

# Characteristics of People Using Medicaid Long-Term Services and Supports, 2021

Cara Stepanczuk, Alexandra Carpenter, and Andrea Wysocki, Mathematica

July 24, 2024

## Background

Medicaid is the largest payer of long-term services and supports (LTSS) in the United States, serving 8.7 million people using a variety of home and community-based services (HCBS) and institutional facilities in 2021. In this brief, we present characteristics of Medicaid LTSS users nationwide in 2021<sup>1</sup> across different HCBS and institutional categories, based on data from the Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF).<sup>2</sup>

## Characteristics of HCBS users

Data from 2021 show that HCBS users<sup>3</sup> are a diverse group in terms of age, eligibility for Medicare, geographic distribution, language, and race and ethnicity. However, as a group, the majority of HCBS users nationwide were younger than age 65; were eligible only for Medicaid (that is, not dually eligible for Medicaid and Medicare); lived in an urban area; and spoke English as their primary language (Tables 1a and 1b). Specifically, among the nearly 7.5 million HCBS users across the United States in 2021, 31 percent were age 20 or younger and 49 percent were age 21 to 64. Slightly more than half of HCBS users nationwide were female, and approximately two thirds (67 percent) were eligible only for Medicaid (not dually eligible for Medicaid and Medicare) for the majority of the year. About 81 percent of HCBS users lived in an urban area; 93 percent spoke English as their primary language and 6 percent spoke Spanish as their primary language. Of all HCBS users, 52 percent were White, non-Hispanic; 22 percent were Black, non-Hispanic; 19 percent were Hispanic (of any race); and 7 percent were either American

### Key findings

- In 2021, the majority of people using HCBS were younger than age 65, were not dually eligible, lived in an urban area, and spoke English as their primary language.
- In 2021, the majority of people using institutional services were older than age 65, were dually eligible for Medicaid and Medicare, lived in an urban area, and spoke English as their primary language.
- Larger proportions of people who identified as members of a racial and ethnic minority group used HCBS relative to institutional services.

<sup>1</sup> Alabama's 2021 LTSS measures have been suppressed due to concerns about the quality of the TAF data used in the calculations. All LTSS measures for the state have been replaced with a value of "NC" indicating that the state's LTSS measures have not been calculated and their data are not included in any national calculations.

<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> The HCBS categories used in this analysis align with those eligible for temporary increase in the federal medical assistance percentage (FMAP) under section 9817 of the American Rescue Plan Act of 2021 (ARP).

Indian and Alaska Native (AIAN), non-Hispanic, Asian and Pacific Islander (API), non-Hispanic, or multiracial, non-Hispanic.

These population characteristics differed among groups enrolled in different programs and authorities that provide HCBS (Tables 1a and 1b):

- **Section 1915(c) waiver program** users had demographic characteristics very similar to HCBS users overall, although these users were more often dually eligible (59 percent of people were full-benefit dually eligible compared to 32 percent among all HCBS users) and White non-Hispanic (62 percent compared to 52 percent among all HCBS users).
- **Section 1915(i) HCBS state plan option** users were older (68 percent were age 65 and older compared to 20 percent age 65 and older among all HCBS users), and more often female (66 percent compared to 54 percent among all HCBS users); dually eligible (76 percent of people were full-benefit dually eligible compared to 32 percent among all HCBS users); living in an urban area (97 percent compared to 81 percent among all HCBS users); and Hispanic, any race (30 percent compared to 19 percent among all HCBS users), or API, non-Hispanic (22 percent compared to 5 percent among all HCBS users). They also more often spoke Spanish or a language other than English or Spanish as their primary language (12 percent and 12 percent, respectively, compared to 6 percent and 2 percent, respectively among all HCBS users).
- **Section 1915(j) self-directed personal assistance service (PAS) option**<sup>4</sup> users were older (38 percent were age 65 and older compared to 20 percent age 65 and older among all HCBS users) and more often dually eligible (62 percent of people were full-benefit dually eligible compared to 30 percent among all HCBS users). They were relatively similar to HCBS users overall in terms of urban and rural residence, primary language, and race and ethnicity distributions.
- **Section 1915(k) Community First Choice** users were older (47 percent were age 65 and older compared to 20 percent age 65 and older among all HCBS users) and were more often dually eligible (63 percent of people were full-benefit dually eligible compared to 32 percent among all HCBS users), living in an urban area (89 percent compared to 81 percent among all HCBS users), and White non-Hispanic (57 percent compared to 52 percent among all HCBS users). They were relatively similar in terms of primary language.
- **Program of All-Inclusive Care for the Elderly (PACE)** users were older (81 percent age 65 and older compared to 20 percent age 65 and older among all HCBS users) and more often dually eligible (80 percent of people were full-benefit dually eligible compared to 32 percent among all HCBS users). These differences are expected, given that the PACE program enrolls people ages 55 and older, many of whom are also dually eligible for Medicaid and Medicare. PACE users also were more often female (66 percent compared to 54 percent among all HCBS users) and living in an urban area (93 percent compared to 81 percent among all HCBS users). They more often spoke Spanish or a language other

---

<sup>4</sup> 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. For more information on the data source, methodology, state anomalies, and data tables, refer to the Methods box at the end.

than English or Spanish (12 percent and 6 percent, respectively, compared to 6 percent and 2 percent, respectively among all HCBS users).

- **State plan personal care service** users were older (43 percent were age 65 and older compared to 20 percent age 65 and older among all HCBS users) and were more often dually eligible (50 percent of people were full-benefit dually eligible compared to 32 percent among all HCBS users), spoke Spanish as their primary language (9 percent compared to 6 percent among all HCBS users), and were Hispanic of any race (32 percent compared to 19 percent among all HCBS users); they were relatively similar in terms of urban and rural residence.
- **State plan home health service** users had very similar demographic characteristics to all HCBS users, although there were some minor differences in the race and ethnicity of these users.
- **State plan rehabilitative service** users were younger (45 and 53 percent were age 0 to 20 and 21 to 64, respectively, compared to 31 and 49 percent, respectively, among all HCBS users) and more often were not dually eligible (89 percent compared to 67 percent among all HCBS users), spoke English as their primary language (97 percent compared to 93 percent among all HCBS users), and were White non-Hispanic (61 percent compared to 52 percent among all HCBS users); they were relatively similar in terms of urban and rural residence.
- **State plan case management service** users were younger (42 percent were age 0 to 20 compared to 31 percent among all HCBS users) and more often male (53 percent compared to 46 percent among all HCBS users) but were relatively similar in terms of dual-eligibility status, urban and rural residence, primary language, and race and ethnicity distributions.
- **State plan private duty nursing service** users were younger (45 percent were age 0 to 20 compared to 31 percent among all HCBS users) and more often not dually eligible (75 percent compared to 70 percent among all HCBS users), speaking English as their primary language (96 percent compared to 93 percent among all HCBS users), and White non-Hispanic (59 percent compared to 52 percent among all HCBS users) but were relatively similar in terms of urban and rural residence.

## Characteristics of institutional service users

Similar to HCBS users, institutional users<sup>5</sup> had diverse characteristics in 2021. When taken as a group, the majority of institutional service users nationwide were older than 65, were dually eligible for Medicaid and Medicare, lived in an urban area, and spoke English as their primary language (Table 2). Specifically, among the nearly 1.5 million institutional service users across the United States in 2021, 63 percent were age 65 and older. More than half of HCBS users nationally were female (59 percent) and 62 percent were full-benefit dually eligible. About 77 percent of institutional service users lived in an urban area; 96 percent spoke English as their primary language and 3 percent spoke Spanish as their primary language. Of all institutional service users, 66 percent were White non-Hispanic; 19 percent were Black non-Hispanic;

---

<sup>5</sup> For these analyses, institutional LTSS include nursing facilities, intermediate care facility for individuals with intellectual disabilities ICFs/IID, and mental health facilities. Although some states cover services for adults ages 21 to 64 in institutions for mental diseases through the 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.

10 percent were Hispanic (of any race); and 4 percent were either AIAN non-Hispanic, API non-Hispanic, or multiracial non-Hispanic.

These population characteristics differed among different institutional facility types (Table 2) when compared to the overall population of institutional users:

- **Nursing facility** users were older (70 percent were age 65 and older compared to 63 percent among all institutional service users) and more often dually eligible (67 percent of people were full-benefit dually eligible compared to 62 percent among all institutional service users) but were relatively similar in terms of urban and rural residence, primary language, and race and ethnicity distributions.
- **Intermediate care facility for individuals with intellectual disabilities (ICF/IID)** users were younger (29 percent were age 65 and older compared to 63 percent among all institutional service users) and more often male (55 percent compared to 41 percent among all institutional service users), dually eligible (68 percent of people were full-benefit dually eligible compared to 62 percent among all institutional service users), living in a rural area (29 percent compared to 21 percent among all institutional service users), and White non-Hispanic (74 percent compared to 66 percent among all institutional service users). They also more often spoke English as their primary language (99 percent compared to 96 percent among all institutional service users).
- **Mental health facility** users were younger (76 percent were age 0 to 20 compared to 8 percent among all institutional service users). They were more often not dually eligible (95 percent compared to 37 percent among all institutional service users) and Hispanic of any race (24 percent compared to 10 percent among all institutional service users).

## Conclusions

The characteristics of LTSS users differed across HCBS and institutional categories, with some service types more likely to be used by people with certain demographic characteristics. For example, among HCBS users, more people receiving section 1915(i) HCBS state plan option services were Hispanic of any race or API non-Hispanic, relative to the overall HCBS population (30 percent and 22 percent, respectively, compared to 19 percent and 5 percent, respectively, among all HCBS users). Among institutional service users, about 70 percent of people using nursing facility services were older than age 65, but 76 percent of people using mental health facilities were age 0 to 20. Relative to institutional service users, HCBS users tended to be younger, were less often dually eligible, and more often identified as members of racial and ethnic minority groups. These differences are important to keep in mind when designing policies that serve both current and future users of HCBS and institutional services.

**Table 1a.** Characteristics of HCBS users by HCBS program, 2021

| Characteristic                             | Any HCBS <sup>a</sup><br>N (%) | Section 1915(c)<br>waiver program<br>N (%) | Section 1915(i)<br>HCBS state plan<br>option<br>N (%) | Section 1915(j)<br>self-directed PAS<br>option <sup>b</sup><br>N (%) | Section 1915(k)<br>Community First<br>Choice<br>N (%) | PACE<br>N (%)        |
|--|--------------------------------|--|---|--|---|----------------------|
| <b>Total count</b>                         | <b>7,461,364 (100%)</b>        | <b>1,715,504 (100%)</b>                    | <b>355,524 (100%)</b>                                 | <b>517,901 (100%)</b>  | <b>153,163 (100%)</b>                                 | <b>71,325 (100%)</b> |
| <b>Age group</b>                           |                                |  |   |  |   |                      |
| 0–20                                       | 2,329,717 (31.2%)              | DS   | 14,462 (4.1%)   | 63,440 (12.2%)   | 11,271 (7.4%)   | DS                   |
| 21–64                                      | 3,628,156 (48.6%)              | 913,130 (53.2%)                            | 99,222 (27.9%)  | 257,016 (49.6%)  | 69,302 (45.2%)  | DS                   |
| 65 and older                               | 1,503,399 (20.1%)              | 563,020 (32.8%)                            | 241,840 (68.0%)                                       | 197,445 (38.1%)  | 72,590 (47.4%)  | 57,568 (80.7%)       |
| Unknown                                    | 92 (0.0%)                      | DS   | 0 (0.0%)  | 0 (0.0%)   | 0 (0.0%)  | 0 (0.0%)             |
| <b>Sex</b>                                 |                                |  |   |  |   |                      |
| Female                                     | 4,021,682 (53.9%)              | 887,418 (51.7%)                            | 232,911 (65.5%)                                       | 299,796 (57.9%)  | 90,511 (59.1%)  | 46,879 (65.7%)       |
| Male                                       | 3,439,488 (46.1%)              | 828,050 (48.3%)                            | 122,613 (34.5%)                                       | DS   | DS  | DS                   |
| Unknown                                    | 194 (0.0%)                     | 36 (0.0%)                                  | 0 (0.0%)  | DS   | DS  | DS                   |
| <b>Dual-eligibility status<sup>c</sup></b> |                                |  |   |  |   |                      |
| Non-dually eligible                        | 4,992,362 (66.9%)              | 696,164 (40.6%)                            | 82,732 (23.3%)  | 193,964 (37.5%)  | 56,485 (36.9%)  | 13,932 (19.5%)       |
| Full-benefit dually eligible               | 2,389,871 (32.0%)              | 1,009,079 (58.8%)                          | 271,503 (76.4%)                                       | 322,123 (62.2%)  | 95,887 (62.6%)  | 56,850 (79.7%)       |
| Partial-benefit dually eligible            | 79,131 (1.1%)                  | 10,261 (0.6%)                              | 1,289 (0.4%)  | 1,814 (0.4%)   | 791 (0.5%)  | 543 (0.8%)           |
| <b>Rural/urban residence</b>               |                                |  |   |  |   |                      |
| Rural                                      | 1,358,248 (18.2%)              | 350,013 (20.4%)                            | 10,304 (2.9%)   | 88,778 (17.1%)   | 16,123 (10.5%)  | 4,531 (6.4%)         |
| Urban                                      | 6,025,056 (80.8%)              | 1,347,836 (78.6%)                          | 342,945 (96.5%)                                       | 425,092 (82.1%)  | 135,917 (88.7%)                                       | 66,060 (92.6%)       |
| Out of state or unknown                    | 78,060 (1.0%)                  | 17,655 (1.0%)                              | 2,275 (0.6%)  | 4,031 (0.8%)   | 1,123 (0.7%)  | 734 (1.0%)           |
| <b>Primary language<sup>d</sup></b>        |                                |  |   |  |   |                      |
| English                                    | 6,900,056 (92.5%)              | 1,605,888 (93.6%)                          | 270,278 (76.0%)                                       | 482,452 (93.2%)  | 137,840 (90.0%)                                       | 59,244 (83.1%)       |
| Spanish                                    | 418,668 (5.6%)                 | 68,944 (4.0%)                              | 42,335 (11.9%)  | 25,634 (4.9%)  | 10,346 (6.8%)   | 8,177 (11.5%)        |
| Any other language                         | 142,640 (1.9%)                 | 40,672 (2.4%)                              | 42,911 (12.1%)  | 9,815 (1.9%)   | 4,977 (3.2%)  | 3,904 (5.5%)         |
| <b>Race and ethnicity<sup>e</sup></b>      |                                |  |   |  |   |                      |
| AIAN, non-Hispanic                         | 83,677 (1.1%)                  | 15,237 (0.9%)                              | 3,422 (1.0%)  | 3,763 (0.7%)   | 1,866 (1.2%)  | 399 (0.6%)           |
| API, non-Hispanic                          | 351,949 (4.7%)                 | 88,019 (5.1%)                              | 77,035 (21.7%)  | 31,526 (6.1%)  | 15,643 (10.2%)  | 5,836 (8.2%)         |

| Characteristic            | Any HCBS <sup>a</sup><br>N (%) | Section 1915(c)<br>waiver program<br>N (%) | Section 1915(i)<br>HCBS state plan<br>option<br>N (%) | Section 1915(j)<br>self-directed PAS<br>option <sup>b</sup><br>N (%) | Section 1915(k)<br>Community First<br>Choice<br>N (%) | PACE<br>N (%)  |
|---------------------------|--------------------------------|--|---|--|---|----------------|
| Black, non-Hispanic       | 1,647,057 (22.1%)              | 342,413 (20.0%)                            | 68,733 (19.3%)  | 139,511 (26.9%)  | 21,620 (14.1%)  | 13,280 (18.6%) |
| Hispanic, any race        | 1,431,198 (19.2%)              | 193,888 (11.3%)                            | 104,856 (29.5%)                                       | 71,878 (13.9%)   | 25,118 (16.4%)  | 14,222 (19.9%) |
| Multiracial, non-Hispanic | 95,691 (1.3%)                  | 14,082 (0.8%)                              | 410 (0.1%)  | 4,600 (0.9%)   | 1,545 (1.0%)  | 415 (0.6%)     |
| White, non-Hispanic       | 3,851,788 (51.6%)              | 1,061,865 (61.9%)                          | 101,069 (28.4%)                                       | 266,622 (51.5%)  | 87,372 (57.0%)  | 37,174 (52.1%) |

Source: Mathematica’s analysis of the 2021 TAF Release 1.

Note: This table shows the number of Medicaid beneficiaries who received program-based HCBS in 2021; program-based HCBS are defined as those for which enrollment information exists (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 demonstration [MFP], and PACE). The HCBS categories were defined based on section 9817 of the ARP. 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 Tables 1a or 1b in this brief because they are not part of section 9817 of the ARP. The number of users across HCBS categories in Tables 1a and 1b does not sum to 100 percent 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. Additionally, all calculations exclude Alabama due to data quality concerns.

<sup>a</sup> This is an unduplicated count of Medicaid beneficiaries who received any HCBS (either program-based [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, and PACE] or state plan benefits [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], presented in Tables 1a and 1b) in 2021. The HCBS categories were defined based on section 9817 of the ARP. State plan benefits refer to section 1905(a) state plan services.

<sup>b</sup> 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.

<sup>c</sup> People with null values for dual-eligibility status were coded as non-dually eligible.

<sup>d</sup> People with null values for primary language were coded as primarily speaking English.

<sup>e</sup> In the TAF Race and Ethnicity Imputation (REI) Companion File we use for the analysis, each enrollee is given a unique probability value of being in each race and ethnicity group. In most cases, an enrollee would have a value of “1” for their self-reported race and ethnicity. Enrollees with missing self-reported race and ethnicity would have a value between 0 and 1 for each of the six race and ethnicity categories. Therefore, both the numerator (number of users for a given race and ethnicity and LTSS category) and the denominator (total number of users for a given LTSS category) in this table are calculated as the sum of the probabilities of users being in a given race and ethnicity group across all users of a given LTSS category, rounded to the nearest integer. A consequence of this approach is that the total number of users in a given LTSS category (which serves as the denominator for the percentages in each column) is slightly different for the race and ethnicity rows than for the other characteristics. For example, the number of HCBS users calculated by summing the probabilities across all races and ethnicities—used as the denominator for the race and ethnicity group percentages—is 7,461,360; in contrast, the true count of HCBS users—used as the denominator for all other characteristics’ group percentages—is 7,461,364. In addition, given the use of the REI file, there are no unknown values for race and ethnicity.

AIAN = American Indian and Alaska Native; API = Asian and Pacific Islander; ARP = American Rescue Plan Act of 2021; DS = data suppressed; HCBS = home and community-based services; N = number; PACE = Program of All-Inclusive Care for the Elderly; PAS = personal assistance service; TAF = T-MSIS Analytic File; T-MSIS = Transformed Statistical Information System.

**Table 1b.** Characteristics of HCBS users by HCBS state plan option, 2021

| Characteristic                             | Any HCBS <sup>a</sup><br>N (%) | State plan personal<br>care services <sup>b</sup><br>N (%) | State plan home<br>health services <sup>c</sup><br>N (%) | State plan<br>rehabilitative<br>services <sup>d</sup><br>N (%) | State plan case<br>management<br>services <sup>e</sup><br>N (%) | State plan private<br>duty nursing<br>services <sup>d</sup><br>N (%) |
|--|--------------------------------|--|--|--|---|--|
| <b>Total count</b>                         | <b>7,461,364 (100%)</b>        | <b>843,438 (100%)</b>                                      | <b>2,303,626 (100%)</b>                                  | <b>2,166,079 (100%)</b>  | <b>1,738,604 (100%)</b>   | <b>53,624 (100%)</b>   |
| <b>Age group</b>                           |                                |  |  |  |   |  |
| 0–20                                       | 2,329,717 (31.2%)              | DS   | 667,365 (29.0%)  | 965,864 (44.6%)  | 725,112 (41.7%)   | 24,026 (44.8%)   |
| 21–64                                      | 3,628,156 (48.6%)              | 326,677 (38.7%)  | 1,181,930 (51.3%)  | 1,140,952 (52.7%)  | 834,561 (48.0%)   | 24,708 (46.1%)   |
| 65 and older                               | 1,503,399 (20.1%)              | 359,001 (42.6%)  | 454,285 (19.7%)  | DS   | 178,895 (10.3%)   | DS   |
| Unknown                                    | 92 (0.0%)                      | DS   | 46 (0.0%)  | DS   | 36 (0.0%)   | DS   |
| <b>Sex</b>                                 |                                |  |  |  |   |  |
| Female                                     | 4,021,682 (53.9%)              | 496,136 (58.8%)  | 1,342,085 (58.3%)  | 1,095,241(50.6%)   | 815,906 (46.9%)   | DS   |
| Male                                       | 3,439,488 (46.1%)              | 347,253 (41.2%)  | 961,476 (41.7%)  | 1,070,824 (49.4%)  | 922,648 (53.1%)   | 27,097 (50.5%)   |
| Unknown                                    | 194 (0.0%)                     | 49 (0.0%)  | 65 (0.0%)  | 14 (0.0%)  | 50 (0.0%)   | DS   |
| <b>Dual-eligibility status<sup>f</sup></b> |                                |  |  |  |   |  |
| Non-dually eligible                        | 4,992,362 (66.9%)              | 360,096 (42.7%)  | 1,642,044 (71.3%)  | 1,933,527 (89.3%)  | 1,217,376 (70.0%)   | 40,441 (75.4%)   |
| Full-benefit dually eligible               | 2,389,871 (32.0%)              | 425,247 (50.4%)  | 655,669 (28.5%)  | 229,749 (10.6%)  | 517,794 (29.8%)   | 13,006 (24.3%)   |
| Partial-benefit dually eligible            | 79,131 (1.1%)                  | 58,095 (6.9%)  | 5,913 (0.3%)   | 2,803 (0.1%)   | 3,434 (0.2%)  | 177 (0.3%)   |
| <b>Rural/urban residence</b>               |                                |  |  |  |   |  |
| Rural                                      | 1,358,248 (18.2%)              | 159,881 (19.0%)  | 350,373 (15.2%)  | 440,438 (20.3%)  | 319,131 (18.4%)   | 9,530 (17.8%)  |
| Urban                                      | 6,025,056 (80.8%)              | 677,658 (80.3%)  | 1,936,830 (84.1%)  | 1,698,886 (78.4%)  | 1,400,086 (80.5%)   | 43,808 (81.7%)   |
| Out of state or Unknown                    | 78,060 (1.0%)                  | 5,899 (0.7%)   | 16,423 (0.7%)  | 26,755 (1.2%)  | 19,387 (1.1%)   | 286 (0.5%)   |
| <b>Primary language<sup>g</sup></b>        |                                |  |  |  |   |  |
| English                                    | 6,900,056 (92.5%)              | 744,316 (88.2%)  | 2,094,199 (90.9%)  | 2,092,497 (96.6%)  | 1,591,248 91.5%)  | 51,600 (96.2%)   |
| Spanish                                    | 418,668 (5.6%)                 | 76,440 (9.1%)  | 156,755 (6.8%)   | 59,522 (2.7%)  | 129,247 (7.4%)  | 1,336 (2.5%)   |
| Any other language                         | 142,640 (1.9%)                 | 22,682 (2.7%)  | 52,672 (2.3%)  | 14,060 (0.6%)  | 18,109 (1.0%)   | 688 (1.3%)   |
| <b>Race and ethnicity<sup>h</sup></b>      |                                |  |  |  |   |  |
| AIAN, non-Hispanic                         | 83,677 (1.1%)                  | 13,017 (1.5%)  | 21,945 (1.0%)  | 26,395 (1.2%)  | 18,441 (1.1%)   | 390 (0.7%)   |
| API, non-Hispanic                          | 351,949 (4.7%)                 | 42,143 (5.0%)  | 126,123 (5.5%)   | 42,135 (1.9%)  | 67,197 (3.9%)   | 1,109 (2.1%)   |
| Black, non-Hispanic                        | 1,647,057 (22.1%)              | 215,714 (25.6%)  | 531,502 (23.1%)  | 443,155 (20.5%)  | 374,028 (21.5%)   | 13,064 (24.4%)   |
| Hispanic, any race                         | 1,431,198 (19.2%)              | 267,205 (31.7%)  | 561,469 (24.4%)  | 299,381 (13.8%)  | 360,452 (20.7%)   | 6,378 (11.9%)  |
| Multiracial, non-Hispanic                  | 95,691 (1.3%)                  | 7,565 (0.9%)   | 22,472 (1.0%)  | 39,070 (1.8%)  | 26,502 (1.5%)   | 818 (1.5%)   |
| White, non-Hispanic                        | 3,851,788 (51.6%)              | 297,793 (35.3%)  | 1,040,114 (45.2%)  | 1,315,942 (60.8%)  | 891,983 (51.3%)   | 31,864 (59.4%)   |

Source: Mathematica's analysis of the 2021 TAF Release 1.

Note: This table shows the number of Medicaid beneficiaries who received state plan HCBS (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) in 2021. State plan benefits refer to section 1905(a) state plan services. The HCBS categories were defined based on section 9817 of the ARP. The number of users across HCBS categories in Tables 1a and 1b does not sum to 100 percent 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. Additionally, all calculations exclude Alabama due to data quality concerns.

<sup>a</sup> This is an unduplicated count of Medicaid beneficiaries who received any HCBS (either program-based [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, and PACE] or state plan benefits [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], presented in Tables 1a and 1b) in 2021. The HCBS categories were defined based on section 9817 of the ARP. 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 Tables 1a or 1b in this brief because they are not part of section 9817 of the ARP. State plan benefits refer to section 1905(a) state plan services.

<sup>b</sup> This category includes state plan personal care services and excludes personal care services covered through the section 1915(j) state plan option.

<sup>c</sup> This category includes state plan benefit services and excludes all relevant services provided through section 1915(c) waiver programs, section 1915(i) HCBS state plan option, section 1915(j) self-directed personal assistance services, and section 1915(k) Community First Choice HCBS authorities. We included all state plan home health claims regardless of the length of service use.

<sup>d</sup> Under section 9817 of the ARP, rehabilitative services rendered in any setting are considered HCBS, while only private duty nursing services rendered in beneficiaries' homes are considered HCBS. To simplify the identification of these services in TAF data, we include rehabilitative and private duty nursing services delivered in non-institutional settings in the definition of HCBS. We excluded claims with the following institutional settings: prisons/correctional facilities, inpatient hospitals, skilled nursing facilities, nursing facilities, custodial care facilities, inpatient psychiatric facilities, ICFs/IID, residential substance abuse treatment facilities, psychiatric residential treatment centers, and comprehensive inpatient rehabilitation facilities.

<sup>e</sup> We included claims reported as either state plan targeted case management or statewide case management.

<sup>f</sup> People with null values for dual-eligibility status were coded as non-dually eligible.

<sup>g</sup> People with null values for primary language were coded as primarily speaking English.

<sup>h</sup> In the TAF Race and Ethnicity Imputation (REI) Companion File we use for the analysis, each enrollee is given a unique probability value of being in each race and ethnicity group. In most cases, an enrollee would have a value of "1" for their self-reported race and ethnicity. Enrollees with missing self-reported race and ethnicity would have a value between 0 and 1 for each of the six race and ethnicity categories. Therefore, both the numerator (number of users for a given race and ethnicity and LTSS category) and the denominator (total number of users for a given LTSS category) in this table are calculated as the sum of the probabilities of users being in a given race and ethnicity group across all users of a given LTSS category, rounded to the nearest integer. A consequence of this approach is that the total number of users in a given LTSS category (which serves as the denominator for the percentages in each column) is slightly different for the race and ethnicity rows than for the other characteristics. In addition, given the use of the REI file, there are no unknown values for race and ethnicity.

AIAN = American Indian and Alaska Native; API = Asian and Pacific Islander; ARP = American Rescue Plan Act of 2021; DS = data suppressed; HCBS = home and community-based services; ICFs/IID = intermediate care facilities for individuals with intellectual disabilities; N = number; TAF = T-MSIS Analytic File; T-MSIS = Transformed Statistical Information System.



**Table 2.** Characteristics of institutional service users by setting, 2021

| Characteristic                             | Any institutional service <sup>a</sup><br>N (%) | Nursing facility<br>N (%) | ICF/IID<br>N (%)     | Mental health facility <sup>b</sup><br>N (%) |
|--|---|---------------------------|----------------------|--|
| <b>Total count</b>                         | <b>1,462,774 (100%)</b>                         | <b>1,271,428 (100%)</b>   | <b>74,498 (100%)</b> | <b>132,299 (100%)</b>                        |
| <b>Age group</b>                           |   |                           |                      |  |
| 0–20                                       | 116,001 (7.9%)                                  | 13,273 (1.0%)             | DS                   | 100,352 (75.9%)                              |
| 21–64                                      | 429,413 (29.4%)                                 | 364,223 (28.6%)           | 48,289 (64.8%)       | 26,792 (20.3%)                               |
| 65 and older                               | 917,320 (62.7%)                                 | 893,894 (70.3%)           | 21,719 (29.2%)       | DS   |
| Unknown                                    | 40 (0.0%)                                       | 38 (0.0%)                 | DS                   | DS   |
| <b>Sex</b>                                 |   |                           |                      |  |
| Female                                     | 857,708 (58.6%)                                 | 756,661 (59.5%)           | DS                   | 74,895 (56.6%)                               |
| Male                                       | 604,988 (41.4%)                                 | 514,692 (40.5%)           | 40,598 (54.5%)       | 57,404 (43.4%)                               |
| Unknown                                    | 78 (0.0%)                                       | 75 (0.0%)                 | DS                   | 0 (0.0%)                                     |
| <b>Dual-eligibility status<sup>c</sup></b> |   |                           |                      |  |
| Non-dually eligible                        | 535,666 (36.6%)                                 | 398,170 (31.3%)           | 23,608 (31.7%)       | 125,182 (94.6%)                              |
| Full-benefit dually eligible               | 909,197 (62.2%)                                 | 855,984 (67.3%)           | 50,341 (67.6%)       | 6,982 (5.3%)                                 |
| Partial-benefit dually eligible            | 17,911 (1.2%)                                   | 17,274 (1.4%)             | 549 (0.7%)           | 135 (0.1%)                                   |
| <b>Rural/urban residence</b>               |   |                           |                      |  |
| Rural                                      | 310,305 (21.2%)                                 | 266,691 (21.0%)           | 21,747 (29.2%)       | 23,410 (17.7%)                               |
| Urban                                      | 1,127,387 (77.1%)                               | 981,317 (77.2%)           | 52,365 (70.3%)       | 107,473 (81.2%)                              |
| Out of state or unknown                    | 25,082 (1.7%)                                   | 23,420 (1.8%)             | 386 (0.5%)           | 1,416 (1.1%)                                 |
| <b>Primary language<sup>d</sup></b>        |   |                           |                      |  |
| English                                    | 1,407,818 (96.2%)                               | 1,223,532 (96.2%)         | 73,925 (99.2%)       | 124,191 (93.9%)                              |
| Spanish                                    | 37,378 (2.6%)                                   | 31,079 (2.4%)             | 249 (0.3%)           | 7,336 (5.5%)                                 |
| Any other language                         | 17,578 (1.2%)                                   | 16,817 (1.3%)             | 324 (0.4%)           | 772 (0.6%)                                   |
| <b>Race and ethnicity<sup>e</sup></b>      |   |                           |                      |  |
| AIAN, non-Hispanic                         | 13,610 (0.9%)                                   | 10,298 (0.8%)             | 558 (0.7%)           | 2,877 (2.2%)                                 |
| API, non-Hispanic                          | 40,483 (2.8%)                                   | 36,389 (2.9%)             | 2,283 (3.1%)         | 3,001 (2.3%)                                 |
| Black, non-Hispanic                        | 283,813 (19.4%)                                 | 246,213 (19.4%)           | 11,183 (15.0%)       | 29,309 (22.2%)                               |
| Hispanic, any race                         | 150,273 (10.3%)                                 | 119,578 (9.4%)            | 4,273 (5.7%)         | 31,223 (23.6%)                               |
| Multiracial, non-Hispanic                  | 9,633 (0.7%)                                    | 6,423 (0.5%)              | 880 (1.2%)           | 2,523 (1.9%)                                 |
| White, non-Hispanic                        | 964,962 (66.0%)                                 | 852,527 (67.1%)           | 55,321 (74.3%)       | 63,367 (47.9%)                               |

Source: Mathematica’s analysis of the 2021 TAF Release 1.

Note: This table shows the number of Medicaid beneficiaries who received any institutional services in 2021. The number of users across institutional types does not sum to 100 percent because some beneficiaries received more than one type of institutional service 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. Additionally, all calculations exclude Alabama due to data quality concerns.

<sup>a</sup> This is an unduplicated count of Medicaid beneficiaries who received any institutional service in 2021.

<sup>b</sup> Mental health facilities include institutions for mental diseases for people ages 65 and older and inpatient psychiatric facilities for people younger than age 21.

<sup>c</sup> People with null values for dual-eligibility status were coded as non-dually eligible.

<sup>d</sup> People with null values for primary language were coded as primarily speaking English.

<sup>e</sup> In the TAF Race and Ethnicity Imputation (REI) Companion File we use for the analysis, each enrollee is given a unique probability value of being in each race and ethnicity group. In most cases, an enrollee would have a value of "1" for their self-reported race and ethnicity. Enrollees with missing self-reported race and ethnicity would have a value between 0 and 1 for each of the six race and ethnicity categories. Therefore, both the numerator (number of users for a given race and ethnicity and LTSS category) and the denominator (total number of users for a given LTSS category) in this table are calculated as the sum of the probabilities of users being in a given race and ethnicity group across all users of a given LTSS category, rounded to the nearest integer. A consequence of this approach is that the total number of users in a given LTSS category (which serves as the denominator for the percentages in each column) is slightly different for the race and ethnicity rows than for the other characteristics. In addition, given the use of the REI file, there are no unknown values for race and ethnicity.

AIAN = American Indian and Alaska Native; API = Asian and Pacific Islander; DS = data suppressed; ICF/IID = intermediate care facility for individuals with intellectual disabilities; TAF = T-MSIS Analytic File; T-MSIS = Transformed Statistical Information System.

---

## Methods

This brief contains a snapshot of the LTSS user and expenditure output, focusing on the characteristics of people using LTSS. All LTSS user and expenditure calculations for 2019 to 2021 are based on the TAF. For the analyses, institutional LTSS include nursing facilities, ICFs/IID, and mental health facilities. For expenditures only, institutional LTSS also include disproportionate share hospital (DSH) payments to mental health facilities. HCBS include 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, 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 them 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 payments. 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 wraparound payments that are add-on payments associated with a specific beneficiary above the negotiated per-service rate and are distinct from supplemental payments made under the Upper Payment Limit (UPL) demonstration. 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 the characteristics of enrollees on the most recent valid values in the calendar year.

In addition, see 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, 2019–2021.”
  - 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, 2019–2021.”
  - Data tables for 2019–2021 are available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.
- 

## Acknowledgments

This research brief was prepared by Mathematica under contract with the Centers for Medicare & Medicaid Services (HHSM-500-2014-00034/75FCMC19F0007). The authors thank the Division of Community Systems Transformation within the Centers for Medicare & Medicaid Services for their guidance and feedback. At Mathematica, we thank Miaomiao Shen, Aparna Kachalia, Michelle Roozeboom-Baker, and Rachel Hildrich Gross for programming support, Caitlin Murray and Michelle Eckstein for technical support, and Jenna Libersky for providing review.

**Suggested citation:** Stepanczuk, Cara, Alexandra Carpenter, and Andrea Wysocki. “Characteristics of People Using Medicaid Long-Term Services and Supports, 2021.” Mathematica, July 24, 2024.