) waivers	\$51,464	\$28,545	\$43,747	\$18,548	\$16,375	\$17,652	\$26,083
State plan services	\$5,979	\$9,685	\$7,894	\$5,326	\$6,897	\$5,868	\$4,253
Institutional LTSS	8,606	\$15,116	\$9,973	\$8,532	\$21,694	\$9,781	\$4,830

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

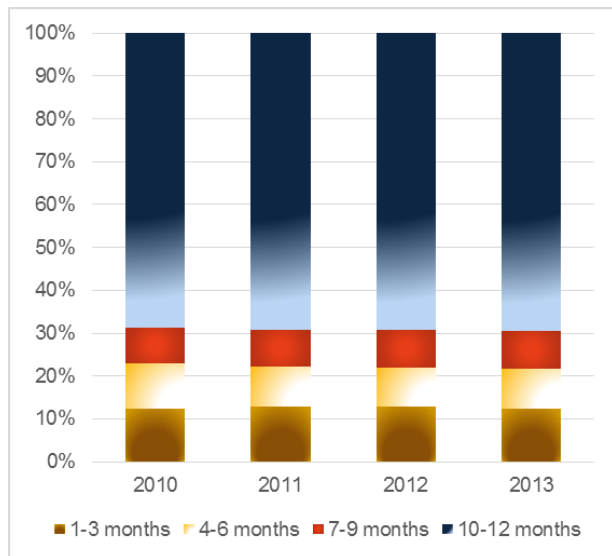
The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/developmental disabilities. 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. All reported expenditures are annualized.

Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

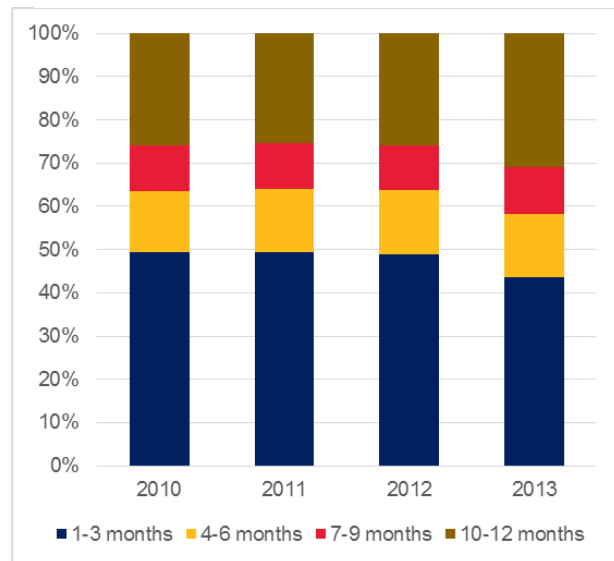
In addition to analyzing the 1915(c) waiver and state plan service expenditures, we reviewed the number of months in which HCBS users had HCBS claims.

- Most HCBS users had state plan service claims for a short period, while HCBS users typically had waiver claims over a longer term. Across years, about 70 percent of HCBS users had waiver claims for 10 to 12 months (Exhibit III.19). In 2010 to 2012, about 50 percent of HCBS users had state plan claims for one to 3 months (Exhibit III.20). In 2013, the proportion of HCBS users with state plan claims for one to 3 months declined slightly to 43.6 percent.
- The number of beneficiaries using waivers or state plan services did not change significantly over time.

**Exhibit III.19. Percentage of HCBS users with 1915(c) waiver claims, by year**



**Exhibit III.20. Percentage of HCBS users with state plan service claims, by year**



Source: Mathematica analysis of 2010–2013 MAX PS, and OT, files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

## **E. HCBS service use**

We used the HCBS taxonomy to understand the types of waiver services that beneficiaries used across years (in Exhibit III.21, we do not depict plan services because the HCBS taxonomy is not applied to state plan services in MAX data).

- All 44 states reported 1915(c) waiver expenditures for day services, caregiver support, and equipment, technology, and modifications. Home-based services were the most commonly used taxonomy service by users, with 47.3 percent of all waiver users having claims for home-based services. Another 40.5 percent of users had waiver claims for case management services.
- Round-the-clock services, home-based services, and day services comprised 77.2 percent of total Medicaid FFS expenditures for waiver users in 2012.
- Across states, the largest proportion of waiver expenditures was for round-the-clock services and home-based services (39.7 and 24.2 percent, respectively).
- The highest spending per user was attributable to round-the-clock services (\$50,411 in 2012). Rent and food expenses for live-in care givers also represented high spending per waiver service user, but this taxonomy category was rarely reported (only Minnesota reports this service in 2012).
- Overall, the percent of waiver service users, by taxonomy category remains consistent across years (Exhibit III.22). The percentage of users with case management claims increased slightly over time, and the percentage of users with home-based services increased slightly from 2010 to 2011. Given that 2013 includes only 25 of the 44 study states, it is difficult to interpret any differences from 2012 to 2013.

**Exhibit III.21. Use of and expenditures for services, by HCBS category, 2012**

HCBS taxonomy	Number of states reporting	Total Medicaid FFS HCBS expenditures	Percent of total Medicaid FFS HCBS expenditures	Total number of 1915(c) waiver service users	Percent of 1915(c) waiver service users	Average Medicaid FFS HCBS expenditures per user
All HCBS taxonomy	44	\$33,211,885,524	100%	1,273,315	100%	\$26,083
1. Case management	40	\$1,189,108,715	3.58%	515,721	40.5%	\$2,306
2. Round-the-clock services	43	\$13,168,033,703	39.65%	261,215	20.51%	\$50,411
3. Supported employment	39	\$452,944,097	1.36%	55,307	4.34%	\$8,190
4. Day services	44	\$4,400,608,828	13.25%	301,842	23.71	\$14,579
5. Nursing services	38	\$406,561,989	1.22%	78,758	6.19%	\$5,162
6. Home-delivered meals	34	\$212,610,360	0.64%	135,910	10.67%	\$1,564
7. Rent and food expenses for live-in care giver	1	\$314,963	0%	10	0%	\$31,496
8. Home-based services	43	\$8,054,424,625	24.25%	602,533	47.32%	\$13,368
9. Caregiver support	44	\$711,101,960	2.14%	162,778	12.78%	\$4,369
10. Other mental health and behavioral services	41	\$986,382,947	2.97%	125,931	9.89%	\$7,833
11. Other health and therapeutic services	39	\$195,121,151	0.59%	99,343	7.8%	\$1,964
12. Services supporting participant direction	15	\$186,120,680	0.56%	41,908	3.29%	\$4,441
13. Participant training	29	\$944,013,446	2.84%	55,890	4.39%	\$16,891
14. Equipment, technology, and modifications	44	\$293,227,976	0.88%	306,309	24.06%	\$957
15. Nonmedical transportation	37	\$484,144,094	1.46%	185,337	14.56%	\$2,612
16. Community transition services	25	\$19,423,254	0.06%	3,277	0.26%	\$5,927
17. Other services	18	\$42,700,407	0.13%	27,448	2.16%	\$1,556
18. Unknown	38	\$1,465,042,330	4.41%	130,773	10.27%	\$11,203

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Exhibit III.22. Percentage of 1915(c) waiver service users by taxonomy category, 2010 to 2013**

HCBS taxonomy category	Percent of 1915(c) waiver service users			
	2010	2011	2012	2013
1. Case management	35.52%	37.69%	40.5%	44.19%
2. Round-the-clock services	20.89%	20.78%	20.51%	26.62%
3. Supported employment	4.44%	4.4%	4.34%	5.12%
4. Day services	23.61%	23.78%	23.71%	28.24%
5. Nursing services	7.51%	7.09%	6.19%	5.95%
6. Home-delivered meals	11.48%	11.03%	10.67%	14.11%
7. Rent and food expenses for live-in care giver	0%	0%	0%	0%
8. Home-based services	43.46%	47.29%	47.32%	41.7%
9. Care giver support	12.16%	12.81%	12.78%	13.01%
10. Other mental health and behavioral services	8.75%	9.77%	9.89%	10.3%
11. Other health and therapeutic services	7.24%	7.51%	7.8%	6.49%
12. Services supporting participant direction	2.86%	3.08%	3.29%	3.85%
13. Participant training	3.85%	4.17%	4.39%	2.78%
14. Equipment, technology, and modifications	25.66%	24.81%	24.06%	22.76%
15. Nonmedical transportation	14.32%	14.53%	14.56%	20.66%
16. Community transition services	0.32%	0.24%	0.26%	0.29%
17. Other services	3.2%	2.43%	2.16%	3.12%
18. Unknown	16.15	13.37%	10.27%	9.39%

Source: Mathematica analysis of 2010–2013 MAX PS and OT files.

Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

- In 2012, 17 states reported that 50 percent or more of their total state waiver expenditures were allocated to round-the-clock services. Seven states reported that 50 percent or more of their total state waiver expenditures were allotted to home-based services (Exhibit III.23). The remaining ten states reported expenditures that were more evenly distributed or reported their state waiver expenditures to a different category.
  - For example, Michigan’s waiver expenses predominately included of home-based services (35.4 percent), other mental health (29.8 percent), and round-the-clock services (12.1 percent). Montana reported 37.9 percent of waiver expenditures were allocated to round-the-clock services, 25.6 percent to home-based services, and 16.3 percent to case management.
  - Arkansas reported 66.3 percent of their waiver expenditures as other mental and behavioral health services.
  - South Dakota reported 94.1 percent of its waiver expenditures were classified as unknown. This is consistent with previous research using the HCBS taxonomy with 2010 MAX data, that found South Dakota did not report procedure codes for over 99 percent of HCBS waiver claims, which were classified as unknown (Peebles & Bohl 2014).
- Exhibit III.23 also identifies states that spent more than the average across all study states for particular taxonomy categories in 2012. For example, across all states, 1.4 percent of waiver expenditures are allocated to supported employment. Three states (Connecticut, Maryland, and Nevada) all report more than five times this amount, or between 7.5 and 8 percent of their state’s waiver expenditures on supported employment.
- States also vary in the percent of total waiver expenditures allocated to services. For example, although only 3.0 percent of waiver expenditures across all states were allocated to other mental health and behavioral health services in 2012, individual states reported much higher and lower expenditures than this average.
  - 66.3 percent of waiver expenditures in Arkansas, almost 30 percent in Michigan, and almost 20 percent in North Carolina were classified as other mental and behavioral health services.
  - 23 states reported less than 1 percent of waiver expenditures were allocated to other mental health services.
- The percent of state expenditures allocated to day services was fairly consistent across states in 2012. Thirteen percent of waiver expenditures were allocated to day services across all states. By state, this ranged from 0.3 percent in South Dakota to 27.5 percent of expenditures in New York.

**Exhibit III.23. Percentage of total Medicaid FFS HCBS Expenditures, by HCBS taxonomy category, 2012**

Percentage of total Medicaid FFS HCBS Expenditures									
State	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
<b>All states</b>	3.58%	<b>39.65%</b>	1.36%	13.25%	1.22%	0.64%	0.00%	24.25%	2.14%
Alabama	5.65%	<b>40.23%</b>	0.74%	15.15%	0.39%	1.83	--	32.54%	2.36%
Alaska	5.79%	<b>54.94%</b>	2.93%	17.17%	0.50%	1.68	--	6.45%	6.42%
Arkansas	2.13%	0.01%	0.26%	1.19%	--	2.76	--	21.67%	4.66%
California	1.18%	<b>46.77%</b>	1.34%	17.23%	2.80%	0.05	--	1.96%	5.00%
Connecticut	1.81%	<b>44.83%</b>	7.52%	10.72%	0.01%	0.84	--	17.82%	0.83%
Delaware	0.55%	<b>72.84%</b>	3.12%	15.76%	0.15%	--	--	6.64%	0.00%
District of Columbia	0.87%	<b>51.74%</b>	0.85%	4.31%	0.01%	--	--	35.05%	0.76%
Florida	<b>31.44%</b>	9.42%	0.45%	7.58%	0.97%	1.12	--	18.01%	2.75%
Georgia	7.02%	24.25%	0.61%	15.92%	1.21%	5.48	--	<b>44.04%</b>	0.10%
Hawaii	0.08%	10.76%	0.09%	21.42%	2.15%	--	--	<b>63.73%</b>	0.63%
Illinois	0.54%	24.38%	0.56%	10.48%	0.21%	0.26	--	<b>48.67%</b>	0.44%
Indiana	2.78%	<b>57.32%</b>	1.28%	9.44%	0.38%	--	--	11.58%	5.48%
Iowa	2.65%	<b>58.74%</b>	0.39%	11.58%	--	0.99	--	10.62%	5.14%
Kentucky	7.62%	<b>29.69%</b>	0.01%	15.43%	0.01%	--	--	1.29%	1.92%
Louisiana	1.83%	0.01%	3.22%	4.18%	1.52%	0.01	--	<b>85.40%</b>	0.18%
Maryland	1.07%	<b>52.77%</b>	8.14%	16.16%	--	0.14	--	17.34%	0.72%
Massachusetts	--	<b>74.56%</b>	2.26%	7.56%	0.03%	0.48	--	8.78%	0.12%
Michigan	0.21%	12.08%	--	1.60%	5.67%	3.19	--	<b>35.38%</b>	6.98%
Minnesota	3.86%	<b>65.27%</b>	1.17%	10.09%	0.09%	0.37	0.02%	9.78%	1.84%
Mississippi	13.52%	2.87%	0.95%	10.68%	--	4.82	--	<b>55.94%</b>	10.10%
Missouri	0.12%	<b>83.33%</b>	0.92%	7.25%	0.01%	--	--	5.53%	0.17%
Montana	16.29%	<b>37.90%</b>	0.02%	1.66%	5.16%	1.21	--	25.61%	0.94%
Nebraska	--	<b>45.41%</b>	0.46%	14.16%	--	0.18	--	27.85%	0.61%
Nevada	1.27%	<b>55.72%</b>	7.66%	12.29%	0.13%	0.66	--	9.78%	0.22%
New Hampshire	5.88%	3.37%	2.02%	17.92%	1.42%	0.38	--	<b>52.66%</b>	0.82%
New Jersey	3.59%	<b>60.03%</b>	0.36%	15.14%	1.97%	0.33	--	12.30%	0.70%
New Mexico	4.12%	<b>53.05%</b>	0.62%	12.02%	0.28%	--	--	8.35%	8.61%
New York	2.12%	<b>66.23%</b>	0.97%	27.50%	0.00%	0.00	--	--	2.02%
North Carolina	3.17%	1.74%	1.40%	24.11%	3.10%	0.04	--	<b>40.28%</b>	4.09%
North Dakota	0.58%	<b>47.53%</b>	0.02%	24.85%	0.00%	0.00	--	11.48%	4.42%



Percentage of total Medicaid FFS HCBS Expenditures									
State	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
Ohio	--	4.65%	1.47%	10.96%	1.63%	2.34%	--	<b>68.19%</b>	0.07%
Oklahoma	11.32%	<b>41.52%</b>	3.62%	3.44%	1.66%	3.26%	--	25.58%	0.99%
Oregon	--	<b>50.38%</b>	--	0.08%	--	0.36%	--	48.74%	0.10%
Pennsylvania	4.35%	<b>39.64%</b>	0.94%	9.05%	2.46%	0.27%	--	36.36%	0.61%
South Carolina	5.20%	0.48%	--	7.77%	5.90%	5.77%	--	<b>59.72%</b>	0.24%
South Dakota	1.01%	--	0.01%	0.03%	0.41%	0.05%	--	3.37%	0.42%
Tennessee	3.02%	<b>56.70%</b>	--	19.06%	2.40%	--	--	7.37%	0.30%
Texas	0.53%	1.26%	0.00%	3.50%	1.90%	0.24%	--	40.60%	4.17%
Utah	6.93%	<b>61.00%</b>	2.74%	16.09%	0.00%	0.15%	--	3.62%	2.63%
Virginia	3.69%	0.07%	1.90%	0.72%	5.30%	--	--	26.08%	4.45%
Washington	0.00%	40.90%	--	0.14%	0.37%	0.06%	--	<b>50.02%</b>	1.59%
West Virginia	7.09%	4.43%	0.52%	5.88%	5.45%	--	--	<b>69.34%</b>	5.37%
Wisconsin	10.22%	<b>26.67%</b>	0.29%	9.36%	0.15%	0.55%	--	17.50%	0.74%
Wyoming	9.39%	<b>51.14%</b>	1.04%	19.79%	2.51%	1.52%	--	4.45%	4.59%

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Bold** text indicates that the state spent majority of their expenditures on this taxonomy category. Dashed cells (--) indicate that the service was not reported in that state in 2012.

**Exhibit III.23. Percentage of total Medicaid FFS HCBS Expenditures, by HCBS taxonomy category, 2012**

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
<b>All states</b>	2.97%	0.59%	0.56%	2.84%	0.88%	1.46%	0.06%	0.13%	4.41%
Alabama	0.48%	0.04%	--	0.03%	0.51%	0.05%	--	--	--
Alaska	0.73%	0.01%	--	--	0.70%	2.51%	--	--	0.18%
Arkansas	<b>66.32%</b>	--	--	--	0.92%	--	--	--	0.11%
California	12.03%	0.29%	--	1.74%	0.36%	5.99%	0.02%	0.70%	2.55%
Connecticut	0.34%	0.15%	0.00%	10.02%	0.47%	0.30%	--	0.00%	4.34%
Delaware	0.01%	0.41%	--	--	0.07%	--	--	--	0.44%
District of Columbia	2.45%	0.54%	--	0.01%	0.37%	--	0.00%	3.05%	--
Florida	8.08%	1.14%	--	9.00%	2.58%	2.46%	0.00%	--	5.00%
Georgia	0.04%	0.01%	0.15%	0.00%	1.04%	0.13%	--	0.01%	--
Hawaii	0.48%	0.32%	--	0.25%	0.00%	0.09%	--	--	--
Illinois	0.72%	0.05%	--	--	0.37%	0.21%	--	0.00%	13.12%
Indiana	0.28%	1.56%	6.99%	--	0.56%	2.34%	--	--	0.00%
Iowa	5.88%	0.73%	--	1.18%	1.11%	0.86%	0.02%	--	0.12%
Kentucky	6.39%	2.72%	1.42%	28.47%	0.40%	--	--	--	4.64%
Louisiana	2.32%	0.16%	--	0.02%	0.44%	0.65%	0.04%	--	0.02%
Maryland	0.14%	0.00%	--	0.00%	0.23%	--	0.65%	0.19%	2.46%
Massachusetts	4.24%	0.00%	--	0.30%	0.08%	1.52%	0.05%	--	0.01%
Michigan	29.75%	0.31%	--	0.09%	2.06%	0.43%	0.87%	0.00%	1.37%
Minnesota	2.55%	0.01%	2.33%	0.00%	0.79%	1.85%	--	--	0.00%
Mississippi	0.11%	0.04%	--	--	0.15%	0.82%	0.00%	--	--
Missouri	0.41%	0.06%	0.03%	0.04%	0.70%	1.42%	0.00%	--	0.00%
Montana	1.93%	0.25%	0.18%	0.00%	7.65%	0.96%	0.01%	--	0.23%
Nebraska	--	0.01%	--	--	0.11%	--	--	--	11.22%
Nevada	0.22%	0.13%	--	--	0.57%	1.01%	--	--	10.33%
New Hampshire	3.24%	0.02%	--	--	0.99%	0.00%	0.00%	--	11.29%
New Jersey	2.01%	0.87%	1.32%	0.21%	0.41%	0.04%	0.00%	--	0.72%
New Mexico	5.90%	4.94%	--	0.00%	0.94%	0.15%	0.00%	--	1.02%
New York	0.15%	0.05%	0.52%	0.30%	0.10%	0.00%	0.01%	0.04%	0.00%

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
North Carolina	19.91%	0.00%	0.00%	--	2.13%	0.00%	0.00%	--	0.03%
North Dakota	--	--	--	--	0.02%	0.00%	7.32%	--	3.76%
Ohio	0.07%	0.01%	--	--	1.81%	8.37%	0.02%	0.00%	0.40%
Oklahoma	0.68%	0.93%	--	--	4.74%	1.91%	0.00%	0.30%	0.05%
Oregon	0.00%	--	--	--	0.10%	0.20%	--	--	0.03%
Pennsylvania	0.47%	2.73%	0.78%	0.13%	0.94%	1.24%	0.01%	0.01%	0.01%
South Carolina	2.39%	0.31%	--	1.56%	8.18%	1.97%	--	0.00%	0.53%
South Dakota	--	--	--	0.02%	0.58%	--	--	--	<b>94.10%</b>
Tennessee	1.57%	2.11%	--	0.01%	0.06%	0.22%	0.01%	0.00%	7.19%
Texas	0.02%	0.57%	--	1.03%	0.72%	0.01%	0.01%	0.69%	<b>44.75%</b>
Utah	2.10%	0.29%	0.42%	0.32%	0.17%	2.71%	0.01%	0.62%	0.19%
Virginia	1.91%	1.78%	--	<b>47.79%</b>	3.83%	0.04%	--	0.19%	2.25%
Washington	1.77%	0.01%	0.01%	0.10%	0.92%	0.59%	0.04%	0.00%	3.48%
West Virginia	0.01%	0.31%	--	--	0.06%	0.57%	--	--	0.97%
Wisconsin	0.53%	--	25.62%	1.36%	1.35%	4.62%	0.01%	0.05%	1.01%
Wyoming	0.08%	0.58%	4.03%	0.20%	0.66%	0.03%	--	--	--

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Bold** text indicates that the state spent majority of their expenditures on this taxonomy category. Dashed cells (--) indicate that the service was not reported in that state in 2012.

- Case management, home-based services, round-the-clock services, and equipment were the most commonly used waiver taxonomy services in 2012 (Exhibit III.24). Twenty-two states reported 50 percent or more of their HCBS users had case management claims. Of these, 17 states (77.3 percent) had at least 75 percent of HCBS users using case management services. Nineteen states reported 50 percent or more of their HCBS users had claims related to home-based services, and of these states, four states (21.1 percent) had at least 75 percent of HCBS users using home-based services. Finally, six states reported 50 percent or more of their users had round-the-clock services, and six other states reported majority of their HCBS users had claims for equipment, technology, and modifications.
- Nine states (Alabama, Connecticut, Georgia, Mississippi, New Hampshire, North Carolina, Oklahoma, South Carolina, and West Virginia) reported 50 percent or more of their users had claims for both case management and home-based services.
- Eight states (California, Delaware, Iowa, Louisiana, Massachusetts, Nebraska, Nevada, and North Dakota) did not report a majority of HCBS users for any one taxonomy category. For example, in California, about 40 percent of users had claims for non-medical transportation, about 30 percent had claims for day services, round-the-clock services and caregiver support services each, and 22 percent had claims for other mental health and behavioral services.
- Some services were not commonly used by HCBS users across states, except for a few instances.
  - Across states, 23.7 percent of HCBS users had claims for day services in 2012. However, 88.6 percent of HCBS users in Tennessee and 60.2 percent of HCBS users in New York had claims for day services (As noted elsewhere in the report, Tennessee expenditures are not representative of all HCBS users in the state because of the statewide MLTSS).
  - Eleven percent of HCBS users across all states in 2012 used home-delivered meals. Seventeen states reported 2 percent or less of state users received this service; however, Mississippi had 54.7 percent of users with claims for home-delivered meals, and Oklahoma had 50.1 percent of HCBS users with claims for home-delivered meals.
  - Across states, 6.2 percent of HCBS users had claims for nursing services. In Oklahoma, 72.6 percent of HCBS users received nursing services.

**Exhibit III.24. Percentage of HCBS service users by HCBS category, 2012**

State	Percentage of HCBS service users								
	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
All states	40.50%	20.51%	4.34%	23.71%	6.19%	10.67%	0.00%	47.32%	12.78%
Alabama	58.67%	19.06%	1.70%	34.81%	0.84%	31.77%	0.00%	65.33%	11.73%
Alaska	97.43%	38.18%	7.04%	33.48%	0.21%	12.43%	0.00%	23.32%	33.00%
Arkansas	33.45%	0.01%	0.84%	2.99%	0.00%	40.94%	0.00%	54.35%	16.92%
California	15.46%	29.88%	2.94%	33.45%	2.52%	1.62%	0.00%	5.38%	31.36%
Connecticut	52.09%	17.19%	16.78%	24.18%	3.86%	19.99%	0.00%	55.53%	4.08%
Delaware	16.16%	32.01%	4.20%	36.25%	10.88%	0.00%	0.00%	41.18%	0.04%
District of Columbia	37.81%	18.93%	4.40%	9.88%	1.68%	0.00%	0.00%	70.20%	7.17%
Florida	95.40%	8.07%	3.42%	24.32%	1.57%	12.11%	0.00%	37.61%	13.42%
Georgia	75.05%	14.11%	3.79%	36.28%	4.12%	40.98%	0.00%	64.50%	1.40%
Hawaii	24.73%	18.07%	0.23%	39.50%	1.78%	0.00%	0.00%	54.06%	2.96%
Illinois	5.02%	8.81%	0.92%	14.87%	0.38%	1.49%	0.00%	60.94%	7.00%
Indiana	40.04%	38.72%	6.69%	20.62%	0.60%	0.00%	0.00%	40.06%	37.67%
Iowa	92.76%	33.10%	4.25%	43.38%	0.00%	17.22%	0.00%	27.76%	21.79%
Kentucky	73.35%	13.39%	0.03%	34.79%	0.02%	0.00%	0.00%	1.91%	11.30%
Louisiana	26.53%	0.02%	8.39%	10.92%	0.29%	0.19%	0.00%	45.38%	0.72%
Maryland	19.15%	37.54%	24.56%	37.76%	0.00%	3.75%	0.00%	26.86%	8.13%
Massachusetts	0.00%	35.42%	11.34%	26.21%	2.60%	20.77%	0.00%	41.57%	1.86%
Michigan	7.64%	12.86%	0.00%	3.70%	16.46%	31.60%	0.00%	52.47%	17.29%
Minnesota	97.47%	52.08%	6.68%	31.91%	0.11%	12.31%	0.02%	34.65%	8.97%
Mississippi	82.62%	2.33%	1.03%	13.28%	0.00%	54.66%	0.00%	86.45%	14.39%
Missouri	4.57%	65.79%	5.46%	36.49%	1.57%	0.00%	0.00%	21.71%	2.32%
Montana	97.64%	21.18%	0.21%	3.15%	8.76%	10.65%	0.00%	33.73%	2.36%
Nebraska	0.00%	27.87%	1.92%	35.26%	0.00%	6.40%	0.00%	34.30%	11.49%
Nevada	46.94%	28.65%	17.71%	23.67%	6.44%	8.89%	0.00%	33.17%	3.47%
New Hampshire	80.29%	8.39%	4.37%	26.10%	22.03%	8.65%	0.00%	51.97%	12.53%
New Jersey	96.72%	44.23%	2.11%	29.14%	6.40%	8.27%	0.00%	36.19%	7.36%
New Mexico	75.74%	61.21%	4.91%	48.12%	0.82%	0.00%	0.00%	17.29%	44.52%
New York	15.46%	55.34%	10.34%	60.18%	0.56%	0.08%	0.00%	0.00%	28.11%
North Carolina	55.57%	1.65%	4.53%	20.86%	2.07%	2.26%	0.00%	76.07%	33.32%
North Dakota	34.89%	30.38%	0.19%	20.53%	0.13%	0.11%	0.00%	25.58%	26.26%

Percentage of HCBS service users									
State	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
Ohio	0.00%	6.47%	7.04%	25.93%	4.89%	29.60%	0.00%	78.82%	0.57%
Oklahoma	79.24%	17.00%	6.93%	10.82%	72.58%	50.12%	0.00%	74.06%	5.65%
Oregon	0.00%	49.34%	0.00%	0.28%	0.00%	3.35%	0.00%	52.66%	0.90%
Pennsylvania	95.42%	12.27%	3.87%	19.17%	2.42%	6.73%	0.00%	49.93%	6.70%
South Carolina	73.44%	0.15%	0.00%	10.89%	1.38%	34.89%	0.00%	63.13%	0.66%
South Dakota	20.42%	0.00%	0.27%	0.33%	7.71%	1.65%	0.00%	14.73%	9.00%
Tennessee	85.44%	56.91%	0.00%	88.57%	4.17%	0.00%	0.00%	24.18%	4.67%
Texas	7.12%	1.56%	0.01%	3.01%	18.70%	3.95%	0.00%	69.68%	6.50%
Utah	94.12%	64.73%	10.71%	37.57%	0.09%	4.30%	0.00%	17.52%	17.64%
Virginia	45.80%	0.13%	4.43%	2.87%	2.71%	0.00%	0.00%	72.90%	32.64%
Washington	0.02%	30.60%	0.00%	15.22%	10.88%	1.15%	0.00%	64.55%	8.71%
West Virginia	91.74%	15.97%	3.90%	35.23%	78.87%	0.00%	0.00%	98.06%	14.80%
Wisconsin	98.75%	28.93%	3.29%	26.38%	5.03%	11.61%	0.00%	39.39%	7.31%
Wyoming	99.22%	38.51%	5.46%	40.15%	28.04%	28.14%	0.00%	34.04%	19.39%

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Exhibit III. 24. Percentage of HCBS service users by HCBS category, 2012 (continued)**

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
All states	9.89%	7.80%	3.29%	4.39%	24.06%	14.56%	0.26%	2.16%	10.27%
Alabama	5.05%	0.72%	0.00%	0.57%	10.52%	1.38%	0.00%	0.00%	0.00%
Alaska	4.81%	0.99%	0.00%	0.00%	20.54%	26.98%	0.00%	0.00%	4.23%
Arkansas	32.81%	0.00%	0.00%	0.00%	45.84%	0.00%	0.00%	0.00%	4.38%
California	21.87%	2.96%	0.00%	6.85%	11.19%	39.66%	0.18%	11.24%	9.25%
Connecticut	4.99%	13.37%	0.47%	13.12%	38.03%	6.96%	0.00%	0.00%	3.89%
Delaware	0.31%	14.53%	0.00%	0.00%	27.70%	0.00%	0.00%	0.00%	6.25%
District of Columbia	11.34%	18.86%	0.00%	0.63%	45.01%	0.00%	0.02%	9.21%	0.00%
Florida	14.79%	13.61%	0.00%	14.28%	36.89%	16.69%	0.00%	0.00%	1.88%
Georgia	0.25%	0.11%	4.05%	0.05%	36.29%	1.34%	0.00%	0.18%	0.00%
Hawaii	1.12%	31.00%	0.00%	2.13%	0.03%	0.66%	0.00%	0.00%	0.00%
Illinois	12.48%	7.71%	0.00%	0.00%	15.40%	2.05%	0.00%	0.12%	13.85%
Indiana	2.52%	21.69%	8.76%	0.00%	27.90%	21.49%	0.00%	0.00%	0.00%
Iowa	27.71%	7.64%	0.00%	3.04%	23.79%	19.79%	0.42%	0.00%	4.39%
Kentucky	20.02%	7.48%	36.78%	45.31%	34.01%	0.00%	0.00%	0.00%	26.70%
Louisiana	39.32%	9.98%	0.00%	1.25%	9.35%	6.13%	0.35%	0.00%	0.80%
Maryland	6.55%	0.19%	0.00%	0.02%	12.63%	0.00%	1.12%	1.44%	67.41%
Massachusetts	8.21%	0.05%	0.00%	2.13%	3.97%	15.24%	0.28%	0.00%	0.61%
Michigan	41.57%	1.80%	0.00%	4.74%	62.83%	16.35%	8.96%	0.02%	17.79%
Minnesota	14.79%	0.02%	7.59%	0.11%	18.14%	40.55%	0.00%	0.00%	0.00%
Mississippi	0.16%	0.07%	0.00%	0.00%	4.43%	5.65%	0.01%	0.00%	0.00%
Missouri	9.51%	2.35%	0.46%	1.85%	23.61%	22.91%	0.13%	0.00%	0.09%
Montana	2.65%	2.21%	0.44%	0.04%	32.44%	20.91%	0.06%	0.00%	1.83%
Nebraska	0.00%	0.62%	0.00%	0.00%	10.59%	0.00%	0.00%	0.00%	30.17%
Nevada	4.82%	2.27%	0.00%	0.00%	27.90%	22.84%	0.00%	0.00%	5.67%
New Hampshire	17.83%	1.39%	0.00%	0.00%	28.54%	0.06%	0.02%	0.00%	12.77%
New Jersey	3.69%	1.54%	5.49%	0.93%	21.84%	1.84%	0.11%	0.00%	42.24%
New Mexico	54.79%	51.76%	0.00%	0.02%	17.66%	7.36%	0.14%	0.00%	23.20%
New York	6.73%	0.29%	1.05%	7.99%	1.63%	0.01%	0.23%	2.98%	0.61%

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
North Carolina	31.74%	0.01%	0.15%	0.00%	50.38%	0.11%	0.00%	0.00%	1.52%
North Dakota	0.00%	0.00%	0.00%	0.00%	0.67%	0.31%	2.73%	0.00%	7.80%
Ohio	1.97%	1.95%	0.00%	0.00%	50.45%	42.18%	0.36%	0.05%	3.38%
Oklahoma	4.68%	10.71%	0.00%	0.00%	72.21%	14.75%	0.03%	0.40%	2.69%
Oregon	0.01%	0.00%	0.00%	0.00%	0.22%	16.42%	0.00%	0.00%	0.25%
Pennsylvania	5.04%	23.12%	21.45%	0.53%	21.54%	13.51%	0.45%	3.76%	0.10%
South Carolina	4.45%	10.77%	0.00%	3.06%	76.66%	8.58%	0.00%	0.11%	3.40%
South Dakota	0.00%	0.00%	0.00%	1.45%	13.20%	0.00%	0.00%	0.00%	71.09%
Tennessee	22.82%	63.34%	0.00%	0.31%	1.67%	15.99%	0.19%	0.32%	19.17%
Texas	0.19%	5.61%	0.00%	2.11%	10.08%	0.11%	0.06%	4.58%	20.93%
Utah	30.03%	14.87%	24.54%	23.13%	10.46%	43.42%	0.58%	5.55%	2.61%
Virginia	8.87%	36.49%	0.00%	31.27%	62.34%	5.39%	0.00%	4.31%	58.58%
Washington	3.57%	0.06%	0.22%	1.80%	29.03%	35.47%	1.26%	0.00%	14.26%
West Virginia	0.04%	6.42%	0.00%	0.00%	2.72%	10.63%	0.00%	0.00%	8.84%
Wisconsin	9.34%	0.00%	33.47%	12.93%	34.59%	30.36%	0.08%	0.96%	4.60%
Wyoming	0.86%	4.55%	16.92%	1.51%	26.56%	4.18%	0.00%	0.00%	0.00%

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.



- In Exhibit III.25, we present correlation coefficients for HCBS users with at least one 1915(c) waiver claim with a positive expenditure during the year (HCBS taxonomy is assigned only to 1915(c) waiver services). A correlation coefficient ( $r$ ) describes the linear relationship between two quantities (i.e., HCBS taxonomy services) and ranges from -1.00 to +1.00. A correlation coefficient of +1.00 means the two services have a perfectly positive linear relationship; that is, higher utilization of one service is perfectly correlated with higher utilization of the other service. A correlation coefficient of -1.00 means that the two services have a perfectly negative linear relationship; that is, higher utilization of one service is perfectly correlated with a lower utilization of the other service. A correlation coefficient of 0.00 means that the two services are not correlated, with no pattern of utilization between the two services.
- A few services are moderately correlated as indicated by the pink cells. For example, home-based services are moderately correlated with case management; round-the-clock services; equipment, technology, and modifications; and non-medical transportation. Day services are moderately correlated with round-the-clock services and non-medical transportation.
- In this matrix, we show that no two services are strongly correlated (correlation coefficient above 0.50), suggesting that there is not a typical national set of services for HCBS. State variations reflect variations in state HCBS populations and the services offered under the various waivers.

**Exhibit III.25. Correlation matrix of types of HCBS taxonomy for all states, 2012**

HCBS Taxonomy	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing services	6. Home-delivered meals	7. Rent and food expenses for live-in caregiver	8. Home-based services	9. Caregiver support	10. Other mental health and behavioral services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Nonmedical transportation	16. Community transition services	17. Other services	18. Unknown
1. Case management	1.00	0.08	0.03	0.11	0.06	0.16	0.00	0.27	0.08	0.06	0.07	0.08	0.06	0.15	0.05	0.00	0.02	-0.01
2. Round-the-clock services	0.08	1.00	0.14	0.33	0.01	-0.01	0.00	-0.01	0.03	0.06	0.06	0.00	0.01	0.00	0.03	0.00	0.04	0.01
3. Supported employment	0.03	0.14	1.00	0.04	0.00	0.00	0.00	0.06	0.01	0.03	0.00	0.00	0.04	0.00	0.18	0.01	0.00	0.01
4. Day services	0.11	0.33	0.04	1.00	0.01	-0.01	0.00	0.11	0.08	0.07	0.05	0.00	0.02	0.00	0.31	0.01	0.00	0.00
5. Nursing services	0.06	0.01	0.00	0.01	1.00	0.04	0.00	0.08	0.01	0.01	0.03	0.00	0.00	0.06	0.00	0.00	0.00	0.00
6. Home-delivered meals	0.16	-0.01	0.00	-0.01	0.04	1.00	0.00	0.26	0.04	0.02	0.00	0.00	0.00	0.23	0.01	0.00	0.00	-0.01
7. Rent and food expenses for live-in caregiver	0.00	0.00	0.00	0.00	0.00	0.00	1.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
8. Home-based services	0.27	-0.01	0.06	0.11	0.08	0.26	0.00	1.00	0.08	0.05	0.01	0.04	0.02	0.25	0.25	0.00	0.01	-0.01
9. Caregiver support	0.08	0.03	0.01	0.08	0.01	0.04	0.00	0.08	1.00	0.13	0.04	0.00	0.02	0.06	0.02	0.00	0.02	0.00
10. Other mental health and behavioral services	0.06	0.06	0.03	0.07	0.01	0.02	0.00	0.05	0.13	1.00	0.05	0.01	0.09	0.02	0.01	0.00	0.01	0.00
11. Other health and therapeutic services	0.07	0.06	0.00	0.05	0.03	0.00	0.00	0.01	0.04	0.05	1.00	0.00	0.10	0.08	0.03	0.00	0.06	0.01
12. Services supporting participant direction	0.08	0.00	0.00	0.00	0.00	0.00	0.00	0.04	0.00	0.01	0.00	1.00	0.05	0.01	0.00	0.00	0.00	0.00
13. Participant training	0.06	0.01	0.04	0.02	0.00	0.00	0.00	0.02	0.02	0.09	0.10	0.05	1.00	0.01	0.06	0.00	0.01	0.00
14. Equipment, technology, and modifications	0.15	0.00	0.00	0.00	0.06	0.23	0.00	0.25	0.06	0.02	0.08	0.01	0.01	1.00	0.02	0.00	0.02	0.00
15. Nonmedical transportation	0.05	0.03	0.18	0.31	0.00	0.01	0.00	0.25	0.02	0.01	0.03	0.00	0.06	0.02	1.00	0.00	0.00	0.00
16. Community transition services	0.00	0.00	0.01	0.01	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1.00	0.00	0.00
17. Other services	0.02	0.04	0.00	0.00	0.00	0.00	0.00	0.01	0.02	0.01	0.06	0.00	0.01	0.02	0.00	0.00	1.00	0.00
18. Unknown	-0.01	0.01	0.01	0.00	0.00	-0.01	0.00	-0.01	0.00	0.00	0.01	0.00	0.00	0.00	0.00	0.00	0.00	1.00

Source: Mathematica analysis of 2012 MAX PS and OT files.

Note: Pink cells indicate correlation coefficients above 0.25.

The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

A correlation coefficient (r) describes the linear relationship between two quantities (i.e., HCBS taxonomy services), and it ranges from -1.00 to +1.00. A correlation coefficient of +1.00 means the two services have a perfectly positive linear relationship -- higher utilization of one service is perfectly correlated with higher utilization of the other service. On the other hand, a correlation coefficient of -1.00 means the two services have a perfectly negative linear relationship -- higher utilization of one service is perfectly correlated with a lower utilization of the other service. A correlation coefficient of 0.00 means that the two services are not correlated -- no pattern of utilization between the two services.

Cells highlighted in pink represent weak to moderate correlations (r = |0.25 to 0.5|). Cells highlighted in green represent moderate to strong correlations (r = |0.5 to 0.99|).

- Exhibit III.26 presents state-level information for the taxonomy services that were moderately correlated as indicated by the pink cells in Exhibit III.25.
- State-level correlations show stronger relationships between some taxonomy services, meaning that higher utilization of one service is correlated with higher utilization of the other service. Moderate to strong correlations ( $r = 0.5$  to  $0.99$ ) were identified between the following two taxonomy services:
  - Case management & home-based services – 9 states
  - Round-the-clock & day services – 11 states
  - Non-medical transportation & day services – 8 states
  - Home-based services & home-delivered meals – 3 states
  - Home-based services & equipment – 8 states
  - Home-based services & non-medical transportation – 4 states

**Exhibit III.26. Correlation matrix of types of HCBS taxonomy, by state, 2012**

State	Case management & home-based services	Round-the-clock & day services	Non-medical transportation & day services	Home-based services & home-delivered meals	Home-based services & equipment	Home-based services & non-medical transportation
All states	0.27	0.33	0.31	0.26	0.25	0.25
Alabama	0.71	0.67	0.02	0.56	0.1	0.15
Alaska	0.37	0.62	0.14	0.37	0.50	0.18
Arkansas	-0.04	0	0	0.39	0.42	0
California	0.18	0.32	0.62	0.02	0.05	0.01
Connecticut	0.57	0.55	0.17	0.27	0.53	0.04
Delaware	0.01	0.58	0	0.17	0.45	0
District of Columbia	0.21	0.42	0	0	0.50	0
Florida	0.45	-0.01	0.40	0.40	0.29	0.06
Georgia	0.43	0.3	0.21	0.36	0.41	0
Hawaii	-0.19	0.09	-0.01	0	0	0.14
Illinois	0.38	0.69	0.21	0	0.29	0.05
Indiana	0.53	0.28	0.51	0.34	0.53	0.01
Iowa	0.65	0.53	0.51	0	0.58	0.05
Kentucky	0.08	0.59	0	0	0.03	0
Louisiana	0.16	0	0.47	0.02	0.23	0.25
Maryland	0.43	0.51	0	0.31	0.39	0
Massachusetts	0	0.43	0.48	0.47	0.16	-0.01
Michigan	-0.01	0.03	0.06	0.46	0.36	0.32
Minnesota	0.23	0.23	0.86	0.11	0.25	0.05
Mississippi	0.77	-0.01	0.03	0.68	0.17	0.22
Missouri	0.14	0.42	0.35	0	0.18	0.12
Montana	0.41	0.05	0.17	0.32	0.5	0.52
Nebraska	0	0.18	0	0.30	0.47	0
Nevada	0.46	0.46	0.42	0.14	0.49	-0.03
New Hampshire	0.32	-0.02	0	0.17	0.31	0.03
New Jersey	0.37	0.31	0.16	0.28	0.48	-0.01
New Mexico	-0.05	0.58	-0.02	0	0.36	0.32
New York	0	0.18	0	0	0	0
North Carolina	0.78	0.04	0.03	0.17	0.64	0.01
North Dakota	0.33	0.22	0	0.10	0.14	0.1
Ohio	0	0.05	0.83	0.21	0.31	0.41
Oklahoma	0.70	0.25	0.26	0.35	0.6	-0.03
Oregon	0	0.01	0.01	0.2	-0.01	0.65
Pennsylvania	0.26	0.39	0.31	0.1	0.22	0.1
South Carolina	0.61	0	0.90	0.53	0.68	0.19
South Dakota	0.22	0	0	0.02	0.02	0
Tennessee	0.13	0.55	0.04	0	0.06	0.69
Texas	0.1	0	0.08	0.08	0.21	0.01
Utah	0.24	0.44	0.73	0.35	0.51	0.11
Virginia	-0.13	0	0.19	0	0.11	-0.04
Washington	0.01	-0.06	0.43	0.08	0.43	0.67
West Virginia	0.45	0.2	0.70	0	0.18	0.48
Wisconsin	0.56	0.36	0.34	0.45	0.54	0.23
Wyoming	0.1	0.78	-0.02	0.23	0.22	0.08

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

A correlation coefficient ( $r$ ) describes the linear relationship between two quantities (i.e., HCBS taxonomy services), and it ranges from -1.00 to +1.00. A correlation coefficient of +1.00 means the two services have a perfectly positive linear relationship -- higher utilization of one service is perfectly correlated with higher utilization of the other service. On the other hand, a correlation coefficient of -1.00 means the two services have a perfectly negative linear relationship -- higher utilization of one service is perfectly correlated with a lower utilization of the other service. A correlation coefficient of 0.00 means that the two services are not correlated -- no pattern of utilization between the two services.

Cells highlighted in pink represent weak to moderate correlations ( $r = |0.25$  to  $0.5|$ ). Cells highlighted in green represent moderate to strong correlations ( $r = |0.5$  to  $0.99|$ ).

## IV. HIGH-COST USER ANALYSIS

### A. High-cost HCBS users and spending in the analytic sample

- From 2010 to 2012, the high-cost population averaged 179,500 HCBS users across 44 states. In the 25 states that had data available for 2013, there were only 113,000 high-cost users. The majority (approximately 75 percent) of high-cost HCBS users were categorized as high-cost in the subsequent year as well (Exhibit HC.1).
- Although it represents 3 percent of the total HCBS user population, the high-cost HCBS user population accounts for 30.6 percent of overall HCBS spending in 2012 (Exhibit HC.2). Relative to the total population of HCBS users, the high-cost population has disproportionate spending on HCBS 1915(c) waiver services—over 40 percent of 1915(c) waiver services are concentrated in the high-cost HCBS population. The greater spending on waiver services compared to state plan services for the high-cost HCBS population is most likely because waiver services cover a wider range of services, often at a greater intensity or frequency than what is offered as state plan services.

#### Exhibit HC.1 High-cost user population expenditures and use, by year

Year	2010	2011	2012	2013
<b>Total number of high-cost HCBS users</b>	182,445	181,931	174,220	113,599
With 1915(c) waiver enrollment	40,139	38,579	33,192	20,817
With 1915(c) waiver claims	154,479	154,037	148,833	101,349
With state plan service claims	150,840	149,458	140,333	93,921
High-cost in subsequent year	137,000	133,606	87,102	N/A
<b>Total MAX HCBS expenditures (\$)</b>	17,888,709,141	18,188,821,797	17,786,219,936	12,787,451,818
1915(c) waivers	13,476,519,211	13,902,028,141	13,667,376,626	10,422,300,206
State plan services	4,412,189,930	4,286,793,657	4,118,843,310	2,365,151,611
<b>Proportion of expenditures accounted for by high-cost HCBS users (%)</b>	31	31	31	30
1915(c) waivers	43	43	41	42
State plan services	17	16	17	13

Source: Mathematica analysis of 2010–2013 MAX PS, and OT files.

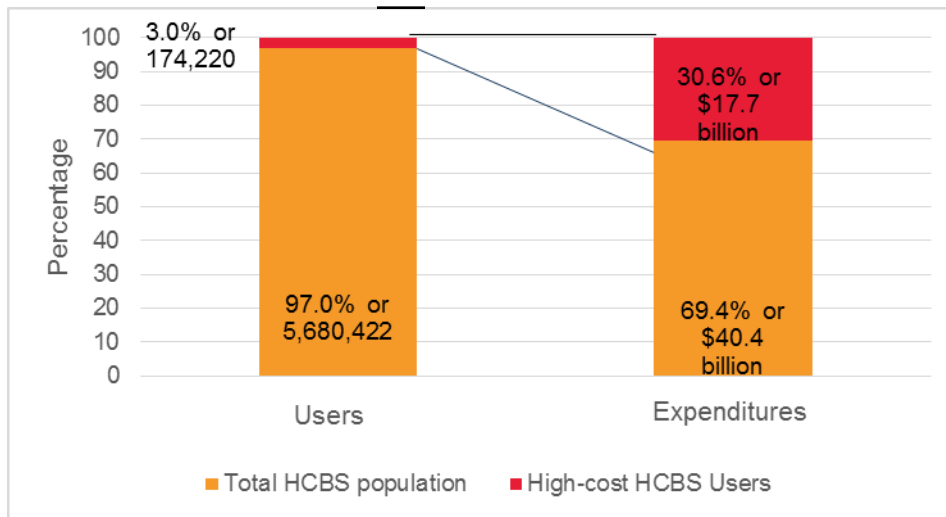
Notes: The 2010–2012 analyses included 44 states and the 2013 analysis included 25 states. For all four years, Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than

1 percent of HCBS users initially identified by the 3 percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

**Exhibit HC.2 Total population and high-cost users and expenditures, 2012**



Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.



**B. State variation in high-cost HCBS users and spending**

- On average, the high-cost HCBS user population accounts for 30.6 percent of all FFS HCBS spending in 2012, but there is substantial variation by state. In Alabama and Wisconsin, the high-cost HCBS users account for more than half of all HCBS spending in each state. In Virginia and Tennessee, high-cost users account for less than 20 percent of all HCBS spending (Exhibit HC.3). In Tennessee, this low number may be due to the fact that most HCBS is provided through managed care plans; at the time, HCBS spending through FFS was devoted to people who are excluded from managed LTSS—that is, people with intellectual and developmental disabilities (IDD)—and round-the-clock services for the IDD population are generally costly. Virginia, on the other hand, is unique in that the most commonly used service is participant training, which highlights a difference in the type of HCBS used in this state.
- In general, for 2012 high-cost HCBS users account for a greater share of 1915(c) waiver services than of state plan services. In all but two states (New Jersey and New Mexico), the high-cost HCBS user population makes up a disproportionate share of state plan services. In all but four states (Mississippi, Oregon, South Carolina, and Texas), the high-cost HCBS user group spending is driven by 1915(c) waiver rather than state plan services.

**Exhibit HC.3 HCBS expenditures accounted for by the high-cost HCBS user population, by state, 2012**

	Proportion of total HCBS expenditures accounted for by the high-cost HCBS user population		
	1915(c) waivers	HCBS state plan services	Total 1915(c) waivers and state plan services <sup>a</sup>
<b>All states</b>	<b>41.2%</b>	<b>16.5%</b>	<b>30.6%</b>
Alabama	81.8%	41.5%	68.0%
Alaska	37.8%	7.9%	24.6%
Arkansas	62.8%	19.2%	39.2%
California	54.3%	11.3%	23.0%
Connecticut	53.8%	8.5%	40.5%
Delaware	39.7%	5.8%	32.7%
District of Columbia	59.8%	5.5%	26.6%
Florida	44.0%	31.7%	38.6%
Georgia	36.9%	31.1%	35.3%
Hawaii	24.2%	4.8%	23.9%
Illinois	28.2%	31.1%	28.9%
Indiana	41.9%	28.1%	35.8%
Iowa	38.1%	17.0%	31.8%
Kentucky	31.9%	5.0%	27.8%
Louisiana	58.0%	12.5%	37.2%
Maryland	37.7%	22.6%	32.0%
Massachusetts	70.0%	15.5%	43.0%
Michigan	46.7%	25.5%	28.8%
Minnesota	25.7%	16.5%	22.8%

Proportion of total HCBS expenditures accounted for by the high-cost HCBS user population			
	1915(c) waivers	HCBS state plan services	Total 1915(c) waivers and state plan services <sup>a</sup>
Mississippi	26.7%	36.0%	29.9%
Missouri	77.0%	9.6%	37.0%
Montana	30.0%	24.9%	26.7%
Nebraska	40.1%	9.9%	32.7%
Nevada	59.7%	15.8%	31.0%
New Hampshire	31.4%	20.4%	29.8%
New Jersey	25.9%	1.9%	20.8%
New Mexico	25.0%	1.8%	24.2%
New York	52.1%	8.2%	31.5%
North Carolina	52.2%	15.9%	31.6%
North Dakota	39.4%	4.6%	32.9%
Ohio	31.7%	18.1%	27.0%
Oklahoma	47.9%	28.3%	43.9%
Oregon	17.8%	38.7%	23.0%
Pennsylvania	33.6%	26.1%	33.2%
South Carolina	7.0%	42.6%	29.8%
South Dakota	27.0%	16.9%	25.3%
Tennessee	15.3%	13.5%	15.0%
Texas	28.3%	42.1%	34.6%
Utah	31.3%	12.3%	25.2%
Virginia	21.0%	3.2%	19.7%
Washington	29.3%	10.8%	22.8%
West Virginia	53.5%	11.4%	42.3%
Wisconsin	77.2%	29.6%	55.8%
Wyoming	27.2%	9.9%	24.4%

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> Because not all high-cost HCBS users have waiver and state plan expenditures, the final column (waiver plus state plan services) does not necessarily equal the sum of the individual columns.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

### **C. Total LTSS and Non-LTSS spending**

In addition to analyzing HCBS spending, we examined total LTSS spending and total non-LTSS expenditure data for high-cost HCBS users in 2012 by using the MAX type-of-service (TOS) codes.

- Total LTSS spending (including HCBS and institutional services) for high-cost HCBS users comprised 90.6 percent of these individuals' total Medicaid expenditures, compared to 66.1 percent for all HCBS users. Less than one percent of total LTSS expenditures were spent on institutional services for the high-cost population, meaning they received virtually all services in home and community-based settings.
- For most types of services, non-LTSS spending of the total HCBS user population is similar to that of the high-cost HCBS user population. The high-cost HCBS population had proportionately similar spending for hospital (inpatient and outpatient), physician, and nursing services, but twice as much spending on dental, prescription, and other practitioner services, relative to the total HCBS population (Exhibit HC.4).
- High-cost HCBS users receiving other services, durable medical equipment, and private duty nursing account for the largest components of non-hospital expenditures. (Other services refer to claims with the TOS code equal to 19, and are likely to include a variety of HCBS, which are then categorized into more specific HCBS taxonomy categories.)

**Exhibit HC.4 FFS Medicaid expenditures for LTSS and non-LTSS for total population vs. high-cost HCBS users, 2012**

	Total HCBS Population	High-cost HCBS users	High cost/ Total
<b>Total number of HCBS users</b>	<b>5,856,105</b>	<b>174,220</b>	<b>3.0%</b>
Total Medicaid expenditures	\$130,733,119,649	\$19,761,658,739	15.1%
<b>Total LTSS expenditures</b>	<b>\$86,402,601,161</b>	<b>\$17,913,381,013</b>	<b>20.7%</b>
1915(c) waiver services	\$33,211,885,524	\$13,667,376,626	41.2%
State plan services	\$24,907,778,199	\$4,118,843,310	16.5%
Institutional services	\$28,282,937,438	\$127,161,077	0.4%
<b>Total non-LTSS expenditures<sup>a</sup></b>			
Total hospital services	\$22,531,274,385	\$727,072,638	3.2%
Inpatient services	\$19,277,151,883	\$647,580,345	3.4%
Outpatient services	\$3,254,122,502	\$79,492,293	2.4%
Total non-hospital services			
Physician services	\$3,516,969,796	\$117,234,898	3.3%
Nurse practitioner services	\$60,239,969	\$1,814,123	3.0%
Other practitioner services	\$447,963,100	\$29,399,043	6.6%
Laboratory and x-ray services	\$2,149,594,210	\$53,156,896	2.5%
Dental services	\$484,254,354	\$30,901,923	6.4%
Prescription drugs	\$8,167,588,697	\$542,628,341	6.6%

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

Only a subset of the total non-hospital services is shown in the table. The other categories include private duty nursing, rehabilitation, PT/OT/speech therapy, psychiatric services, durable medical equipment, and others.

<sup>a</sup>Total non-LTSS expenditures and total nonhospital 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 and we do not report overall expenditures.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010

**D. HCBS user demographics**

- In 2012, compared with the total HCBS population, the high-cost HCBS users have similar characteristics; however, a greater proportion of high-cost HCBS users were qualified for Medicaid based on a disability (86.6 vs. 63.9 percent), were between the ages of 19 and 64 (73.3 vs. 51.8 percent), were male (56.7 vs. 42.5 percent), or were of white, non-Hispanic race/ethnicity (62.9 vs. 49.9 percent) (Exhibit HC.5).
- Across the most frequently reported diagnoses for HCBS users, the high-cost HCBS user group is more than three times as likely as the total HCBS population to have claims with diagnosis code related to autism, epilepsy, intellectual disabilities, or other developmental delays. Also, high-cost HCBS users with these diagnoses have LTSS expenditures that are roughly twice as high as those of the overall high-cost HCBS user population. Non-LTSS spending is particularly high for HCBS users with intellectual and developmental disabilities (Exhibit HC.6).

**Exhibit HC.5 HCBS users in subpopulation, overall vs. high-cost users, 2012**

	Total HCBS Population	High-cost HCBS Users	Difference
<b>Total number of HCBS users</b>	<b>5,877,367</b>	<b>174,220</b>	<b>5,703,147</b>
<b>Medicaid eligibility</b>			
Aged	29.8%	11.4%	-18.4%
Blind/disabled	63.9%	86.6%	22.7%
Adults	1.6%	0.1%	-1.5%
Children	4.7%	1.9%	-2.8%
<b>Dual status</b>			
Full dual	32.9%	35.4%	2.5%
Partial dual	24.4%	21.0%	-3.4%
Medicaid only	42.7%	43.7%	1.0%
<b>Age</b>			
0–18 years	15.5%	13.9%	-1.6%
19–64 years	51.8%	73.3%	21.5%
65–84 years	24.8%	9.0%	-15.8%
85 years and older	8.0%	3.8%	-4.2%
<b>Gender</b>			
Female	57.5%	43.3%	-14.2%
Male	42.5%	56.7%	14.2%
<b>Race/ethnicity</b>			
White, non-Hispanic	49.9%	62.9%	13.0%
Black, non-Hispanic	22.7%	17.5%	-5.2%
Hispanic	11.2%	6.2%	-5.0%
Other non-white, non-Hispanic	16.2%	13.4%	-2.8%

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

**Exhibit HC.6 Proportion of HCBS users and expenditures in high-cost HCBS population, by chronic condition, 2012**

Chronic health conditions	High-cost users as share of HCBS users with condition	Proportion of Medicaid FFS expenditures	Proportion of LTSS total expenditures	Proportion of Non-LTSS total expenditures
<b>All HCBS users</b>	<b>3.0%</b>	<b>15.1%</b>	<b>20.7%</b>	<b>12.4%</b>
<b>ADHD, conduct disorders, hyperkinetic syndrome</b>	<b>6.4%</b>	<b>27.6%</b>	<b>38.7%</b>	<b>17.7%</b>
Alzheimer’s disease/dementia	2.2%	5.3%	5.7%	9.0%
Anxiety disorders	2.6%	12.0%	21.1%	7.3%
<b>Autism spectrum disorders</b>	<b>11.3%</b>	<b>35.5%</b>	<b>41.9%</b>	<b>26.4%</b>
Bipolar disorders	4.0%	17.3%	28.7%	11.2%
Chronic heart failure	1.3%	4.5%	6.6%	4.3%
Chronic kidney disease	1.4%	5.2%	8.8%	4.3%
COPD and bronchiectasis	1.5%	8.2%	12.5%	7.3%
Depression	2.2%	9.5%	15.4%	7.2%
Diabetes	1.4%	6.6%	10.0%	5.5%
<b>Epilepsy</b>	<b>10.3%</b>	<b>28.1%</b>	<b>36.5%</b>	<b>23.2%</b>
Hyperlipidemia	2.1%	10.1%	16.8%	6.3%
Hypothyroidism	3.8%	14.8%	20.8%	11.1%
Ischemic heart disease	0.7%	3.1%	4.8%	2.6%
<b>Intellectual disabilities and related conditions</b>	<b>18.8%</b>	<b>40.8%</b>	<b>43.6%</b>	<b>37.7%</b>
<b>Learning disabilities</b>	<b>4.9%</b>	<b>28.8%</b>	<b>38.5%</b>	<b>20.2%</b>
Mobility impairments	6.0%	15.9%	20.4%	16.8%
<b>Other developmental delays</b>	<b>10.2%</b>	<b>35.1%</b>	<b>46.7%</b>	<b>24.1%</b>
Post-traumatic stress disorder	2.1%	11.2%	23.2%	6.5%
Peripheral vascular disease	1.8%	6.4%	8.8%	5.2%
Rheumatoid arthritis/osteoarthritis	0.9%	4.6%	7.1%	3.5%
Schizophrenia and other psychotic disorders	4.0%	14.4%	21.5%	10.2%
Stroke/transient ischemic attack	1.7%	5.2%	7.7%	5.2%

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

This table presents the most common 29 conditions that were reported among the high-cost user group. To identify these 29 conditions we looked at the top 20 conditions in each state across all years, and then removed any conditions that did not occur in at least 2 states in at least 2 years (for example, deleted conditions that only appeared in one state or in one year). Beneficiaries may also have more than one

chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.



## E. HCBS service use

We used the HCBS taxonomy to examine the most common types of waiver services used by high-cost HCBS users.

- Round-the-clock services, home-based services, and day services comprised about 80 percent or more of total Medicaid HCBS FFS expenditures for high-cost HCBS waiver users in the sample consistently each year.
- In 2012, the majority (57.1 percent) of expenditures were for round-the-clock services (Exhibit HC.7). Round-the clock (56.1 percent) and day services (52.0 percent) were the most commonly used taxonomy services.
- No HCBS taxonomy category was universally reported by all states for the high-cost HCBS population, but 43 of the 44 states reported waiver expenditures for day services, caregiver support, and equipment, technology, and modifications in 2012.
- In 2012, compared to the total HCBS population, high-cost HCBS users were more than twice as likely to use round-the-clock, day, and other mental health and behavioral services. However, compared with the total HCBS population, high-cost HCBS users were less likely to use for 8 of 18 HCBS taxonomy category services, such as home delivered meals, services supporting participant direction, and equipment, technology, and modifications.
- The highest average spending per person in 2012 was attributable to round-the-clock services (\$93,635), and the second highest was attributable to home-based services (\$48,510).
- Across all HCBS taxonomy categories, the high-cost HCBS group had greater average Medicaid FFS HCBS expenditures compared with the total HCBS population.
- For 26 of 44 states, round-the-clock services were used by at least half of the high-cost HCBS users and was the most commonly used taxonomy category. For 7 of the 18 states that did not fit this trend, home-based services were most commonly used. The exceptions include Arkansas, where other mental and behavioral services are used by 88.6 percent of high-cost HCBS users. Virginia is another state that has a unique high-cost HCBS user group, where the majority (71.3 percent) use participant training services (Exhibit HC.8).
- In the majority of states, high-cost HCBS users were more likely than the total HCBS user population to use round-the-clock and nursing services. However, in the majority of states, high-cost users were often less likely to use many categories of service, including case management, supported employment, day services, home-delivered measures, home-based services, caregiver support, and equipment, technology, and modifications (Exhibit HC.8 compared with Exhibit III.23).
- Among the high-cost HCBS user population, the services that are most commonly used together (correlation > 0.25) are: (1) day services and round-the-clock services, (2) non-medical transportation and home-based services, and (3) other mental health and behavioral services and caregiver support (Exhibit HC.9).

**Exhibit HC.7 Use of and expenditures for services for high-cost population, by HCBS category, 2012**

	Number of states reporting	Percentage of total Medicaid FFS HCBS expenditures	Percentage of 1915(c) waiver service users	Ratio of use relative to total population	Average Medicaid FFS HCBS expenditures per user	Ratio of average expenditures vs. total population
<b>All HCBS taxonomy</b>	<b>44</b>	<b>100.00%</b>	<b>100.00%</b>	<b>100.00</b>	<b>\$91,919</b>	<b>3.52</b>
1. Case management	35	2.11%	30.93%	0.76	\$6,274	2.72
2. Round-the-clock services	39	57.13%	56.08%	2.73	\$93,635	1.86
3. Supported employment	35	0.90%	6.82%	1.57	\$12,135	1.48
4. Day services	43	12.53%	52.03%	2.19	\$22,134	1.52
5. Nursing services	35	2.22%	7.60%	1.23	\$26,806	5.19
6. Home delivered meals	26	0.03%	1.75%	0.16	\$1,762	1.13
7. Rent and food expenses for live-in caregiver <sup>a</sup>	1	0.00%	0.00%	NS	\$63,378	2.01
8. Home-based services	42	12.81%	24.28%	0.51	\$48,510	3.63
9. Caregiver support	43	0.96%	11.40%	0.89	\$7,762	1.78
10. Other mental health and behavioral services	37	3.48%	22.35%	2.26	\$14,293	1.82
11. Other health and therapeutic services	35	0.28%	8.13%	1.04	\$3,137	1.60
12. Services supporting participant direction	13	0.33%	1.26%	0.38	\$24,205	5.45
13. Participant training	23	1.92%	4.88%	1.11	\$36,182	2.14
14. Equipment, technology, and modifications	43	0.35%	14.04%	0.58	\$2,260	2.36
15. Non-medical transportation	33	1.01%	22.85%	1.57	\$4,052	1.55
16. Community transition services	15	0.04%	0.17%	0.65	\$21,859	3.69
17. Other services	15	0.06%	1.73%	0.80	\$3,409	2.19
18. Unknown	33	3.84%	10.73%	1.04	\$32,888	2.94

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> The only state that received “7. Rent and food expenses for live-in caregiver services” in 2012 was Minnesota, with 10 HCBS users.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

**Exhibit HC.8 Percentage of total Medicaid FFS HCBS Expenditures for high-cost HCBS users, by HCBS taxonomy category and state, 2012**

Percentage of total Medicaid FFS HCBS Expenditures									
State	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
<b>All states</b>	2.11%	<b>57.13%</b>	0.90%	12.53%	2.22%	0.03%	0.00%	12.81%	0.96%
Alabama	1.69%	49.04%	0.51%	13.50%	0.47%	0.52%	0.00%	31.58%	1.56%
Alaska	2.18%	<b>70.74%</b>	4.13%	18.15%	1.31%	0.03%	0.00%	1.25%	1.50%
Arkansas	2.07%	0.00%	0.32%	0.20%	0.00%	0.33%	0.00%	6.27%	1.54%
California	0.08%	<b>63.40%</b>	0.26%	10.70%	4.84%	0.00%	0.00%	2.41%	1.69%
Connecticut	0.01%	<b>69.76%</b>	4.71%	9.39%	0.00%	0.00%	0.00%	2.73%	0.22%
Delaware	0.00%	<b>84.13%</b>	3.13%	12.50%	0.06%	0.00%	0.00%	0.00%	0.00%
District of Columbia	0.07%	<b>78.66%</b>	0.76%	4.73%	0.00%	0.00%	0.00%	8.38%	0.29%
Florida	39.73%	13.19%	0.12%	6.14%	2.07%	0.02%	0.00%	10.61%	0.47%
Georgia	2.87%	<b>56.79%</b>	0.34%	16.75%	2.08%	0.17%	0.00%	19.83%	0.03%
Hawaii	0.00%	3.44%	0.00%	1.74%	4.11%	0.00%	0.00%	<b>88.24%</b>	0.42%
Illinois	0.02%	<b>73.72%</b>	0.68%	17.13%	0.30%	0.02%	0.00%	5.81%	0.35%
Indiana	0.92%	<b>77.38%</b>	0.07%	8.30%	0.00%	0.12%	0.00%	3.29%	3.34%
Iowa	0.12%	<b>80.48%</b>	1.13%	10.25%	0.74%	0.00%	0.00%	1.37%	0.32%
Kentucky	4.45%	<b>60.69%</b>	0.00%	13.44%	0.02%	0.00%	0.00%	0.14%	0.62%
Louisiana	0.05%	0.01%	1.80%	1.33%	2.61%	0.00%	0.00%	<b>93.13%</b>	0.12%
Maryland	0.00%	<b>72.87%</b>	4.93%	13.00%	0.00%	0.00%	0.00%	7.33%	0.05%
Massachusetts	0.00%	<b>89.70%</b>	1.06%	5.68%	0.00%	0.01%	0.00%	1.26%	0.01%
Michigan	0.05%	11.41%	0.00%	1.62%	10.27%	1.31%	0.00%	33.19%	9.19%
Minnesota	1.79%	<b>81.74%</b>	0.61%	8.14%	0.33%	0.00%	0.04%	2.71%	1.53%
Mississippi	3.40%	0.03%	2.99%	12.47%	0.00%	0.67%	0.00%	<b>67.93%</b>	11.27%
Missouri	0.08%	<b>88.21%</b>	0.81%	5.55%	0.01%	0.00%	0.00%	3.45%	0.06%
Montana	10.26%	17.59%	0.01%	2.76%	15.17%	0.67%	0.00%	37.84%	1.13%
Nebraska	0.00%	<b>65.02%</b>	0.13%	6.66%	0.00%	0.00%	0.00%	26.68%	0.17%
Nevada	0.00%	<b>68.83%</b>	6.87%	10.89%	0.16%	0.01%	0.00%	0.06%	0.01%
New Hampshire	2.27%	0.00%	0.66%	16.88%	0.01%	0.00%	0.00%	<b>71.45%</b>	0.03%
New Jersey	1.73%	<b>69.48%</b>	0.41%	20.81%	4.53%	0.00%	0.00%	0.00%	0.10%
New Mexico	2.01%	<b>74.38%</b>	0.12%	14.35%	0.37%	0.00%	0.00%	1.68%	0.02%
New York	0.08%	<b>77.73%</b>	0.23%	21.66%	0.00%	0.00%	0.00%	0.00%	0.12%

**Exhibit HC.8** (continued)

State	Percentage of total Medicaid FFS HCBS Expenditures								
	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing	6. Home delivered meals	7. Rent and food for caregiver	8. Home-based	9. Caregiver support
North Carolina	0.26%	3.09%	2.29%	40.86%	5.52%	0.00%	0.00%	15.01%	6.02%
North Dakota	0.00%	<b>60.37%</b>	0.00%	27.41%	0.00%	0.00%	0.00%	1.48%	0.03%
Ohio	0.00%	0.48%	0.85%	11.26%	2.26%	0.02%	0.00%	<b>78.18%</b>	0.01%
Oklahoma	0.00%	<b>70.62%</b>	4.78%	3.91%	1.77%	0.00%	0.00%	10.39%	1.47%
Oregon	0.00%	15.80%	0.00%	0.01%	0.00%	0.01%	0.00%	<b>84.06%</b>	0.01%
Pennsylvania	1.96%	<b>72.39%</b>	0.64%	7.70%	6.35%	0.00%	0.00%	9.54%	0.16%
South Carolina	1.16%	0.00%	0.00%	1.57%	<b>67.42%</b>	0.00%	0.00%	16.24%	0.60%
South Dakota	0.04%	0.00%	0.00%	0.00%	0.01%	0.00%	0.00%	0.26%	0.01%
Tennessee	1.17%	<b>68.87%</b>	0.00%	9.08%	6.20%	0.00%	0.00%	0.01%	0.26%
Texas	0.64%	1.00%	0.00%	6.17%	4.71%	0.00%	0.00%	6.36%	4.40%
Utah	2.62%	<b>74.02%</b>	0.88%	16.78%	0.00%	0.00%	0.00%	0.07%	0.01%
Virginia	2.67%	0.00%	1.36%	0.01%	16.38%	0.00%	0.00%	0.91%	0.40%
Washington	0.00%	<b>78.41%</b>	0.00%	0.02%	0.38%	0.00%	0.00%	17.20%	0.94%
West Virginia	4.84%	6.26%	0.71%	7.19%	8.80%	0.00%	0.00%	<b>64.55%</b>	5.25%
Wisconsin	6.86%	29.20%	0.22%	8.43%	0.17%	0.10%	0.00%	15.46%	0.61%
Wyoming	2.75%	<b>66.23%</b>	0.22%	24.39%	4.75%	0.02%	0.00%	0.55%	0.09%

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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.

<sup>a</sup>The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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.

**Bold** text indicates that the state spent majority of their expenditures on this taxonomy category. If the service was not reported, the table shows 0.00. High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

**Exhibit HC.8 Percentage of total Medicaid FFS HCBS Expenditures for high-cost HCBS users, by HCBS taxonomy category and state, 2012 (continued)**

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
<b>All states</b>	3.48%	0.28%	0.33%	1.92%	0.35%	1.01%	0.04%	0.06%	3.84%
Alabama	0.53%	0.05%	0.00%	0.03%	0.46%	0.06%	0.00%	0.00%	0.00%
Alaska	0.26%	0.01%	0.00%	0.00%	0.19%	0.23%	0.00%	0.00%	0.01%
Arkansas	<b>88.64%</b>	0.00%	0.00%	0.00%	0.51%	0.00%	0.00%	0.00%	0.12%
California	10.58%	0.19%	0.00%	0.96%	0.21%	4.12%	0.00%	0.06%	0.51%
Connecticut	0.12%	0.07%	0.00%	7.07%	0.01%	0.10%	0.00%	0.00%	5.82%
Delaware	0.00%	0.19%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
District of Columbia	3.83%	0.60%	0.00%	0.02%	0.03%	0.00%	0.00%	2.63%	0.00%
Florida	7.91%	1.36%	0.00%	6.37%	1.11%	2.07%	0.00%	0.00%	8.80%
Georgia	0.06%	0.00%	0.07%	0.00%	0.83%	0.16%	0.00%	0.00%	0.00%
Hawaii	1.28%	0.00%	0.00%	0.74%	0.01%	0.02%	0.00%	0.00%	0.00%
Illinois	1.66%	0.02%	0.00%	0.00%	0.10%	0.00%	0.00%	0.00%	0.18%
Indiana	5.15%	0.41%	0.00%	0.14%	0.56%	0.31%	0.00%	0.00%	0.00%
Iowa	0.00%	0.02%	3.36%	0.00%	0.04%	2.18%	0.00%	0.00%	0.00%
Kentucky	8.92%	5.48%	0.03%	4.55%	0.23%	0.00%	0.00%	0.00%	1.42%
Louisiana	0.05%	0.01%	0.00%	0.00%	0.32%	0.52%	0.05%	0.00%	0.00%
Maryland	0.14%	0.00%	0.00%	0.00%	0.04%	0.00%	0.01%	0.24%	1.37%
Massachusetts	1.35%	0.00%	0.00%	0.03%	0.02%	0.86%	0.02%	0.00%	0.00%
Michigan	29.44%	0.46%	0.00%	0.13%	1.55%	0.40%	0.29%	0.00%	0.71%
Minnesota	0.51%	0.03%	0.76%	0.00%	0.52%	1.28%	0.00%	0.00%	0.00%
Mississippi	0.34%	0.15%	0.00%	0.00%	0.28%	0.46%	0.00%	0.00%	0.00%
Missouri	0.34%	0.05%	0.03%	0.03%	0.59%	0.78%	0.00%	0.00%	0.00%
Montana	1.49%	0.45%	0.41%	0.00%	10.91%	1.05%	0.01%	0.00%	0.24%
Nebraska	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	1.34%
Nevada	0.29%	0.18%	0.00%	0.00%	0.00%	1.08%	0.00%	0.00%	11.63%
New Hampshire	2.25%	0.00%	0.00%	0.00%	0.55%	0.00%	0.00%	0.00%	5.88%
New Jersey	0.68%	1.31%	0.03%	0.33%	0.02%	0.01%	0.00%	0.00%	0.56%
New Mexico	2.75%	4.16%	0.00%	0.00%	0.10%	0.02%	0.00%	0.00%	0.05%

**Exhibit HC.8** (continued)

Percentage of total Medicaid FFS HCBS Expenditures									
State	10. Other mental health services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
New York	0.04%	0.00%	0.08%	0.04%	0.02%	0.00%	0.00%	0.00%	0.00%
North Carolina	25.94%	0.00%	0.00%	0.00%	0.96%	0.01%	0.00%	0.00%	0.05%
North Dakota	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	8.62%	0.00%	2.09%
Ohio	0.02%	0.00%	0.00%	0.00%	0.51%	6.02%	0.00%	0.00%	0.36%
Oklahoma	1.21%	1.57%	0.00%	0.00%	1.27%	3.00%	0.00%	0.01%	0.00%
Oregon	0.00%	0.00%	0.00%	0.00%	0.08%	0.01%	0.00%	0.00%	0.01%
Pennsylvania	0.68%	0.23%	0.02%	0.11%	0.13%	0.09%	0.00%	0.00%	0.00%
South Carolina	1.44%	0.32%	0.00%	0.00%	10.99%	0.08%	0.00%	0.01%	0.17%
South Dakota	0.00%	0.00%	0.00%	0.00%	0.05%	0.00%	0.00%	0.00%	<b>99.61%</b>
Tennessee	1.96%	0.93%	0.00%	0.00%	0.04%	0.00%	0.00%	0.00%	11.50%
Texas	0.02%	0.27%	0.00%	1.40%	0.32%	0.01%	0.00%	0.74%	<b>73.95%</b>
Utah	2.85%	0.47%	0.00%	0.35%	0.00%	1.73%	0.00%	0.05%	0.16%
Virginia	0.76%	1.47%	0.00%	<b>71.25%</b>	3.09%	0.01%	0.00%	0.25%	1.45%
Washington	0.66%	0.01%	0.00%	0.01%	0.28%	0.07%	0.00%	0.00%	2.01%
West Virginia	0.01%	0.26%	0.00%	0.00%	0.03%	0.78%	0.00%	0.00%	1.32%
Wisconsin	0.61%	0.00%	30.73%	1.09%	0.99%	4.72%	0.01%	0.05%	0.74%
Wyoming	0.00%	0.93%	0.00%	0.00%	0.07%	0.00%	0.00%	0.00%	0.00%

Source: Mathematica analysis of 2012 MAX PS, OT, IP, and LT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

**Bold** text indicates that the state spent majority of their expenditures on this taxonomy category. . If the service was not reported, the table shows 0.00. High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

**Exhibit HC.9 Correlation matrix of types of HCBS taxonomy for high-cost users for all states, 2012**

HCBS Taxonomy	1. Case management	2. Round-the-clock services	3. Supported employment	4. Day services	5. Nursing services	6. Home delivered meals	7. Rent and food expenses for live-in caregiver	8. Home-based services	9. Caregiver support	10. Other mental health and behavioral services	11. Other health and therapeutic services	12. Services supporting participant direction	13. Participant training	14. Equipment, technology, and modifications	15. Non-medical transportation	16. Community transition services	17. Other services	18. Unknown
1. Case management	1.00	0.03	-0.02	-0.01	0.09	0.00	0.01	0.03	0.09	0.01	0.05	0.04	0.03	0.01	-0.02	-0.01	-0.01	-0.07
2. Round-the-clock services	0.03	1.00	0.16	0.30	-0.04	-0.03	0.00	-0.12	-0.06	0.03	0.04	-0.03	-0.02	-0.02	-0.07	-0.01	0.06	-0.08
3. Supported employment	-0.02	0.16	1.00	-0.01	-0.02	-0.01	0.00	0.07	0.00	0.02	-0.01	0.02	-0.02	-0.02	0.11	0.00	0.00	-0.02
4. Day services	-0.01	0.30	-0.01	1.00	-0.05	-0.03	0.00	0.06	0.02	0.03	0.01	-0.03	-0.02	-0.05	0.19	-0.01	-0.03	-0.10
5. Nursing services	0.09	-0.04	-0.02	-0.05	1.00	0.04	0.00	0.09	0.01	-0.02	0.03	0.00	-0.01	0.13	-0.02	0.00	0.00	-0.02
6. Home delivered meals	0.00	-0.03	-0.01	-0.03	0.04	1.00	0.00	0.14	0.04	0.05	-0.01	0.00	-0.01	0.19	0.01	0.01	0.00	-0.01
7. Rent and food expenses for live-in caregiver	0.01	0.00	0.00	0.00	0.00	0.00	1.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
8. Home-based services	0.03	-0.12	0.07	0.06	0.09	0.14	0.00	1.00	0.11	0.10	0.00	0.01	0.02	0.08	0.40	0.00	-0.01	-0.06
9. Caregiver support	0.09	-0.06	0.00	0.02	0.01	0.04	0.00	0.11	1.00	0.30	0.03	-0.01	0.00	0.04	-0.03	0.00	0.01	-0.04
10. Other mental health and behavioral services	0.01	0.03	0.02	0.03	-0.02	0.05	0.00	0.10	0.30	1.00	0.06	-0.01	0.02	0.01	-0.04	0.00	0.00	-0.05
11. Other health and therapeutic services	0.05	0.04	-0.01	0.01	0.03	-0.01	0.00	0.00	0.03	0.06	1.00	-0.01	0.20	0.15	0.01	0.00	0.06	-0.03
12. Services supporting participant direction	0.04	-0.03	-0.01	-0.03	0.00	0.00	0.00	0.01	-0.01	-0.01	-0.01	1.00	0.00	0.00	-0.01	0.00	0.00	-0.01
13. Participant training	0.03	-0.02	0.02	-0.02	-0.01	-0.01	0.00	0.02	0.00	0.02	0.20	0.00	1.00	0.02	0.04	0.00	0.01	-0.01
14. Equipment, technology, and modifications	0.01	-0.02	-0.02	-0.05	0.13	0.19	0.00	0.08	0.04	0.01	0.15	0.00	0.02	1.00	0.00	0.00	0.01	-0.02
15. Non-medical transportation	-0.02	-0.07	0.11	0.19	-0.02	0.01	0.00	0.40	-0.03	-0.04	0.01	-0.01	0.04	0.00	1.00	0.00	-0.01	-0.05
16. Community transition services	-0.01	-0.01	0.00	-0.01	0.00	0.01	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1.00	0.00	0.00
17. Other services	-0.01	0.06	0.00	-0.03	0.00	0.00	0.00	-0.01	0.01	0.00	0.06	0.00	0.01	0.01	-0.01	0.00	1.00	-0.01
18. Unknown	-0.07	-0.08	-0.02	-0.10	-0.02	-0.01	0.00	-0.06	-0.04	-0.05	-0.03	-0.01	-0.01	-0.02	-0.05	0.00	-0.01	1.00

Source: Mathematica analysis of 2012 MAX PS, and OT files.

Notes: 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

Light blue cells indicate correlation coefficients above 0.25.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010



**F. Consistently high-cost HCBS users in the analytic sample**

Consistently high-cost HCBS users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state, for two consecutive study years. We compared the characteristics of users who report high costs for multiple years and HCBS users who have high costs in a given year to determine whether these two user groups had different demographic characteristics. Exhibit HC.10 presents the number of high-cost and consistently high-cost users.

**Exhibit HC.10 High-cost user population expenditures and use, by year**

Year	2010	2011	2012	2013
Total number of high-cost HCBS users	182,445	181,931	174,220	113,599
Total number of consistently high-cost users (in subsequent year) (%)	137,000 (75.1%)	133,606 (73.4%)	87,102 (76.7%) <sup>a</sup>	N/A

Source: Mathematica analysis of 2010 - 2013 MAX PS, and OT files.

Notes: 2010-2011 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2012 - 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> Because only 25 states had data for 2013, we calculated the percentage of consistently high-cost HCBS users in 2012 only considering those states.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010

Consistently high-cost users are defined as beneficiaries with expenditures in the top 3 percent of our analytic sample, by state, for two consecutive study years.

Given that roughly 75 percent of high-cost HCBS users are consistently high-cost HCBS users, we did not find any observations in the consistently high-cost group that were not also in the overall high-cost HCBS user group.

- Similar to the high-cost HCBS users, consistently high-cost HCBS users were more likely to be Medicaid-eligible based on disability, below the age of 65, male, or of white, non-Hispanic race/ethnicity, compared with the overall HCBS population.
  - Compared with the overall population in 2012, consistently high-cost HCBS users in 2011-2012 were more likely to be Medicaid-eligible based on disability (91.3 vs. 63.9 percent), 19-64 (78.3 vs. 51.8 percent), male (58.8 vs. 42.5 percent), or of white, non-Hispanic race/ethnicity (63.5 vs. 49.9 percent).
- Most of the consistently high-cost users in 2011-2012 reported intellectual disabilities (67.5 percent). Other common conditions among this group include cerebral palsy (16.8 percent) and epilepsy (15.4 percent) (data not shown).
- Consistently high-cost HCBS users reported slightly higher average costs per user (about 8 percent larger), when compared to high-cost users (Exhibit HC.11).
- In 2012, average Medicaid FFS expenditures per user (for both high-cost and consistently high-cost) were greatest for children, not dually eligible for Medicare, under 18, male and Hispanic. For the total population HCBS group, average Medicaid FFS expenditures per user were highest for individuals eligible for Medicaid based on blindness/disability, not dually eligible for Medicare, age 85 and older, male, and white non-Hispanic (Exhibit HC.12).

**Exhibit HC.11 Average cost per user, by year, for high-cost and consistently high-cost users**

Year	2010	2011	2012	2013
High-cost HCBS users	\$98,050	\$99,976	\$102,091	\$112,567
Consistently high-cost users (in subsequent year) <sup>a</sup>	\$106,079	\$108,461	\$120,133 <sup>b</sup>	N/A

Source: Mathematica analysis of 2010 - 2013 MAX PS, and OT files.

Notes: 2010 - 2011 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> Average cost per user for the consistently high cost group is calculated by taking total expenditures for 1915(c) waivers and state plan services, and dividing by the total number of consistently high-cost users over a two-year period. Because expenditures cover a two-year period, we divide by two to calculate average cost per user, for one year.

<sup>b</sup> Because only 25 states had data for 2013, we calculated the percentage of consistently high-cost HCBS users in 2012 only considering those states.

High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b) had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010

Consistently high-cost users are defined as beneficiaries with expenditures in the top 3 percent of our analytic sample, by state, for two consecutive study years.

**Exhibit HC.12. Average fee-for-service Medicaid expenditures for high-cost in 2012 and consistently high-cost users in 2011-2012, by subpopulation for high-cost users**

	High-Cost HCBS Users (2012)		Consistently High-Cost Users (2011-2012) <sup>a</sup>	
	Total number of users	Average Medicaid FFS expenditures per user	Total number of users	Average Medicaid FFS expenditures per user <sup>b</sup>
<b>All HCBS users</b>	<b>174,220</b>	<b>\$113,429</b>	<b>133,600</b>	<b>\$118,329</b>
<b>Medicaid eligibility</b>				
Aged	19,869	\$93,948	9,234	\$120,072
Blind/disabled	150,841	\$115,105	121,980	\$117,383
Adults	162	\$113,036	111	\$130,104
Children	3,348	<b>\$153,579</b>	2,275	<b>\$161,423</b>
<b>Dual status</b>				
Full dual	61,606	\$110,010	48,273	\$116,350
Partial dual	36,536	\$101,522	26,226	\$109,676
Medicaid only	76,078	<b>\$121,917</b>	59,102	<b>\$123,786</b>
<b>Age</b>				
0 to 18 years	24,170	<b>\$144,114</b>	17,872	<b>\$147,950</b>
19 to 64 years	127,624	\$111,435	104,638	\$113,909
65 to 84 years	15,754	\$100,883	9,292	\$116,785
85 years and older	6,672	\$70,040	1,798	\$89,126
<b>Gender</b>				
Female	75,421	\$109,394	55,039	\$116,084
Male	98,799	<b>\$116,510</b>	78,561	<b>\$119,903</b>
<b>Race/ethnicity</b>				
White, non-Hispanic	109,502	\$113,557	84,829	\$119,515
Black, non-Hispanic	30,412	\$104,969	23,130	\$108,688
Hispanic	10,875	<b>\$123,970</b>	8,215	<b>\$127,545</b>
Other non-white, non-Hispanic	23,431	\$118,922	17,426	\$121,012

Source: Mathematica analysis of 2011 - 2012 MAX PS, and OT files.

Notes: 2011 - 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

<sup>a</sup> We compare high-cost users in 2012 to consistently high cost users in 2011–2012 in this table. Data for consistently high-cost users in 2012–2013 only includes 25 states with data available in 2013.

<sup>b</sup> Average Medicaid FFS expenditures per user are calculated by taking total Medicaid FFS expenditures, and dividing by the total number of consistently high-cost users over a two-year period. Because expenditures cover a two-year period, we divide by two to calculate average cost per user, for one year. High-cost users are defined as HCBS users with expenditures in the top three percent of our analytic sample, by state. After examining the data for users in the top three percent of HCBS costs, we further excluded from the sample high-cost HCBS users who (a) lived fewer than three months of the year and (b)

had HCBS spending greater than \$1 million and did not have HCBS service use in categories that could explain such high costs (for example, round-the-clock services). We excluded 1,482 HCBS users (less than 1 percent of HCBS users initially identified by the three percent cutoff), primarily from California, Florida, New York, and Texas, because they lived fewer than three months in 2012. We also excluded one HCBS user in New York who reported almost \$10 million in annualized expenditures in 2010.

Consistently high-cost users are defined as beneficiaries with expenditures in the top 3 percent of our analytic sample, by state, for two consecutive study years.

- Learning disabilities, osteoporosis, spina bifida, COPD, and hearing and visual impairments were the top five conditions with the highest average Medicaid FFS expenditures per user in 2012, for both the high-cost and consistently high-cost users (Exhibit HC.13).
- By comparing chronic conditions, high-cost and consistently high cost users report similar average Medicaid FFS expenditures per user in 2012.

**Exhibit HC.13 Proportion of HCBS users and average Medicaid expenditures per user in high-cost HCBS population in 2012, and in consistently high-cost users from 2011-2012, by chronic condition**

Chronic health conditions	High-Cost HCBS Users (2012)		Consistently High-Cost Users (2011-2012) <sup>a</sup>	
	Total number of users	Average Medicaid FFS expenditures per user	Total number of users	Average Medicaid FFS expenditures per user <sup>b</sup>
<b>All HCBS users</b>	<b>174,220</b>	<b>\$113,429</b>	<b>133,600</b>	<b>\$118,329</b>
ADHD, Conduct Disorders, Hyperkinetic Syndrome	16,604	\$129,642	13,273	\$131,651
Alzheimer’s Disease/dementia	9,647	\$92,063	4,281	\$112,209
Anxiety Disorders	13,550	\$123,442	9,920	\$125,844
Autism Spectrum Disorders	16,552	\$108,944	12,453	\$112,478
Bipolar Disorders	16,068	\$121,478	12,436	\$122,972
Cerebral Palsy	28,395	\$126,935	22,384	\$131,108
Chronic Heart Failure	6,211	\$118,305	3,394	\$126,008
Chronic Kidney Disease	7,076	\$141,833	4,170	\$148,389
COPD and Bronchiectasis	10,388	\$143,308	6,701	\$157,587
Depression	21,747	\$112,219	16,180	\$114,154
Diabetes	16,673	\$110,674	11,656	\$115,583
Epilepsy	26,416	\$136,051	20,544	\$139,672
Hearing and visual impairments overall	8,248	\$148,896	6,514	\$151,955
Hyperlipidemia	14,489	\$121,292	11,508	\$125,009
Hypothyroidism	9,969	\$131,695	7,663	\$135,954
Ischemic Heart Disease	4,532	\$111,064	2,622	\$123,471
Intellectual Disabilities and related conditions	103,675	\$122,782	90,160	\$123,412
Learning Disabilities	5,694	\$160,735	4,348	\$168,203
Mobility Impairments	11,224	\$137,303	8,209	\$143,310
Osteoporosis	2,979	\$153,248	2,293	\$163,680
Other Developmental Delays	18,154	\$116,021	14,208	\$114,870
Post-Traumatic Stress Disorder	2,043	\$122,496	1,371	\$124,542
Peripheral Vascular Disease	4,064	\$124,626	2,749	\$138,216
Pressure and Chronic Ulcers	5,963	\$129,204	3,696	\$135,524
Rheumatoid Arthritis/Osteoarthritis	5,336	\$105,245	3,650	\$113,617
Schizophrenia and Other Psychotic Disorders	18,214	\$116,934	14,624	\$119,126
Spina Bifida and Other Anomalies of the Nervous System	4,867	\$157,723	3,698	\$158,367
Stroke/Transient Ischemic Attack	3,829	\$112,582	2,084	\$123,916
Traumatic Brain Injury	1,555	\$140,835	1,208	\$139,889

Source: Mathematica analysis of 2011 - 2012 MAX PS, and OT files.

Notes: 2011 - 2012 analyses included 44 states. Arizona was excluded due to insufficient number of fee-for-service (FFS) claims; Colorado, Idaho, Kansas, Maine, and Rhode Island were excluded because of incomplete MAX data in 2010–2013; and Vermont was excluded due to data reliability issues. For 2013, 19 additional states were excluded due to incomplete MAX data.

The analysis includes all states that had FFS HCBS expenditures, including states that provided HCBS through other program types and authorities, such as 1115 waivers, or provided FFS HCBS to specific populations not enrolled in managed LTSS, such as beneficiaries with intellectual/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. All reported expenditures are annualized.

This table presents the most common 29 conditions that were reported among the high-cost user group. To identify these 29 conditions we looked at the top 20 conditions in each state across all years, and then removed any conditions that did not occur in at least 2 states in at least 2 years (for example, deleted conditions that only appeared in one state or in one year). Beneficiaries may also have more than one chronic condition in a study year. We determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year.

<sup>a</sup> We compare high-cost users in 2012 to consistently high cost users in 2011–2012 in this table. Data for consistently high-cost users in 2012–2013 only includes 25 states with data available in 2013. Consistently high-cost users are defined as beneficiaries with expenditures in the top 3 percent of our analytic sample, by state, for two consecutive study years.

<sup>b</sup> Average Medicaid FFS expenditures per user are calculated by taking total Medicaid FFS expenditures, and dividing by the total number of consistently high-cost users over a two-year period. Because expenditures cover a two-year period, we divide by two to calculate average cost per user, for one year.



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## V. CONCLUSION

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Consistent with the patterns identified in previous research, we found that a diverse population of Medicaid beneficiaries use HCBS, with the majority of HCBS spending concentrated in waiver services (MACPAC 2014). However, because of the varying LTSS needs of HCBS users, as well as state-specific waiver programs, there is considerable variation in HCBS user characteristics and spending by state. These findings are generally consistent across our study years (2010-2013).

In addition to updating results on HCBS expenditures and utilization, we provided expanded person-level analysis of all HCBS users (not just dual-eligible enrollees who use HCBS), with detailed information on chronic conditions. Previous work has analyzed chronic conditions in the HCBS population, but these results were just for risk adjustment, and descriptive statistics were not reported (Bohl, Ross and Ayele 2015). We applied a modified version of the CCW algorithm to MAX data to understand differences in services received by HCBS users with different chronic conditions and diagnoses. For purposes of this analysis, we modified the CCW algorithm to use diagnosis codes and include claims related to long-term care so that the algorithm is more appropriate and relevant to HCBS users. We find that, the prevalence of chronic health conditions, as well as disabilities, are high among HCBS users, highlighting the complexity of care for this population.

This study is also unique in that it assessed the characteristics and utilization of high-cost HCBS users. The results of this analysis—majority of high-cost outliers were eligible for Medicaid based on a disability, between the ages of 19 and 64, male, or white, non-Hispanic race/ethnicity, and used round-the-clock services, home-based services, and day services—are consistent with findings of related work on the Money Follows the Person demonstration (Irvin et al. 2017). However, we found that the HCBS taxonomy categories used by high-cost HCBS users vary by state, again pointing to the varying HCBS populations and waiver programs available in each state.

### A. Limitations

These results are based on the application of the HCBS taxonomy to the MAX claims data, which is limited to the data reported on Medicaid claims. MAX files generally do not include payments made by managed care plans to providers (i.e., encounter claims are usually assigned \$0 for claim payment), which means that they omit spending for HCBS users enrolled in MLTSS programs. Some states, such as Tennessee, Michigan, and Hawaii, provide HCBS through several program types and authorities for different populations, for example, MLTSS for older adults and people with physical disabilities and HCBS 1915(c) waivers for people with intellectual or developmental disabilities. Although we did not exclude such states from the analysis, their FFS HCBS expenditures are not representative of the entire HCBS population, so their results are not comparable to results from states in which FFS spending covers all HCBS users. Additionally, given that many of these people are dually eligible for Medicare, our analysis does not take into account Medicare expenditures, which are not available in MAX data.

Furthermore, the taxonomy is only applied to FFS waiver claims, meaning that state plan, and more importantly, managed care claims, are not included. Unlike waiver services, state plan services are not limited to beneficiaries who require HCBS and may be used by beneficiaries who have acute care needs. As a result, the HCBS taxonomy, or a similar classification system, cannot be applied to state plan services because the data does not accurately differentiate state plan services between HCBS and non-HCBS.

## **B. Future Research**

While the current report provides insights into the variation in characteristics and spending of HCBS users by state, future work should try to isolate populations that are common across and within each state. For instance, identifying populations based on multiple characteristics—basis of eligibility and service use—would facilitate state-by-state comparisons of HCBS service use for similar beneficiaries. Or, for the high-cost HCBS user population, more detailed subgroup analyses could help to tailor waiver programs to their LTSS needs and characteristics.

Additional research could also expand these analyses to managed care expenditures, or expand the application of the HCBS taxonomy to state plan services, especially since HCBS programs continue to evolve to meet the growing needs of Medicaid beneficiaries. This will be necessary as more states engage managed care organizations to meet the needs of LTSS populations.

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## **APPENDIX A**

### **DETAILED METHODOLOGY**

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## DETAILED METHODOLOGY

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This appendix describes the data elements extracted and created from the MAX files to construct the analytic files. It also summarizes the data quality checks we conducted to ensure the accuracy of data included in the Findings sections. We also briefly discuss limitations of the data sources and analytic approach.

### A. Analytic file development

#### 1. Universe of HCBS users

To begin developing the analytic files, we identified all beneficiaries in the MAX PS and OT files (by unique MSIS\_ID and STATE\_CD combination) who could be considered as HCBS users. Given that states offer HCBS through different programs and waiver authorities, we initially aimed to capture the maximum number of beneficiaries who could have used HCBS during any of the study years. We defined potential HCBS users as beneficiaries who had at least one month of 1915(c) waiver enrollment (MAX\_WAIVER\_TYPE\_<1-3>\_MO\_<1-12> = G through P) or at least one OT claim with a valid FFS community-based long-term care flag during the study years (CLTC\_FLAG = 11 through 20 or 30 through 40 with service end date in a given study year). The 1915(c) waivers included those for aged and disabled, aged, physically disabled, people with brain injuries, people with HIV/AIDS, intellectually disabled/developmentally disabled, people with mental illness/serious emotional disturbance, technology dependent/medically fragile, people with autism/autism spectrum disorder, and unspecified or unknown populations. HCBS state plan services included personal care, private duty nursing, adult day care, home health care, residential care, rehabilitation for aged or disabled enrollees, targeted case management for aged or disabled enrollees, transportation, hospice, or durable medical equipment.

#### 2. Key data elements from MAX files

After identifying the universe of HCBS beneficiaries, we pulled all relevant data elements from the MAX PS, OT, and LT files to create six types of beneficiary-level variables:

**Demographic variables.** For the subpopulation analysis, we created variables on age (EL\_DOB), sex (EL\_SEX\_CD), race and ethnicity (EL\_RACE\_ETHNCY\_CD), Medicaid basis of eligibility (MAX\_ELG\_CD\_MO\_<1-12>), dual-eligible status (EL\_MDCR\_DUAL\_ANN), and whether the beneficiary died during the study year (SSA\_DOD, MDCR\_DOD, or EL\_DOD).

**Monthly enrollment and service use indicators.** The MAX PS file records up to three waiver types per month for each beneficiary (MAX\_WAIVER\_TYPE\_1\_MO\_<1-12>, MAX\_WAIVER\_TYPE\_2\_MO\_<1-12>, and MAX\_WAIVER\_TYPE\_3\_MO\_<1-12>), including 1115, 1915(b), 1915(b)/(c), and 1915(c) waivers. We created an overall monthly 1915(c) waiver enrollment indicator to flag months in which a beneficiary had 1915(c) waiver enrollment in any of the three waiver-type variables during the month. For consistency, we also created monthly HCBS utilization indicators by flagging months in which the beneficiary had at least one HCBS-related claim (identified by CLTC\_FLAG). We created the monthly HCBS utilization indicators separately for state plan services (CLTC\_FLAG = 11 through 20) and for 1915(c) waiver services (CLTC\_FLAG = 30 through 40). Similarly, we created monthly

institutional care utilization indicators by flagging months in which the beneficiary had at least one mental hospital service, inpatient psychiatric facility, intermediate care facility, or nursing facility claim from the MAX LT file.

**Annual enrollment and service use indicators.** After creating the monthly indicators, we created binary annual variables to indicate whether beneficiaries had at least one month of 1915(c) waiver enrollment, 1915(c) waiver service claims, state plan service claims, or institutional service claims in each of the study years.

**HCBS claim count variables.** For all beneficiaries included in the universe of HCBS users, we counted the number of 1915(c) waiver service claims, number of state plan service claims, number of unique 1915(c) waiver service claims, and number of unique state plan service claims.

**Expenditure variables.** To minimize data processing times, we used prepopulated payment variables included in the MAX PS file to construct expenditure variables for the analysis. In particular, we used the following variables:

- 21 FFS payment by CLTC\_FLAG variables (CLTC\_FFS\_PYMT\_AMT\_<11-40>) that represent beneficiaries' total FFS expenditures for each CLTC\_FLAG code
- 31 FFS payment by type of service (TOS) variables (FFS\_PYMT\_AMT\_<TOS code>) that represent beneficiaries' total FFS expenditures for each type of service code (MAX\_TOS) in the MAX files
- 18 FFS payment by HCBS waiver taxonomy variables (HCBS\_FFS\_PYMT\_AMT\_<01-99>) that represent beneficiaries' total FFS expenditures for each HCBS taxonomy

We summed the CLTC FFS payment variables to calculate the total FFS expenditures on all HCBS, 1915(c) waiver services, and state plan services. We summed the TOS FFS payment variables to calculate the total FFS expenditures on institutional LTSS care, non-institutional LTSS care, hospital care, and non-hospital care. The HCBS taxonomy FFS payment variables were retained without any manipulation to report expenditures by taxonomy category.

### 3. Chronic conditions flags

We applied a modified version of the Chronic Conditions Warehouse (CCW) algorithm to MAX data to understand differences in services received by HCBS users with different conditions and diagnoses.<sup>10</sup> The original CCW algorithm, developed for Medicare beneficiaries, categorizes all relevant claims into one of 60 conditions based on diagnosis codes, procedure codes, and Medicare Severity-Diagnosis Related Groups (MS-DRGs) associated with the claims.<sup>11</sup> The 60 chronic conditions appear in Appendix B. The algorithm also automatically

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<sup>10</sup> As an alternative to using the CCW algorithm, we considered using the Chronic Illness and Disability Payment System (CDPS) to analyze health conditions because it was designed for use with Medicaid populations and categorizes beneficiaries based on severity of risk. However, we opted to use CCW because it covers a broader range of diagnostic groups related to chronic conditions, disabilities, mental health, and substance abuse than does CDPS.

<sup>11</sup> The CCW algorithm for chronic conditions and other potentially disabling conditions is available at <https://www.ccwdata.org/web/guest/condition-categories>.



excludes certain types of claims that are not considered to be acute care, such as long-term services and personal care services.

For purposes of this analysis, we modified the CCW algorithm to use diagnosis codes and include claims related to long-term care so that the algorithm is more appropriate and relevant to HCBS users.<sup>12</sup> For each year, we focused only on the MAX OT, LT, and IP claims<sup>13</sup> occurring in that year for all beneficiaries included in the universe of HCBS users. In other words, we did not use a look-back period beyond each study year. For example, for 2011, the universe of claims for identifying chronic conditions included only those with a service end date between January 1, 2011, and December 31, 2011. After applying the modified CCW algorithm, which flags chronic conditions at the claim level, we rolled up the flags to the beneficiary level for each year. That is, we determined a beneficiary as having a chronic condition in a given year if the beneficiary had at least one claim with that chronic condition flag during the study year. Beneficiaries may also have more than one chronic condition in a study year.

For the total HCBS population analysis, we focused on the 26 most common conditions; for the high-cost user population, we focused on the 29 most common conditions. We identified these “top” conditions by examining the top 20 conditions in each state across all years, and then removing any conditions that did not occur in at least 2 states in at least 2 years (for example, we deleted conditions that only appeared in one state or in one year).

#### **4. Annualization of expenditures for deceased beneficiaries**

For fair comparison of expenditures across beneficiaries, states, and study years, we annualized all expenditure variables so that they represent Medicaid payment amounts for 12 months. Each year, some HCBS users die. Consequently, expenditures may be greater for beneficiaries who survive the entire year because they continue to use services. To address this potential bias, we adjusted the expenditures for deceased beneficiaries by a factor of  $(12/(d - 0.5))$ , where  $d$  is the numeric month of death. This factor accounts for the number of months a beneficiary survived in a given calendar year. In the denominator, we subtract 0.5 from the numeric month of death to assume that all deceased beneficiaries lived at least half of the month of death. For example, if a beneficiary died in October, we adjusted his or her expenditures by  $(12/9.5) = 1.263$ . The adjustment calculates the amount of Medicaid expenditures the beneficiary would have incurred had he or she survived the entire year and continued to use services as he or she did before death. For beneficiaries who did not die during the year, we did not apply any annualization adjustments because the expenditures reflected the full 12 months of service utilization.

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<sup>12</sup> The modified CCW algorithm is based on the original CCW algorithm revised in July 2016. Mathematica Policy Research developed and has used the modified CCW algorithm in other projects.

<sup>13</sup> We did not include claims from the MAX RX file because it does not contain diagnosis codes that are required to apply the CCW algorithm.

## 5. Exclusions

To define the final analytic sample of HCBS users from the universe of HCBS beneficiaries, we excluded states with incomplete MAX files and beneficiaries with inconsistent or invalid demographic data and service utilization patterns.

**State exclusions.** We excluded seven states from the analysis for all study years: Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont. We excluded Arizona because it operated statewide MLTSS for all populations from 2010 to 2013 and so the state had noticeably few FFS HCBS claims (about 3.0 to 4.0 percent of all Medicaid claims in each year). We excluded Vermont because of data inconsistencies. Even though Vermont covers HCBS through an 1115 demonstration waiver and does not operate any 1915(c) waivers, it reported 1915(c) waiver expenditures. We excluded the remaining five states because they had incomplete MAX files for at least one of the study years. In Exhibit A.1, we present file availability as of May 2017 for these five states. After excluding all seven states, the final HCBS analytic files included 44 states for 2010, 2011, and 2012 (all states and the District of Columbia) and 25 states for 2013. Appendix C presents the list of states included in the analysis for each study year.

- **Exhibit A.1. MAX file availability status in states excluded from analysis**

State	MAX file availability (as of May 2017)
Colorado	No files available in 2011, 2012, and 2013.
Idaho	No MAX OT file in 2011.
Kansas	No MAX OT file in 2010. No files available in 2012 and 2013.
Maine	No MAX OT file in 2010. No files available in 2013.
Rhode Island	No files available in 2012 and 2013.

**Beneficiary exclusions.** After identifying the universe of HCBS users, we conducted preliminary analyses to identify beneficiary-level exclusions based on data anomalies or inconsistencies. We found that a small percentage of beneficiaries in the HCBS user universe was missing key demographic information needed for the subpopulation analysis, including age, sex, race/ethnicity, Medicaid basis of eligibility, and dual-eligible status. We excluded beneficiaries with missing or undefined demographic information. We also identified a small percentage of beneficiaries whose date of death occurred before the study year but who were included in the MAX file for that study year; we therefore excluded these beneficiaries. In addition to basing exclusions on missing or undefined demographic variables, we excluded beneficiaries whose claims did not suggest that they were true HCBS users, such as:

Beneficiaries with 1915(c) waiver enrollment but no 1915(c) waiver or state plan service claims during the year.

Beneficiaries with 12 months of concurrent 1915(c) waiver claims and institutional care claims in a given year.

Beneficiaries with 12 months of state plan service claims for transportation, hospice care, or durable medical equipment services and no other types of HCBS during a given study year (CLTC\_FLAG = 18, 19, or 20). We excluded these beneficiaries because these

services alone often indicate beneficiaries who reside in institutions for an extended period.

Finally, we excluded beneficiaries who did not have any FFS HCBS expenditures. Some of the beneficiaries included in the universe of HCBS users who were not excluded based on demographic variables or inconsistent claim patterns, as outlined above, had claims that appeared to be FFS HCBS claims but were actually covered by managed care organizations (these claims were flagged by FFS indicators but had a \$0 claim payment amount). Given that these beneficiaries were technically not FFS, we excluded them from the analytic files.

## **B. Data quality checks**

Given the volume of MAX data we processed for the analysis, we conducted several data quality checks to ensure accurate creation of the analytic files and the data tables.

- 1. Compared MAX expenditure data to CMS-64 expenditure data.** MAX and CMS-64 are the two main data sources used to study Medicaid service utilization and expenditures. MAX files are created from state-submitted eligibility and claims data and they track adjudicated claims. CMS-64 data are created from federal and state financial budget and grant systems. Because MAX and CMS-64 collect and report data according to different methods and definitions, aggregate expenditures usually differ as well. However, it is useful to compare Medicaid LTSS expenditures reported in MAX and CMS-64 data to determine if the amounts are generally similar in magnitude and spending trends over time.
- 2. Compared HCBS expenditures in the analytic file sample to other MAX analyses.** We compared waiver expenditures in our sample to previous reports on waiver expenditures in 2010 across states and by HCBS taxonomy category (Peebles and Bohl 2014). We also worked with the MAX production team at Mathematica to compare total waiver spending in our population to total waiver spending in MAX by state. Finally, we discussed state data anomalies with the MAX team.
- 3. Conducted code reviews with the research team and senior programmers.** To ensure that our programming code was accurate, we conducted several rounds of code reviews with researchers and senior programmers with extensive experience in MAX file construction and use of MAX for research.
- 4. Submitted data tables for review by HCBS experts at Mathematica.** Once the data tables, we asked senior HCBS and LTSS experts at Mathematica to review the outputs to ensure that they aligned with their understanding of and expertise in Medicaid HCBS users. In addition to observing national trends, they focused on state-level data, particularly with respect to the various 1915(c) waiver and state plan service programs operated by states.

## **C. Limitations of data sources**

Although MAX data support analysis of Medicaid utilization and service expenditures at the enrollee level, they have some limitations:

**MAX data do not include all types of Medicaid expenditures.** MAX data are based on claims submitted by providers to states for reimbursement and therefore do not include

other types of payments made outside of claims, such as disproportionate share hospital (DSH) payments and supplemental payments that states provide to nursing homes or hospitals (CMS 2014). Furthermore, MAX files generally do not include payments made by managed care plans to providers (i.e., encounter claims are usually assigned \$0 for claim payment), which means that they omit spending for HCBS users enrolled in MLTSS programs. Consequently, in states that operate MLTSS programs for all or a significant share of HCBS users, total FFS HCBS spending is not comparable to states that operate all HCBS programs through FFS waivers or state plan services.

**Data quality and completeness vary by state.** Some states' MAX files have missing or inconsistent data. As noted, we excluded five states because of incomplete MAX data for certain files or years. Other states exhibited data anomalies; for example, Vermont had 1915(c) waiver expenditures even though the state did not operate any 1915(c) waivers. In other states, we identified beneficiaries with \$0 HCBS claims that were indicated by FFS HCBS flags, but the claims were actually covered by managed care organizations and should not have been flagged by FFS variables in MAX. We also identified a small percentage of beneficiaries whose date of death occurred before the year of the MAX file but who were still included in the MAX files for that year. Our ability to differentiate HCBS services by category in the HCBS taxonomy also depended on the quality of state reporting.

**State plan services are not sorted by HCBS taxonomy.** We were unable to categorize HCBS provided as state plan benefits by HCBS taxonomy category because HCBS taxonomy is applied only to waiver claims. Unlike waiver services, state plan services are not limited to beneficiaries who require HCBS and may be used by beneficiaries who have acute care needs. As a result, the HCBS taxonomy, or a similar classification system, cannot be applied to state plan services because the data does not accurately differentiate state plan services between HCBS and non-HCBS (Wenzlow, Peebles, and Kuncaitis 2011).

## **APPENDIX B**

### **LIST OF CHRONIC CONDITIONS AND POTENTIALLY DISABLING CONDITIONS**

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**LIST OF CHRONIC CONDITIONS AND POTENTIALLY DISABLING CONDITIONS**

As listed below, the CCW algorithm identifies 27 common chronic conditions and 35 other chronic or potentially disabling conditions.

Common chronic conditions	Chronic or other potentially disabling conditions
<ul style="list-style-type: none"> <li>• Acquired Hypothyroidism</li> <li>• Acute Myocardial Infarction (AMI)</li> <li>• Alzheimer’s Disease</li> <li>• Alzheimer’s Disease, Related Disorders, or Senile Dementia</li> <li>• Anemia</li> <li>• Asthma</li> <li>• Atrial Fibrillation</li> <li>• Benign Prostatic Hyperplasia</li> <li>• Cancer, Colorectal</li> <li>• Cancer, Endometria</li> <li>• Cancer, Breast</li> <li>• Cancer, Lung</li> <li>• Cancer, Prostrate</li> <li>• Cataract</li> <li>• Chronic Kidney Disease</li> <li>• Chronic Obstructive Pulmonary Disease (COPD)</li> <li>• Depression</li> <li>• Diabetes</li> <li>• Glaucoma</li> <li>• Heart Failure (HF)</li> <li>• Hip/Pelvic Fracture</li> <li>• Hyperlipidemia</li> <li>• Hypertension</li> <li>• Ischemic Heart Disease (IHD)</li> <li>• Osteoporosis</li> <li>• Rheumatoid Arthritis/Osteoarthritis</li> <li>• Stroke/Transient Ischemic Attack</li> </ul>	<ul style="list-style-type: none"> <li>• ADHD, Conduct Disorders, and Hyperkinetic Syndrome</li> <li>• Alcohol Use Disorders</li> <li>• Anxiety Disorders</li> <li>• Autism Spectrum Disorders</li> <li>• Bipolar Disorders</li> <li>• Cerebral Palsy</li> <li>• Cystic Fibrosis and Other Metabolic Development Disorders</li> <li>• Depressive Disorders</li> <li>• Drug Use Disorders</li> <li>• Epilepsy</li> <li>• Fibromyalgia, Chronic Pain and Fatigue</li> <li>• HIV/AIDS</li> <li>• Intellectual Disabilities and Related Conditions</li> <li>• Learning Disabilities</li> <li>• Leukemias and Lymphomas</li> <li>• Liver Disease, Cirrhosis and Other Liver Conditions</li> <li>• Migraine and Chronic Headache</li> <li>• Mobility Impairments</li> <li>• Multiple Sclerosis and Transverse Myelitis</li> <li>• Muscular Dystrophy</li> <li>• Obesity</li> <li>• Other Developmental Delays</li> <li>• Peripheral Vascular Disease (PVD)</li> <li>• Personality Disorders</li> <li>• Post-Traumatic Stress Disorder (PTSD)</li> <li>• Pressure and Chronic Ulcers</li> <li>• Schizophrenia</li> <li>• Schizophrenia and Other Psychotic Disorders</li> <li>• Sensory – Blindness and Visual Impairment</li> <li>• Sensory – Deafness and Hearing Impairment</li> <li>• Spina Bifida and Other Congenital Anomalies of the Nervous System</li> <li>• Spinal Cord Injury</li> <li>• Tobacco Use</li> <li>• Traumatic Brain Injury and Nonpsychotic Mental Disorders due to Brain Damage</li> <li>• Viral Hepatitis</li> </ul>

Source: CCW Chronic Conditions, <https://www.ccwdata.org/web/guest/condition-categories>.

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**APPENDIX C**

**STATES INCLUDED IN EACH STUDY YEAR**

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**STATES INCLUDED IN EACH STUDY YEAR**

For all study years, we excluded seven states from the analysis: Arizona, Colorado, Idaho, Kansas, Maine, Rhode Island, and Vermont. The list below shows states included in the analysis for each study year. For 2010 to 2012, we included 44 states, including the District of Columbia. For 2013, we included 25 states, including District of Columbia. We included fewer states in 2013 because of incomplete MAX data.

2010, 2011, 2012	2013
Alabama	Arkansas
Alaska	California
Arkansas	Connecticut
California	Georgia
Connecticut	Hawaii
Delaware	Indiana
District of Columbia	Iowa
Florida	Louisiana
Georgia	Massachusetts
Hawaii	Michigan
Illinois	Minnesota
Indiana	Mississippi
Iowa	Missouri
Kentucky	New Jersey
Louisiana	New York
Maryland	Ohio
Massachusetts	Oklahoma
Michigan	Oregon
Minnesota	Pennsylvania
Mississippi	South Dakota
Missouri	Tennessee
Montana	Utah
Nebraska	Washington
Nevada	West Virginia
New Hampshire	Wyoming
New Jersey	
New Mexico	
New York	
North Carolina	
North Dakota	
Ohio	
Oklahoma	
Oregon	
Pennsylvania	
South Carolina	
South Dakota	
Tennessee	
Texas	
Utah	
Virginia	
Washington	
West Virginia	
Wisconsin	
Wyoming	

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