

# Medicaid Long-Term Services and Supports Users and Expenditures Among People Ages 0 to 20, 2022

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## Background

State Medicaid programs provide long-term services and supports (LTSS) to people of all ages. Although most people using Medicaid LTSS are over age 20, people ages 0 to 20 made up 28.6 percent of total people using Medicaid LTSS and 10.3 percent of total Medicaid LTSS expenditures in 2022. Little is known about the trends in service use and expenditures for home and community-based services (HCBS) and institutional LTSS for this age group. This brief compares the quantity of users and sum of expenditures across various HCBS and institutional categories for 2022 and the shares of total LTSS users and expenditures attributed to HCBS among people ages 0 to 20 to that of LTSS users and expenditures among people in other age groups. Calculations are based on data from the Transformed Medicaid Statistical Information System Analytic Files (TAF).<sup>2</sup>

### Key findings

- In 2022, 2.5 million HCBS users ages 0 to 20 accounted for \$17.0 billion in HCBS spending.
- In 2022, about 100,000 institutional users ages 0 to 20 accounted for \$3.5 billion in institutional spending.
- The most common category of HCBS among users ages 0 to 20 was state plan rehabilitative services and the most common institutional service type was mental health facility services.<sup>1</sup>
- The share that people ages 0 to 20 comprised of total LTSS users and expenditures varied widely across states.

The following 10 HCBS categories used in this analysis align with the services eligible for a temporary increase of 10 percentage points in the federal medical assistance percentage (FMAP) under section 9817 of the American Rescue Plan Act of 2021 (ARP):<sup>3</sup> section 1915(c) waiver programs; the section 1915(i) HCBS state plan option; section 1915(j) self-directed personal assistance services (PAS) option; section 1915(k) Community First Choice; the Program of All-Inclusive Care for the Elderly (PACE); state plan

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<sup>1</sup> For people ages 0 to 20, the relevant type of mental health facilities includes inpatient psychiatric facilities for people younger than 21.

<sup>2</sup> When interpreting findings, please note that the completeness, quality, and consistency of TAF data varies by state. For more information on the data source, methodology, state anomalies, and data tables, see the Methods box at the end of this brief.

<sup>3</sup> For more information on HCBS categories eligible for the temporary FMAP increase under the ARP section 9817, refer to <https://www.medicaid.gov/sites/default/files/2022-03/smd21003-update.pdf>.

personal care services; state plan home health services; state plan rehabilitative services; state plan case management services; and state plan private duty nursing services.<sup>4</sup>

We defined four institutional categories that align with previously published expenditure analyses:<sup>5</sup> nursing facility, intermediate care facility for individuals with intellectual disabilities (ICF/IID), mental health facility, and mental health facility disproportionate-share hospital (DSH) payments.<sup>6,7</sup>

## Distribution of Medicaid HCBS users and expenditures

**HCBS users by category.** Nationwide, 2,518,438 people ages 0 to 20 received HCBS in 2022 through a variety of Medicaid HCBS programs and state plan options; this age group comprised 32.1 percent of all HCBS users in 2022.<sup>8</sup> There were 3,794,851 people ages 21 to 64 using HCBS (48.4 percent of all HCBS users) and 1,531,843 people ages 65 and older using HCBS (19.5 percent of all HCBS users).<sup>9,10</sup> State plan rehabilitative services had the highest proportion of HCBS users ages 0 to 20 in 2022 (41.7 percent of all HCBS users ages 0 to 20), followed by state plan case management services (30.3 percent of all HCBS users ages 0 to 20), and state plan home health services (29.0 percent of all HCBS users ages 0 to 20) (Figure 1). Other categories of HCBS were less commonly used by people ages 0 to 20, with less than 2 percent of people using HCBS in this age group using section 1915(k) Community First Choice, state plan private duty nursing services, or the section 1915(i) HCBS state plan option.<sup>11</sup> Compared with other age groups, people ages 0 to 20 were more likely to use state plan HCBS like rehabilitative services and case

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<sup>4</sup> We assigned each claim to one category, with program-based services, for which enrollment information exists, assigned first (including section 1915(c) waiver programs, section 1915(i) HCBS state plan option, section 1915(j) self-directed PAS option, section 1915(k) Community First Choice, Money Follows the Person [MFP] demonstration, and PACE), followed by state plan services. State plan benefits refer to section 1905(a) state plan services. MFP demonstration services are included as an individual category in accompanying table output, but they are not included in the aggregate calculations of total HCBS or total LTSS expenditures or users in this brief because they are not part of section 9817 of the ARP.

<sup>5</sup> LTSS expenditure reports for prior years are available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.

<sup>6</sup> Mental health facilities include institutions for mental disease for people ages 65 and older and inpatient psychiatric facilities for people younger than 21. Hospitals are not included in the definition of institutional LTSS, although these are Medicaid facilities. CMS has not historically counted hospitals as part of institutional LTSS for tracking LTSS expenditures and use.

<sup>7</sup> As required by federal law, state Medicaid agencies distribute DSH payments to institutions that serve a large number of Medicaid beneficiaries and people without insurance to support the institutions' financial stability. These direct provider payments can be viewed as part of a state's overhead cost for providing institutional LTSS to people with low resources.

<sup>8</sup> The percentage of users across different HCBS categories does not sum to 100 because some beneficiaries received more than one type of HCBS during the year.

<sup>9</sup> The TAF lacked the information needed to identify the ages of 55 HCBS users.

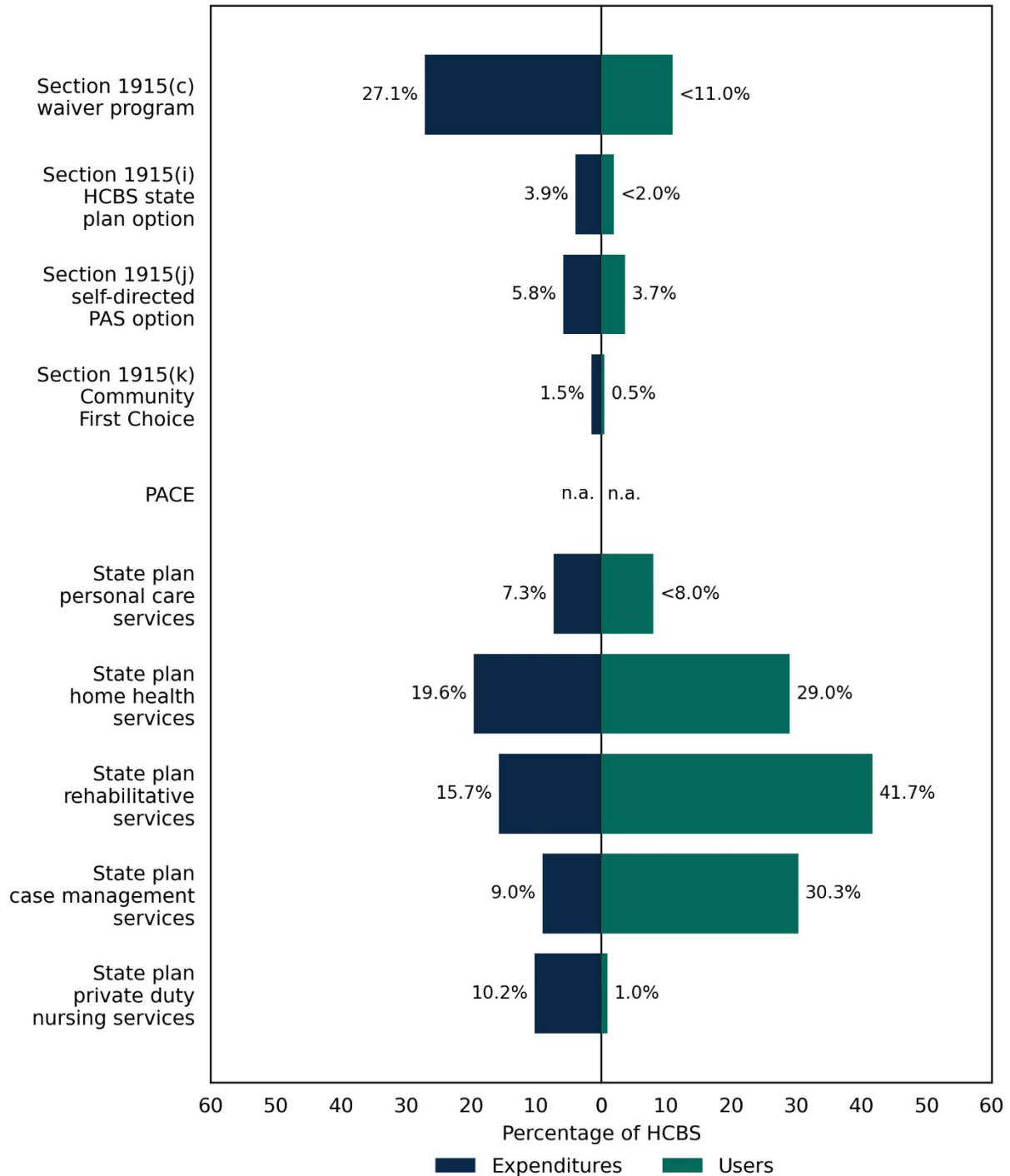
<sup>10</sup> Detailed results on HCBS and institutional users and expenditures stratified by age group are available in 2022 data tables, available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.

<sup>11</sup> Certain data points have been suppressed based on small cell sizes (1 to 10). Data have also been suppressed in cases where it would have been possible to derive the small cell values. In these cases, either the phrase "DS" (representing "data suppressed") or coarsened data (representing an approximate but not precise value) are shown.

management services and less likely to use program-based HCBS like section 1915(k) Community First Choice and section 1915(c) waiver programs.

**HCBS expenditures by category.** Medicaid expenditures for HCBS in 2022 for people ages 0 to 20 totaled \$17,026,507,342 (13.2 percent of all HCBS expenditures). HCBS expenditures for people ages 21 to 64 totaled \$72,718,095,164 (56.2 percent of all HCBS expenditures) and \$39,630,667,003 for people ages 65 and older (30.6 percent of all HCBS expenditures). The HCBS categories with the highest and lowest proportion of expenditures for people ages 0 to 20 differed from those with the highest and lowest proportion of users for people ages 0 to 20. The largest share of HCBS expenditures for people ages 0 to 20 was for section 1915(c) waiver programs (27.1 percent of all HCBS expenditures for people ages 0 to 20), followed by state plan home health services (19.6 percent of all HCBS expenditures for people ages 0 to 20), and state plan rehabilitative services (15.7 percent of all HCBS expenditures for people ages 0 to 20) (Figure 1). Differences in the shares of expenditures and users for people ages 0 to 20 for certain HCBS categories likely reflects the volume, complexity (that is, the various types of service providers delivering care and clinical intensity of services), cost per unit, and frequency of service use for people who receive these types of HCBS relative to other HCBS categories. For example, state plan private duty nursing services are an intensive and complex service type that involves skilled nursing care in the home, but this is not a common service type for people ages 0 to 20; this category accounted for 1.0 percent of HCBS users ages 0 to 20 and 10.2 percent of HCBS expenditures for people ages 0 to 20. The \$70,860 per user per year rate for these services in 2022 reflects the complexity and frequency of state plan private duty nursing services that ultimately results in high costs per user per year. In contrast, state plan case management services tend to be less intensive and frequent compared with other types of HCBS, as they focus on coordination and support, but are more commonly used by people ages 0 to 20. State plan case management services accounted for 30.3 percent of HCBS users ages 0 to 20 and 9.0 percent of HCBS expenditures for people ages 0 to 20, reflecting a rate of \$2,012 per user per year in 2022.

**Figure 1.** Distribution of Medicaid HCBS users and expenditures among people ages 0 to 20 by category, 2022



Source: Mathematica’s analysis of the 2022 TAF Release 1.

Note: The HCBS categories used in this analysis align with those eligible for the temporary increase in the FMAP under section 9817 of the ARP. The results are limited to people using Medicaid HCBS who were ages 0 to 20 as of January 1, 2022. The percentage of users across the categories does not sum to 100 because some beneficiaries received more than one type of HCBS during the year. Certain cells have been suppressed based on small cell sizes (1 to 10). Data have also been suppressed in cases where it would have been possible to derive the small cell values. In cases where the data is suppressed

in the figure, we provide an approximate value using the operator "<." PACE is for people ages 55 and older; we show this category as "n.a." in the figure because the sample only includes people ages 0 to 20. Based on data quality checks and feedback from states, relative to other categories, many states misreported section 1915(j) self-directed PAS option claims, resulting in higher counts than expected; therefore, these counts should be interpreted with caution.

ARP = American Rescue Plan Act of 2021; FMAP = federal medical assistance percentage; HCBS = home and community-based services; n.a. = not applicable; PACE = Program of All-Inclusive Care for the Elderly; PAS = personal assistance services; TAF = Transformed Medicaid Statistical Information System Analytic File.

## Distribution of Medicaid institutional LTSS users and expenditures

**Institutional service users by category.** Nationwide, 117,599 people ages 0 to 20 received institutional services in 2022, which was far fewer than the number in this age group who received HCBS.<sup>12</sup> People in this age group comprised 8.0 percent of all people using institutional services in 2022; 410,138 people ages 21 to 64 (27.8 percent of all institutional users) used institutional services and 946,981 people ages 65 and older (64.2 percent of all institutional users) used institutional services.<sup>13</sup> The majority of people ages 0 to 20 using institutional services received mental health facility services (87.8 percent of all institutional users ages 0 to 20), followed by nursing facility services (8.9 percent of all institutional users ages 0 to 20) (Figure 2).<sup>14</sup> Less than 4 percent of people ages 0 to 20 using institutional services received intermediate care facility for ICF/IID services. Compared with other age groups, people ages 0 to 20 were more likely to use mental health facilities and less likely to use nursing facilities and ICFs/IID.

**Institutional LTSS expenditures by category.** Medicaid expenditures for institutional services in 2022 for people ages 0 to 20 totaled \$3,515,151,752<sup>15</sup> and accounted for 5 percent of all institutional expenditures in 2022; expenditures for people ages 21 to 64 totaled \$22,617,777,464 (31.9 percent of all institutional expenditures) and \$44,777,700,147 for people ages 65 and older (63.1 percent of all institutional expenditures).<sup>16</sup> The ordering of categories for total institutional expenditures among people ages 0 to 20 was the same as for total institutional users in that age group (that is, mental health facilities had the highest proportion of expenditures *and* users, followed by nursing facilities and ICFs/IID). However, due to the higher average costs for nursing facility and ICF/IID services (both an average of more than \$80,000 per user per year) when compared with mental health facility services (less than \$20,000 per user per year on average), the share of expenditures is more evenly dispersed among the categories than the share of users for people ages 0 to 20. The largest share of institutional expenditures for people ages 0 to 20 was

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<sup>12</sup> The percentage of users across different institutional categories does not sum to 100 because some beneficiaries received more than one type of institutional services during the year.

<sup>13</sup> The TAF lacked the information needed to identify the ages of 60 institutional users in 2022.

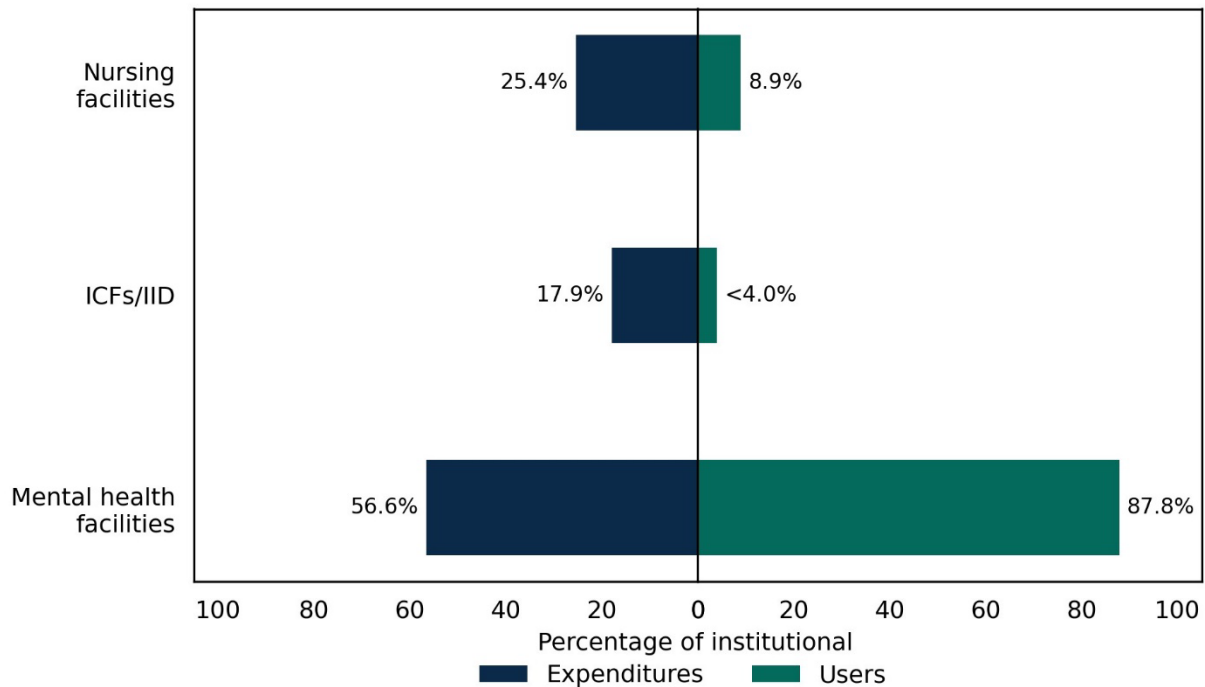
<sup>14</sup> For people ages 0 to 20, the relevant type of mental health facilities includes inpatient psychiatric facilities for people younger than 21. In the full population, mental health facilities also include institutions for mental diseases for people ages 65 and older. Although some states cover services for adults ages 21 to 64 in institutions for mental diseases through section 1115 demonstration authority, we were unable to ensure this group was included in the mental health facilities category because there was no recommended (tested) method of reliably identifying this population in the TAF.

<sup>15</sup> DSH payments for mental health facilities are not included in this total because they are state payments that cannot be attributed to individual users.

<sup>16</sup> Institutional expenditures for people with unknown age totaled \$439,630 in 2022 (0.0 percent of all institutional expenditures).

for mental health facility services (56.6 percent of all institutional expenditures for people ages 0 to 20), followed by nursing facility services (25.4 percent of all institutional expenditures for people ages 0 to 20) and ICF/IID services (17.9 percent of all institutional expenditures for people ages 0 to 20) (Figure 2).

**Figure 2.** Distribution of Medicaid institutional users and expenditures among people ages 0 to 20 by category, 2022



Source: Mathematica’s analysis of the 2022 TAF Release 1.

Note: The results are limited to people using Medicaid institutional LTSS who were ages 0 to 20 as of January 1, 2022. Certain cells have been suppressed based on small cell sizes (1 to 10). Data have also been suppressed in cases where it would have been possible to derive the small cell values. In cases where the data is suppressed in the figure, we provide an approximate value using the operator “<.”

ICFs/IID = intermediate care facilities for individuals with intellectual disabilities; TAF = Transformed Medicaid Statistical Information System Analytic File.

## National user and expenditure rebalancing ratios for Medicaid LTSS

States continue to focus on rebalancing their Medicaid LTSS systems by increasing HCBS and reducing reliance on institutional care. Measuring national and state progress toward this goal includes examining the share of total Medicaid LTSS users receiving HCBS and the share of total Medicaid LTSS spending devoted to HCBS. These measures are commonly referred to as LTSS user and expenditure rebalancing

ratios. We examined the expenditure and user rebalancing ratios by age group to understand how states have made progress in rebalancing for people with different demographic characteristics.<sup>17</sup>

**LTSS user rebalancing ratio.** In 2022, 97.0 percent of LTSS users ages 0-20 received HCBS. By comparison, 92.4 percent of LTSS users ages 21 to 64 and 64.9 percent of LTSS users ages 65 and older received HCBS. These patterns in the proportion of LTSS users receiving HCBS (also known as the LTSS user rebalancing ratio) reflect the higher use of HCBS and lower use of institutional care among younger age groups.

**LTSS expenditure rebalancing ratio.** In 2022, 82.9 percent of LTSS expenditures for Medicaid beneficiaries ages 0-20 were spent on HCBS. By comparison, 76.3 percent of LTSS expenditure for Medicaid beneficiaries ages 21 to 64 and 47.0 percent of LTSS expenditures for Medicaid beneficiaries ages 65 and older were spent on HCBS. These trends in the proportion of Medicaid LTSS expenditures spent on HCBS (also known as the LTSS expenditure rebalancing ratio) were similar to those for the user rebalancing ratio, reflecting greater expenditures for HCBS and lower expenditures for institutional care for younger age groups.

## State trends in Medicaid LTSS users, expenditures, and rebalancing ratios

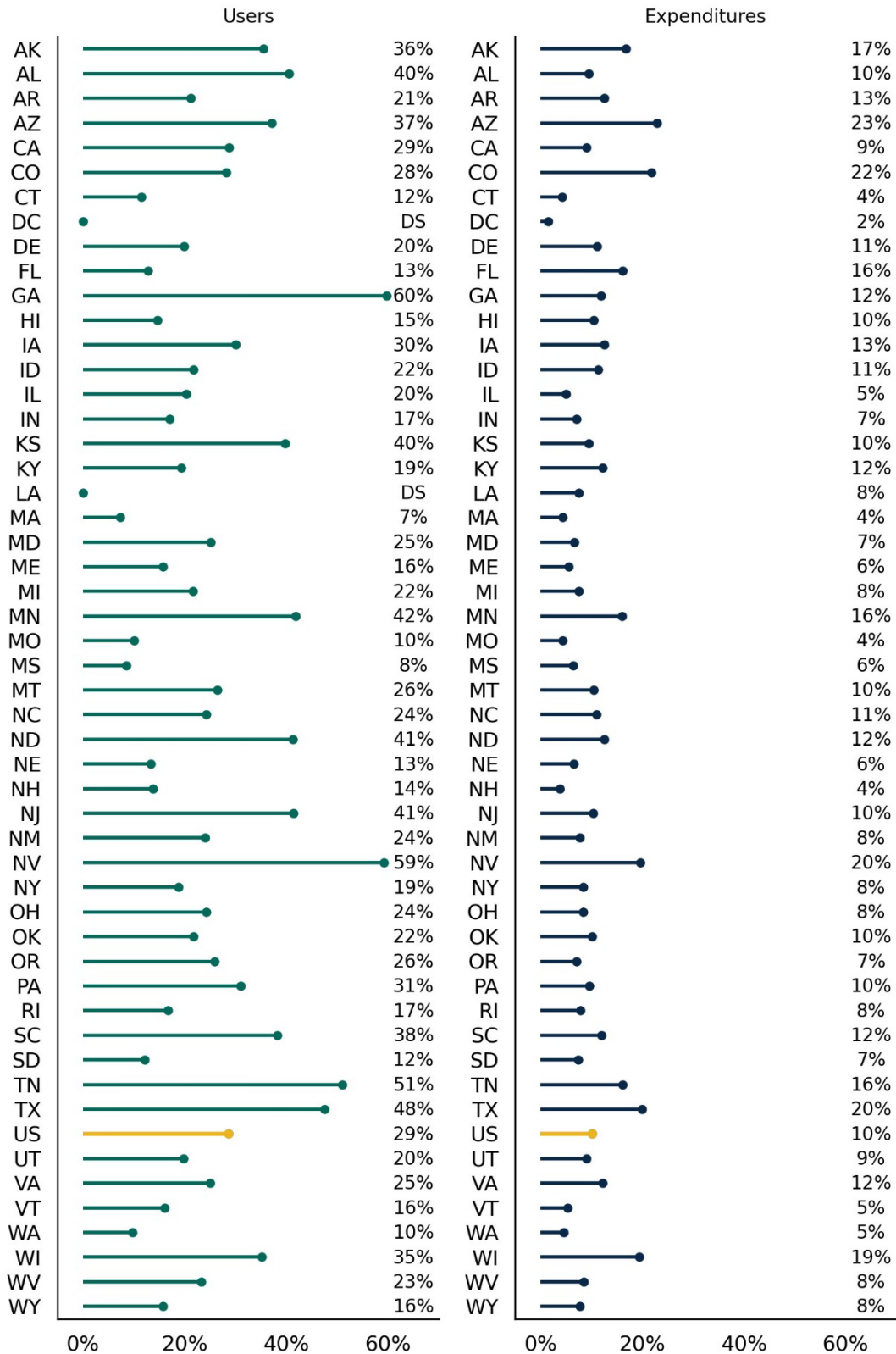
**State LTSS user trends.** Nationwide, 28.6 percent of all people using Medicaid LTSS (HCBS and institutional users of all ages) in 2022 were ages 0 to 20. Examining this percentage within states, we find the percentage of people ages 0 to 20 out of all people using Medicaid LTSS ranged from 7.4 percent in Massachusetts to 59.7 and 59.2 percent in Georgia and Nevada, respectively (Figure 3). The range across states in this percentage likely reflects different population characteristics and LTSS needs across states, differences in eligibility criteria and coverage of various LTSS across states, variation in the use of state plan versus program-based services across states, and potential missing data or data quality issues, which can all contribute in various ways to these patterns. For states with a higher percentage of users ages 0 to 20, there is high use of state plan services including state plan rehabilitative services, state plan case management services, and state plan home health services. Other factors, such as whether a state has a medically needy option for Medicaid coverage and the extent to which inpatient psychiatric facilities are available and used, might influence the percentage of total LTSS users in a state that are ages 0 to 20.

**State LTSS expenditure trends.** Nationwide, about 10.3 percent of total Medicaid LTSS expenditures (HCBS and institutional expenditures for all age groups) in 2022 were for people ages 0 to 20. We find that within states, the percentage of total LTSS expenditures for people ages 0 to 20 ranged from 1.5 percent in the District of Columbia to 23.0 percent in Arizona (Figure 3). As noted previously, expenditure patterns differ from user patterns due to factors such as the volume, complexity, and frequency of use of services delivered to people ages 0 to 20, as well as the share of expenditures devoted to HCBS versus institutional services since HCBS is typically less costly than institutional services.

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<sup>17</sup> For more information on the user and expenditure rebalancing ratios, refer to the brief “Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022,” available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.

**Figure 3.** Percentage of total Medicaid LTSS users and expenditures for people ages 0 to 20 by state, 2022





Source: Mathematica's analysis of the 2022 TAF Release 1.

Note: The results are limited to people using Medicaid LTSS who were ages 0 to 20 as of January 1, 2022. Values in the figure are rounded to whole numbers. Certain data points have been suppressed based on small cell sizes (1 to 10). Data have also been suppressed in cases where it would have been possible to derive the small cell values. "DS" is listed in these cases in the figure to represent "data suppressed."

DS = data suppressed; HCBS = home and community-based services; LTSS = long-term services and supports; TAF = Transformed Medicaid Statistical Information System Analytic File.

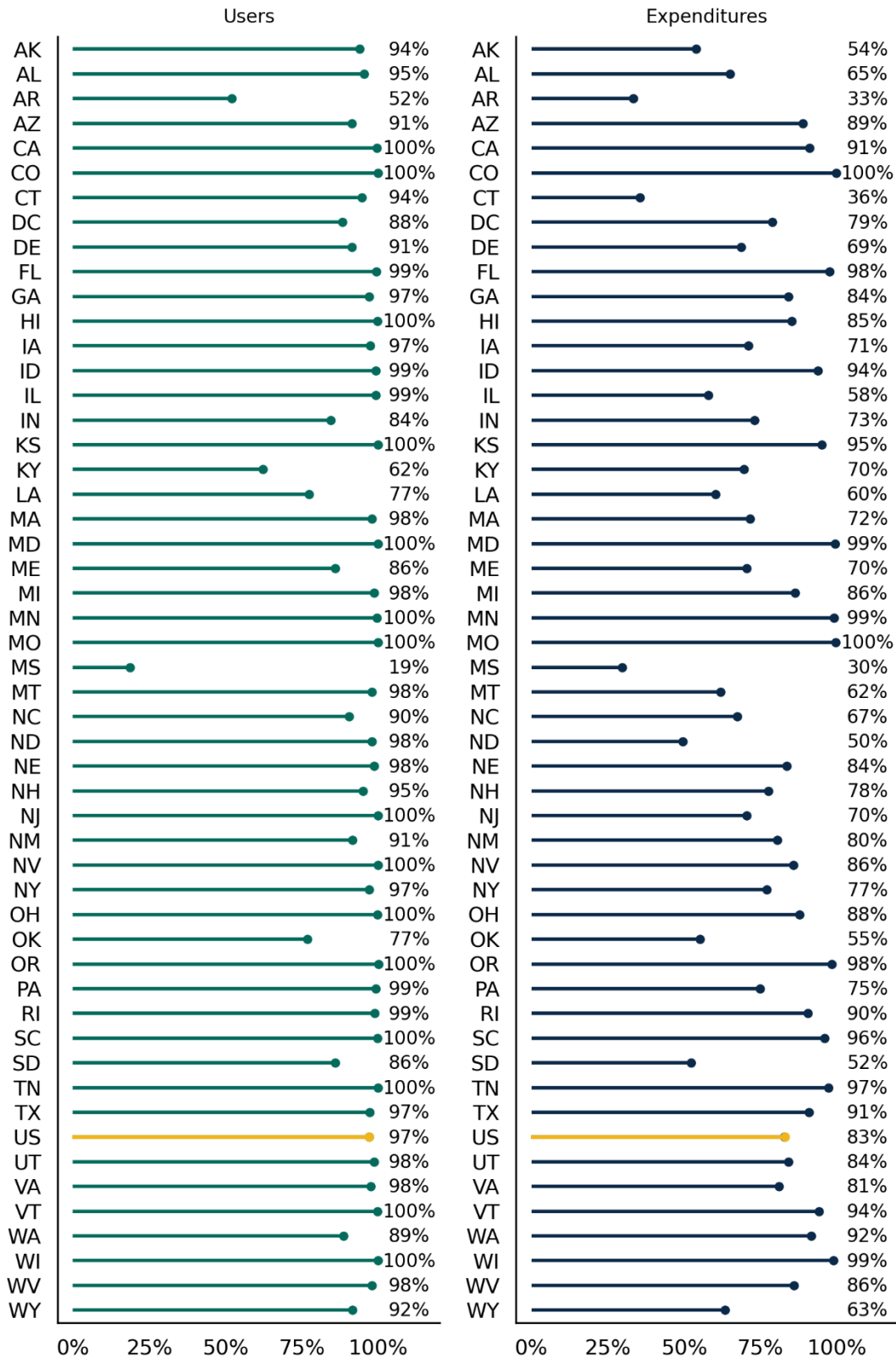
**State LTSS user rebalancing ratios.** Across all states, the user rebalancing ratio in 2022 for people ages 0 to 20 was 97.0 percent. Mississippi had the lowest user rebalancing ratio for people ages 0 to 20, with 18.7 percent of LTSS users ages 0 to 20 receiving HCBS, while Oregon had the highest user rebalancing ratio for this age group with 100 percent of LTSS users receiving HCBS (Figure 4).<sup>18</sup> Forty-one states had user rebalancing ratios for people ages 0 to 20 that exceeded 90 percent, reflecting that most states have few institutional users who are ages 0 to 20.

**State LTSS expenditure rebalancing ratios.** Across all states, the expenditure rebalancing ratio in 2022 for people ages 0 to 20 was 82.9 percent. There is more variation at the state-level in the expenditure rebalancing ratio than the user rebalancing ratio for people ages 0 to 20 because of factors such as the complexity and generally higher cost of institutional services compared to many types of HCBS. The expenditure rebalancing ratio ranged from 29.9 percent in Mississippi to 99.8 percent in Colorado for people ages 0 to 20 (Figure 4). Sixteen states had expenditure rebalancing ratios for people ages 0 to 20 that exceeded 90 percent compared to the 41 that had user rebalancing ratios that exceeded 90 percent, which is consistent with the higher costs of institutional services compared to HCBS.

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<sup>18</sup> Out of 139,086 total LTSS users ages 0-20 in Oregon, 139,084 used HCBS and 22 used institutional LTSS.

**Figure 4.** User and expenditure rebalancing ratios for Medicaid LTSS for people ages 0 to 20 by state, 2022



Source: Mathematica's analysis of the 2022 TAF Release 1.

Note: The results are limited to people using Medicaid LTSS who were ages 0 to 20 as of January 1, 2022. Values in the figure are rounded to whole numbers. The LTSS user rebalancing ratio is the total unduplicated number of HCBS users as a percentage of the total unduplicated number of LTSS users. The LTSS expenditure rebalancing ratio is calculated as the total HCBS expenditures as a percentage of total LTSS expenditures.

HCBS = home and community-based services; LTSS = long-term services and supports; TAF = Transformed Medicaid Statistical Information System Analytic File.

## Conclusions

People ages 0 to 20 represented more than a quarter of all Medicaid LTSS users in 2022, with almost all LTSS users in this age group using HCBS and a very small proportion using institutional services. The most commonly used HCBS categories among this age group included state plan rehabilitative services, state plan case management services, and state plan home health services. The most commonly used institutional service category among this age group was mental health facility services. A substantial share of Medicaid LTSS (28.6 percent) across states is delivered to people ages 0 to 20, so it is important for states to consider the range of diverse people using Medicaid LTSS when designing and implementing their LTSS programs. Future studies focused on understanding the range of services provided to children and other characteristics of children receiving LTSS can inform efforts to reduce institutional service use and increase HCBS.

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## Methods

This brief contains a snapshot of LTSS user and expenditure output, focusing on trends in HCBS and institutional users and expenditures for people ages 0 to 20. All LTSS user and expenditure calculations are based on TAF data. For this analysis, institutional LTSS include nursing facilities, ICFs/IID, and mental health facilities. Hospitals are not included in the definition of institutional LTSS, although these are Medicaid facilities. For expenditures only, institutional LTSS also include DSH payments to mental health facilities. HCBS include section 1915(c) waiver programs, the section 1915(i) HCBS state plan option, the section 1915(j) self-directed personal assistance services option, section 1915(k) Community First Choice, the PACE, state plan personal care services, state plan home health services, state plan rehabilitative services, state plan case management services, and state plan private duty nursing services. We reported Money Follows the Person demonstration services as an individual category in accompanying table output but did not include these services in the aggregate calculations of total HCBS or total LTSS expenditures or users. Except for PACE expenditures and DSH payments to mental health facilities, LTSS expenditures include fee-for-service (FFS) expenditures, managed care plan payments to providers for managed care services, and supplemental wraparound payments that are associated with a specific beneficiary above the negotiated per-service rate; these add-on payments are distinct from the supplemental payments made under the Upper Payment Limit (UPL) demonstration. We assigned these expenditures to a specific LTSS category based on relevant TAF claim codes, including type of service, benefit type, program type, and waiver type. For PACE expenditures, we used capitation payment records and service-tracking claims. For DSH payments to mental health facilities, we used service-tracking claims and supplemental payment records. Except for PACE, we identified LTSS users for each LTSS category using FFS claims and managed care encounters, based on the same codes used to identify claims for the expenditure calculations. For PACE user counts, we identified enrollees based on enrollment records. Except for dual-eligibility status, which is based on the majority of enrolled months, we based enrollee characteristics on the most recent valid values in the calendar year.

In addition, refer to the following resources:

- More information on data and methods can be found in the accompanying document titled “Methodology for Identifying Medicaid Long-Term Services and Supports Expenditures and Users, 2022.”
- State data and anomaly notes are included in the accompanying document titled “Data Notes for Medicaid TAF Long-Term Services and Supports Annual Expenditures and Users, 2022.”
- Data tables for 2022 are available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.

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