

# **MEDICAID SECTION 1915(c) WAIVER PROGRAMS ANNUAL EXPENDITURES AND BENEFICIARIES REPORT**

**ANALYSIS OF CMS 372 ANNUAL REPORTS, 2017 – 2018**

**December 9, 2021**



**Suggested Citation: Jessica Ross, Kristie Liao, Andrea Wysocki. “Medicaid Section 1915(c) Waiver Programs Annual Expenditures and Beneficiaries Report: Analysis of CMS 372 Annual Reports, 2017-2018.” Chicago, IL: Mathematica, December 9, 2021.**

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## **Acknowledgements**

A number of people made important contributions to this report. We thank Susan Cummins from CMS and the Waiver Management Systems (WMS) Help Desk staff for answering our questions about the 372 annual reports and other WMS data. At Mathematica, Dean Miller, Megan Baker, Margaret Luo, and Ian Huff provided programming support, while Carol Irvin reviewed the report findings and summary.

This report was produced by Mathematica under contract with the Centers for Medicare & Medicaid Services (HHSM-500-2014-00034I/75FCMC19F0007).

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## List of Acronyms

AIDS = acquired immunodeficiency syndrome

ASD = autism spectrum disorder

CMS = Centers for Medicare & Medicaid Services

DD = developmental disabilities

HCBS = home and community-based services

HIV = human immunodeficiency virus

ID = intellectual disabilities

LTSS = long-term services and supports

OD = other disabilities

PD = physical disabilities

SED = serious emotional disturbances

TD = technology dependent

TE = temporary extension

WMS = Waiver Management System

## Executive Summary

**Purpose of this report.** Section 1915(c) of the Social Security Act (the Act) enlarged the scope of the Medicaid program to allow for the provision of comprehensive long-term care services in home and community-based settings as an alternative to institutional care. Introduced as part of the Omnibus Budget Reconciliation Act of 1981, state use of section 1915(c) waiver programs grew slowly but steadily. Over the past several decades, states have used section 1915(c) waiver programs, several other federal authorities, and federally funded demonstrations and grant programs to develop a broad range of home and community-based services (HCBS) to provide alternatives to institutionalization for eligible Medicaid beneficiaries.

The Centers for Medicare & Medicaid Services (CMS) requires states that operate section 1915(c) waiver programs to provide annual information via CMS Form 372(S), hereafter referred to as the annual 372 report, that includes (1) demonstrating they meet assurances on cost-neutrality; (2) details of the type, amount, and cost of services provided; and (3) assessment of other aspects of the waiver programs including quality assurances (CMS 2018). CMS and its contractors have produced summary reports of these data in most years since 2013, covering data back to 2009. This is the eighth CMS report analyzing information from annual 372 report submissions, and it focuses on trends in section 1915(c) waiver program participants, service use, and expenditures for 2018. To establish changes during 2018 in section 1915(c) waiver program participants, service use, and expenditures compared to the prior year, we also calculate results for 2017; we obtained results from prior years (2016 and earlier) from previous reports and did not recalculate them.

States vary markedly in the types of section 1915(c) waiver programs offered. As in past years, Arizona, Rhode Island, and Vermont had no waiver programs because they provide similar services via demonstrations authorized under section 1115(a) of the Social Security Act. In addition, New Jersey had no active section 1915(c) waiver programs during 2018 and only one active program during 2017; however, since the state did not submit a 372 report with an accepted status in 2017 or in the four years prior, the state did not meet reporting requirements for inclusion in our analyses for 2017.<sup>1</sup> Thus, 46 states and the District of Columbia (DC) are included in this report, and we reference them as 47 states with active section 1915(c) waiver programs.

**Findings.** Nationally, about 1.8 million beneficiaries participated in 267 section 1915(c) waiver programs offered by states in 2018, representing a 4.9 percent increase in participants from the prior year. When normalized to the overall U.S. population, there were about 5.81 section 1915(c) waiver program participants per 1,000 total U.S. residents in 2018 (Figure ES.1).<sup>2</sup> Similar to observed increases in participation from 2017 to 2018, average waiver program and total Medicaid (waiver and non-waiver program) expenditures per participant also increased during this time period. In 2017, average section 1915(c) waiver program expenditures per participant per year were \$28,044, and in 2018, they were \$29,453. In both years, waiver program expenditures constituted around 72 percent of total Medicaid

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<sup>1</sup> The 372 reports can have a status of accepted, submitted, unlocked, unsubmitted, or unaccepted. The analyses in this report are limited to 372 reports that were accepted, indicating that CMS reviewed the CMS 372 report completely, and the report met the reporting requirements.

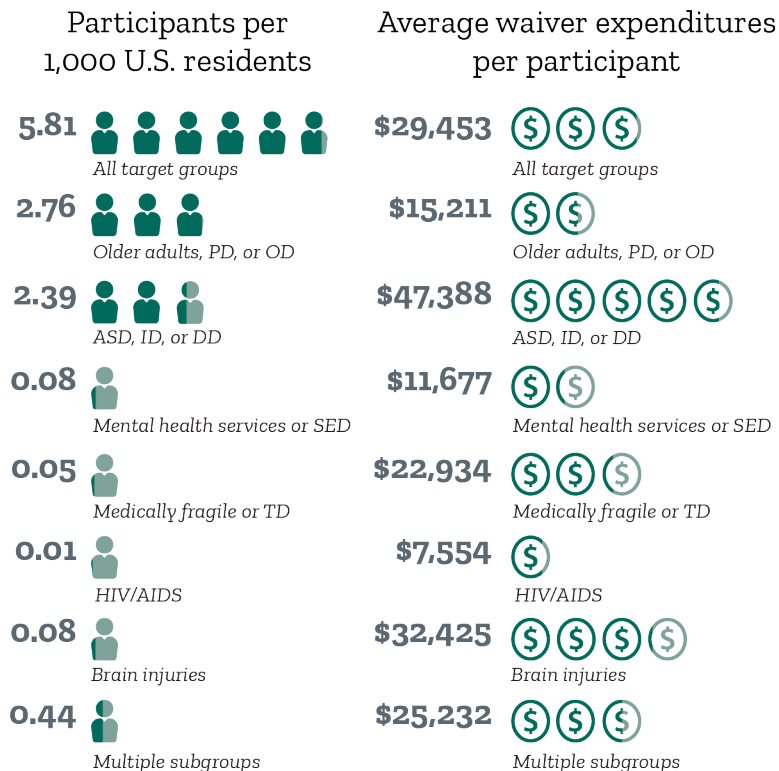
<sup>2</sup> To determine the national number of section 1915(c) waiver program participants per 1,000 residents, we divided the total number of participants by the sum of the U.S. Census Bureau population estimate for all states, excluding Arizona, Rhode Island, Vermont, and New Jersey. In addition, although most results in this report are rounded to one decimal place, two decimal places are used to report national statistics about section 1915(c) waiver program participants per 1,000 residents to show differences among the smaller target groups (for example, people receiving mental health services, with serious emotional disturbances, with brain injuries, or with HIV/AIDS).

expenditures for section 1915(c) waiver program participants; the remainder were for non-waiver services.

As in previous years, there was considerable variation in section 1915(c) waiver program participation, service use, and expenditures across the various long-term services and supports (LTSS) target group populations: (1) older adults, people with physical disabilities (PD), or people with other disabilities (OD); (2) people with autism spectrum disorder (ASD), intellectual disabilities (ID), or developmental disabilities (DD); (3) people receiving mental health services or with serious emotional disturbances (SED); (4) people with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS); (5) people who are medically fragile or technology dependent (TD); (6) people with brain injuries; or (7) program waivers that serve multiple subgroups.<sup>3</sup>

In 2018, the target groups with the highest participation nationally were those serving (1) older adults or people with PD or OD; and (2) people with ASD, ID, or DD. There were 2.76 participants in section 1915(c) waiver programs per 1,000 residents for older adults and people with PD or OD and 2.39 for people with ASD, ID, or DD in 2018. In 2018, waiver programs serving the older adults, PD, or OD target group, and those for people with ASD, ID, or DD, had the highest proportion of participants per 1,000 residents and comprised about 89 percent of total waiver program participants. Waiver programs focusing on the other five LTSS target groups

**Figure ES.1. Key 2018 statistics for section 1915(c) waiver program participants**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports for 2018, Waiver Management System Waiver Finder System file, Waiver Target Group, Subgroups, and Age file and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbances; TD = technology dependent.

<sup>3</sup> These populations correspond to the target group and subgroup categories selected in the section 1915(c) waiver program application. The multiple subgroups category includes waivers with unique or rare combinations of subgroups that are not necessarily comparable to other waivers. For example, North Carolina’s *Community Alternatives Program* (#4141) includes older adults, people with PD, or people who are medically fragile, which effectively combines the older adults, PD, or OD target group with the medically fragile or TD target group. Likewise, Wisconsin’s *Family Care Waiver* (#0367) includes older adults and people with PD, OD, DD, or ID, incorporating both the older adults, PD, or OD target group and the ASD, ID, or DD target group.



served fewer than 1 participant per 1,000 U.S. residents. Among these five target groups, the waiver programs serving multiple subgroups had the highest proportion of participants per 1,000 residents, followed by people receiving mental health services or with SED, people with brain injuries, people who are medically fragile or TD, and people with HIV/AIDS.

National average annual section 1915(c) waiver program expenditures in 2018 also ranged markedly across the seven target groups. Among the two target groups with the highest participation, section 1915(c) waiver programs serving people with ASD, ID, or DD had the highest average expenditures per person at \$47,388, which was about three times as much as the average expenditures per person for the older adults or people with PD or OD LTSS target group, at \$15,211. Among the smaller target groups, average per person expenditures ranged from \$7,554 (HIV/AIDS) to \$32,425 (brain injuries) in 2018.

In 2018, all 47 states offered waiver programs for the ASD, ID, or DD target group, and 42 of 47 (89.4 percent) offered waiver programs for the older adult, PD, or OD target group. For the remaining five target groups, 17 states (36.2 percent) offered waiver programs for people with brain injuries, 16 states (34.0 percent) served the medically fragile or TD population, 10 (21.3 percent) served people receiving mental health services or with SED, 5 were for people with HIV/AIDS (10.6 percent), and 6 served multiple subgroups (12.8 percent).

Among the 47 states, participation per 1,000 residents and average section 1915(c) waiver program expenditures varied overall and across the LTSS target groups. Wisconsin, Minnesota, Oregon, Illinois, Idaho, and Pennsylvania all had greater than 10 total section 1915(c) waiver program participants per 1,000 residents in 2018, listed from highest (Wisconsin) to lowest (Pennsylvania). Among the remaining states, Kansas, Ohio, Mississippi, Iowa, Wyoming, Washington, Colorado, and Connecticut had more than 8 total section 1915(c) waiver program participants per 1,000 residents, and Delaware and Tennessee had about 1 participant per 1,000 residents.

For section 1915(c) waiver programs serving older adults or people with PD or OD, Minnesota, Illinois, Oregon, Mississippi, Pennsylvania, and Idaho served the greatest number of participants as a proportion of their populations, exceeding 6 per 1,000 residents in 2018 (11.3 in Minnesota and 6.3 in Idaho). In contrast, North Dakota, Oregon, Idaho, South Dakota, New York, Wyoming, and Iowa had section 1915(c) waiver programs serving the most people with ASD, ID, or DD relative to their total populations, exceeding 4 per 1,000 residents. In these two LTSS population groups (older adults or people with PD or OD as well as people with ASD, ID, or DD), however, states with the highest participation rates did not necessarily have the highest average waiver program expenditures. Only Pennsylvania and Minnesota appeared among the states with the highest average section 1915(c) waiver program expenditures for the older adult or people with PD or OD LTSS population, ranking second and sixth, respectively. Among waivers with the highest participation in ASD, ID, or DD waivers per 1,000 residents, New York ranked highest for average waiver expenditures at ninth place; the remainder were in the bottom 50 percent.

For the waiver programs serving the other five target groups, different states generally had the greatest participation per 1,000 residents. In 2018, Kansas, Louisiana, and Colorado had the largest participation rates for the waiver programs serving people using mental health services or with SED (0.7 participants per 1,000 residents or above), and Pennsylvania, Iowa, Illinois, and Wyoming had the highest participants per 1,000 residents for their waiver programs serving people with brain injuries (0.25 participants per 1,000 residents or above). South Carolina and Illinois had the highest participation rates for their waiver programs serving people with HIV/AIDS in 2018 (0.15 and 0.12 per 1,000 residents, respectively), which was more than three times that of the next highest state (California). Colorado, South Carolina, Alaska,

Utah, and Texas each served 0.20 or more medically fragile or TD participants per 1,000 residents in 2018, and Wisconsin had the highest participation rates for its waiver programs for multiple subgroups (15.4 per 1,000 residents). Similar to the patterns overall and for the two waiver program types serving the largest number of beneficiaries (older adults or people with PD or OD as well as people with ASD, ID, or DD), states with higher participation rates in the remaining five groups did not necessarily have higher average waiver program expenditures per participant.

**Conclusion.** Section 1915(c) waiver programs comprise an important component of LTSS delivery systems for most states. Nationally, about 1.8 million beneficiaries participated in section 1915(c) waiver programs in 2018 and average section 1915(c) waiver program expenditures per participant per year were \$29,453, varying markedly across the seven target groups. The results in this report underscore the utility of 372 annual reports for understanding national trends and state variation in section 1915(c) waiver program participation, service use, and expenditures for all participants as well as by specific LTSS population target groups.

## I. Introduction

Section 1915(c) of the Social Security Act (the Act) enlarged the scope of the Medicaid program to allow for the provision of comprehensive long-term care services in home and community-based settings as an alternative to institutional care. Introduced as part of the Omnibus Budget Reconciliation Act of 1981, state use of section 1915(c) waiver programs grew slowly but steadily. Over the past several decades, states have used section 1915(c) waiver programs, several other federal authorities, and federally funded demonstration and grant programs to develop a broad range of home and community-based services (HCBS) to provide alternatives to institutionalization for eligible Medicaid beneficiaries. Consistent with many beneficiaries' preferences of where they would like to receive their care, section 1915(c) waiver programs have become a critical component of the Medicaid program and are part of a larger framework of progress toward community integration of older adults and individuals with disabilities that spans a variety of different efforts across the federal government.

The Centers for Medicare & Medicaid Services (CMS) requires states operating section 1915(c) waiver programs to provide annual information that includes (1) demonstrating states met their assurances on cost neutrality; (2) details of the type, amount, and cost of services provided; and (3) assessment of other aspects of the waiver programs including quality assurances (CMS 2018). States submit this information in CMS Form 372(S), hereafter referred to as the annual 372 reports, via the Waiver Management System (WMS). The WMS is a web-based system that includes the annual 372 reports and other information about section 1915(c) waiver programs, such as their eligible target groups and subgroups and associated minimum and maximum ages. As such, the submission of the annual 372 reports, along with other information available in the WMS, provides an important means of monitoring states' provision of HCBS via section 1915(c) waiver programs.

The annual 372 reports reflect information from waiver program years. A waiver program year can begin on any day of the year and generally corresponds to the approval date of the initial waiver program application, renewal, or modification. States have 18 months following the end of the waiver program year to submit the 372 report. For example, a waiver program year that began on March 26, 2017, and ended on March 25, 2018, would be considered a report for waiver program year 2018, and the corresponding annual 372 report would be due by September 25, 2019. A more detailed account of all the data sources, key variables, and methods used in this report is available in Appendix A.

This report analyzes information about section 1915(c) waiver program participants, service use, and expenditures submitted by states in their annual 372 reports for 2018.<sup>4</sup> CMS has published seven reports to date using annual 372 data to analyze section 1915(c) waiver program trends, which cover 2009 to 2017 (Ross et al. 2021; Amos et al. 2018; Eiken 2017; Eiken 2016; Eiken 2015; Eiken 2014; Eiken and Lelchook 2013).<sup>5</sup> The current report continues the following changes made in the most recent prior report (Ross et al. 2021)<sup>6</sup> in: (1) displaying national-, state-, and waiver-level results in an accompanying Appendix B Excel attachment for ease of stakeholder use; (2) omitting a comparison with Form CMS-64 expenditure data; and (3) updating the waiver program-level labels describing the populations of

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<sup>4</sup> To establish changes in section 1915(c) waiver program participants, service use, and expenditures for 2018, we also calculate results for 2017.

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

<sup>6</sup> Medicaid Section 1915(c) Waiver Programs Annual Expenditures and Beneficiaries Report: Analysis of CMS 372 Annual Reports, 2015- 2017." Chicago, IL: Mathematica, January 7, 2021. Available at <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/cms-372-report-2015-2017.pdf>.

Medicaid beneficiaries and recategorizing some waivers to reflect the included target groups and subgroups in the section 1915(c) waiver program applications.<sup>7</sup> In addition, Appendix B of this year’s report identifies subgroups that only include children as opposed to adults only or a mixed population of adults and children, using an updated, standardized approach. Appendix A details the method used for identifying section 1915(c) waiver programs that serve children younger than age 18.

Table I.1 presents the seven long-term services and supports (LTSS) target groups and subgroups served by the section 1915(c) waiver programs analyzed in this report. The groups appear in the same order throughout the report.<sup>8</sup> In Appendix B, the waiver program-level tables for 2017 and 2018 include each waiver program’s target group and subgroups. A section 1915(c) waiver program target group includes a specific group or groups of people who meet the requirements for institutional level of care as defined in 42 CFR §441.301(b)(6), and a target subgroup is a smaller subset of people within a target group. For example, in the section 1915(c) waiver program application, “Aged” is a subgroup within the target group of “Aged or Disabled, or Both – General” (CMS 2019).

**Table I.1. Section 1915(c) waiver program target groups and subgroups**

LTSS target group label for this report	Section 1915(c) waiver program application target subgroups
1. Older adults, PD, or OD	Aged, Disabled (Physical), or Disabled (Other)
2. ASD, ID, or DD	Autism, Developmental Disability, or Intellectual Disability
3. Mental health services or SED	Mental Illness or Serious Emotional Disturbance
4. Medically fragile or TD	Medically Fragile or Technology Dependent
5. HIV/AIDS	HIV/AIDS
6. Brain injuries	Brain Injury
7. Multiple subgroups	Waiver includes people from two or more target groups 1 to 6

Source: Mathematica’s analysis of Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

Note: Additional details regarding LTSS target group assignments are available in Appendix A.

ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; LTSS = long-term services and supports; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbances; TD = technology dependent.

The accuracy of this report reflects the completeness and quality of annual 372 reports for 2017 and 2018. Although the report focuses primarily on section 1915(c) waiver programs active in 2018, we also recalculated results for programs active in 2017, to reflect information from annual 372 reports that were submitted since the previous year’s report. This serves as the second and final analysis of 372 reports for

<sup>7</sup> We omitted this comparison because of significant differences in reporting periods between the 372 and Form CMS-64 data sources. The 372 report data correspond to the waiver program year, which can begin on any day of the year and is not tied to a calendar or fiscal year. For example, at the time of this report, 2018 was the most recent year for which all section 1915(c) waiver programs were required to have 372 reports. The 2018 waiver program year, however, covers a wide range of possible reporting periods from January 2, 2017, to December 31, 2018, and does not necessarily align with the calendar, state, or federal fiscal year. In contrast, CMS-64 data are analyzed by federal fiscal year. Analyses of federal fiscal year 2019 section 1915(c) waiver program expenditures submitted via Form CMS-64 are available in the most recent Medicaid Long Term Services and Supports Annual Expenditures Report (Murray et al. 2021).

<sup>8</sup> Although the section 1915(c) waiver programs serving the most participants are shown first and second, respectively, the report results are not necessarily presented from the highest to lowest number of participants per 1,000 residents for every target group.

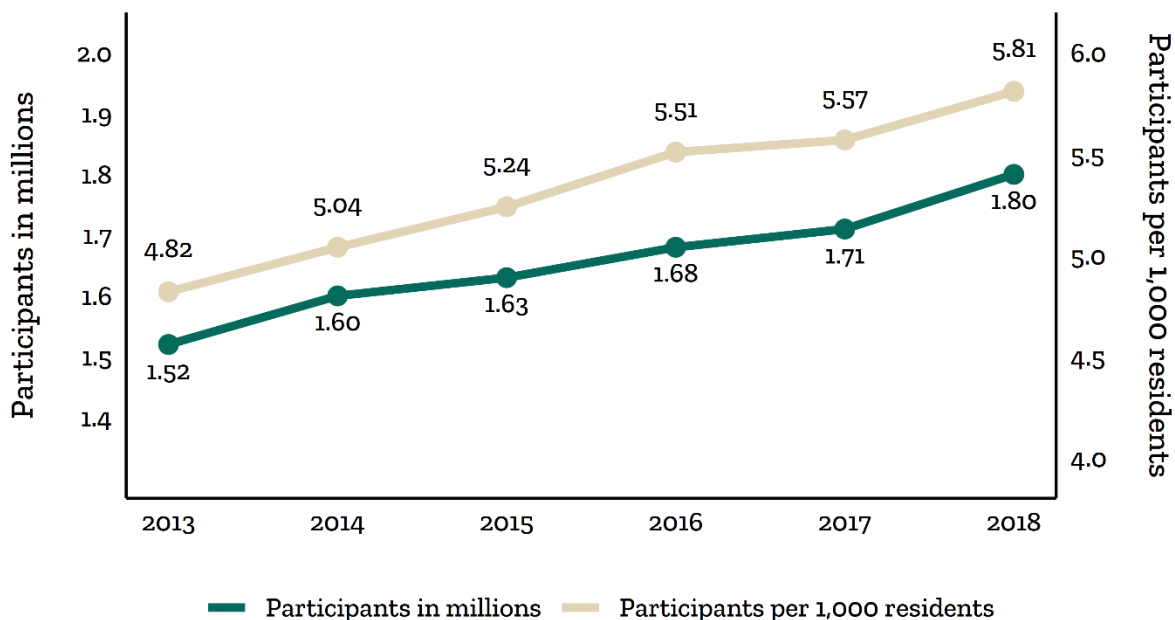
2017. During these years, three states (Arizona, Rhode Island, and Vermont) did not have section 1915(c) waiver programs. Instead, these states provided similar services to HCBS-eligible populations in demonstrations authorized under section 1115(a) of the Social Security Act. During 2017, the remaining 47 states and the District of Columbia (DC) had one or more section 1915(c) waiver programs for which they were required to submit a 372 report. Not all section 1915(c) waiver programs, however, had an accepted report at the time of this analysis. In these cases, this report uses data from the most recently accepted 372 report within the prior four years to estimate current year trends. Waiver programs with no accepted report within the past four years do not contribute to the analyses but are listed as “Not Reported” in the waiver program-level tables in Appendix B. For example, New Jersey operated one section 1915(c) waiver program during 2017 but submitted its last accepted 372 report in 2011. Because those data are more than four years old for the 2017 waiver program year, we did not use that 2011 report to estimate participants, service use, or expenditures. Consequently, we did not use data for New Jersey to calculate the 2017 national estimates in Chapter II, and we present waiver-level results as “Not Reported” in Appendix Table B.2. In 2018, New Jersey had no remaining active section 1915(c) waiver programs and provided HCBS entirely under the state’s section 1115(a) demonstration, similar to Arizona, Rhode Island, and Vermont. We discuss the process for using prior year data to estimate missing current year 372 report information in more detail in Appendix A, and we note waiver programs with either estimated or absent current year data in Appendix B.

In the remaining sections of this report, we summarize information about section 1915(c) waiver program participants, service use, and expenditures for the 2018 waiver program year. In Chapter II, we examine national-level trends for 2018 and most recent five years (2013 to 2017). We present more detailed national information for 2018 in Chapter III for the seven section 1915(c) waiver program target groups, and Chapter IV includes an analysis of section 1915(c) waiver program participation and expenditures by state. In Chapter V, we present our conclusions.

## II. National trends in section 1915(c) waiver program participation and expenditures (2013 to 2018)

**Participants.** National participation in section 1915(c) waiver programs increased during 2018 relative to 2017, continuing a trend of annual increases observed in the prior five years (Figure II.1). In 2018, the total number of waiver program participants was about 1.8 million, representing an increase of 4.9 percent relative to 2017 (Figure II.2).

**Figure II.1. Section 1915(c) waiver program participants, waiver program years ending in 2013–2018**

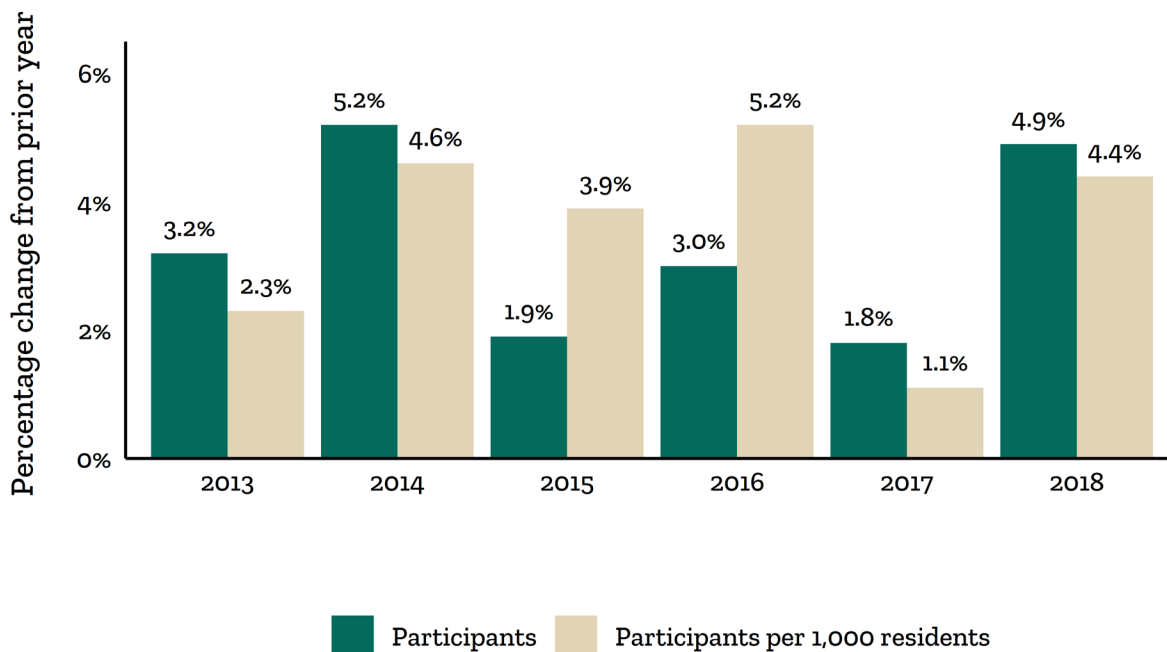


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data from 2015 to 2018. We obtained data for 2013 to 2014 from Amos et al. (2018) and data from 2015 to 2016 from Ross et al. (2021).

Note: Data reported on participants per 1,000 residents for 2015 and 2016 differs from Ross et al. (2021) because of changes in determining national population estimates. We recalculated results to remove states that did not have active section 1915(c) waiver programs in these waiver program years.

The number of section 1915(c) waiver program participants per 1,000 U.S. residents increased slightly, following the same pattern over the five-year period. For every 1,000 U.S. residents, 5.81 were section 1915(c) waiver program participants in 2018 (Figure II.1), representing an increase of 4.4 percent from the prior year (Figure II.2), when the proportion of residents using section 1915(c) waiver program services was 5.57 per 1,000.

Figure II.2. Change in section 1915(c) waiver program participants, waiver program years ending in 2013–2018



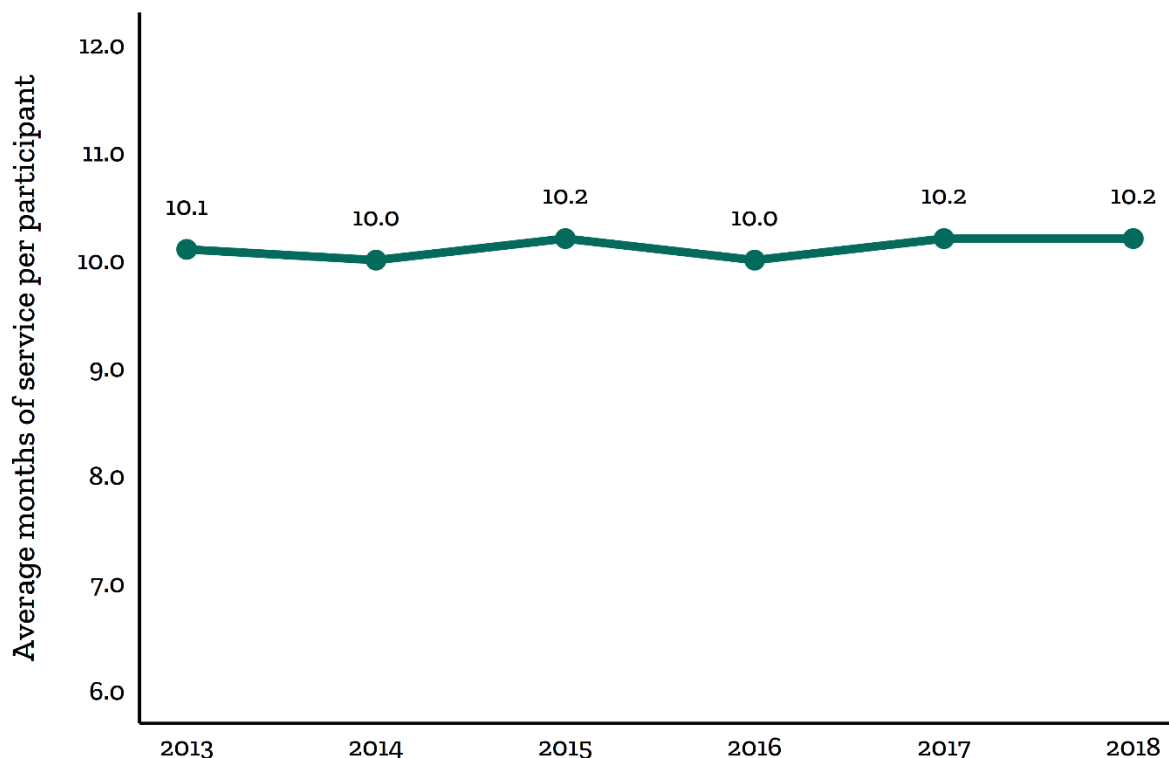
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data 2015 to 2018. We obtained data for 2012 to 2014 from Amos et al. (2018) and data from 2015 to 2016 from Ross et al. (2021).

Note: Data reported on participants per 1,000 residents for 2015 and 2016 differs from Ross et al. (2021) because of changes in determining national population estimates. We recalculated results to remove states that did not have active section 1915(c) waiver programs in these waiver program years.

**Service use.** Despite the overall national growth in section 1915(c) waiver program participation from 2013 to 2018, average months of service use remained essentially unchanged in 2018 and during the past five years (Figure II.3). The average months of section 1915(c) waiver program service use per participant fluctuated between 10.0 and 10.2 average months from 2013 to 2018, aligning with trends from 2012 and earlier years.<sup>9</sup> In 2018, the average participant used section 1915(c) waiver program services for 10.2 months, the same average duration of service use reported in 2017. We explore how average months of service use varies across different target groups of section 1915(c) waiver program participants in Chapter III.

<sup>9</sup> Reports from prior years are available from CMS at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>

**Figure II.3. Average months of section 1915(c) waiver program service per participant, waiver program years ending in 2013–2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports 2017 to 2018. We obtained data for 2013 to 2014 from Amos et al. (2018) and data from 2015 to 2016 from Ross et al. (2021).

**Expenditures.** Nationally, average annual total Medicaid expenditures (including waiver and non-waiver expenditures) for section 1915(c) waiver program participants reached \$40,835 in 2018 (Figure II.4). This represents a 4.3 percent increase in average annual total Medicaid spending from 2017 (\$39,144), and continues the pattern of increases over the past five years.

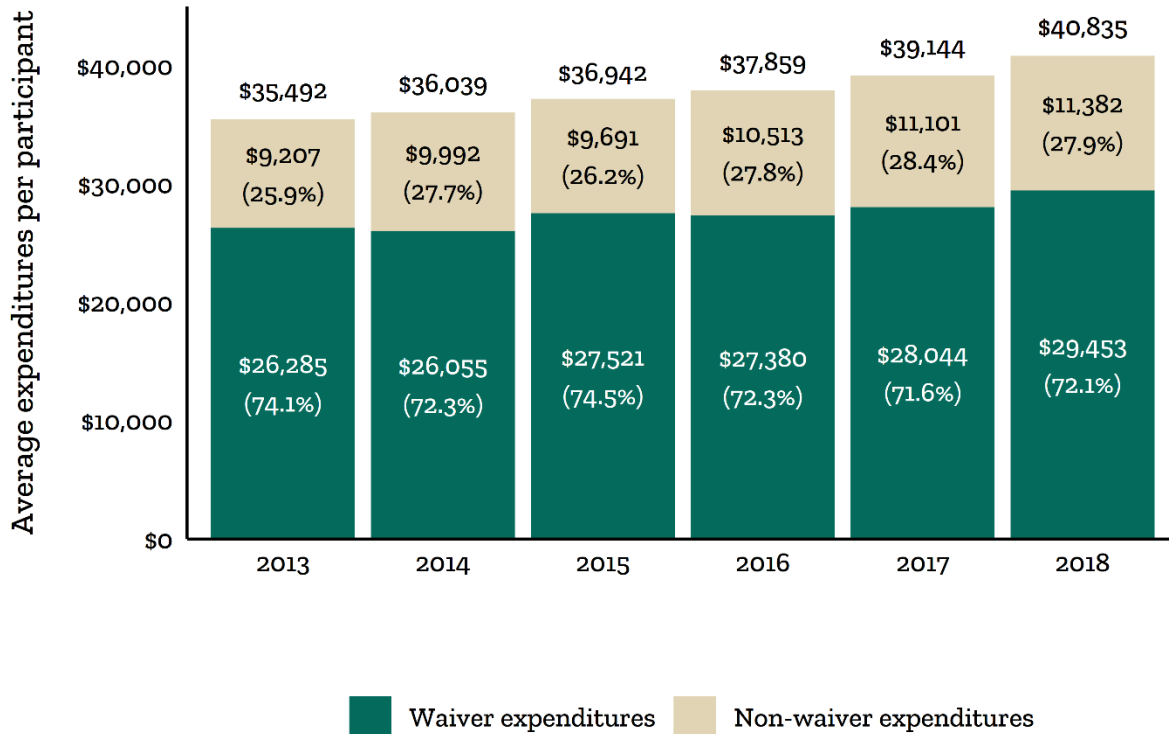
Annual waiver program expenditures per section 1915(c) waiver program participant grew from 2013 to 2018, with most years experiencing annual positive increases relative to the prior year. From 2013 to 2014, average waiver program expenditures fell slightly by less than 1 percent, but in the following year, average waiver program expenditures grew by 5.6 percent to an average of \$27,521 per participant in 2015. In 2016, this number declined slightly by 0.5 percent to \$27,380, and then in 2017, it increased by 2.4 percent to \$28,044. In 2018, the average increased more markedly by 5.0 percent to reach \$29,453.

Despite the fluctuations, average annual per-person waiver program expenditures remained a fairly stable proportion of the total annual per-person Medicaid spending among waiver program participants during 2013 to 2018. A slight downward trend was observed over 2016 to 2018 relative to 2013 to 2015, with the proportion of average annual per-person waiver program spending falling slightly to 72.3 percent of total annual per-person Medicaid spending in 2016 and then decreasing slightly again to 71.6 percent in 2017 before increasing to 72.1 percent in 2018 (Figure II.4).



During the same period, the annual average Medicaid non-waiver expenditures among section 1915(c) waiver program participants increased in every year except 2015. Relative to 2015, average annual non-waiver program Medicaid expenditures increased by 8.5 percent to \$10,513 in 2016, and continued to grow in 2017, reaching \$11,101 (a 5.6 percent increase from 2016), and in 2018, reaching \$11,382 (a 2.5 percent increase from 2017) (Figure II.4).

**Figure II.4. Average annual waiver, non-waiver, and total Medicaid expenditures per section 1915(c) waiver program participant, waiver program years ending in 2013–2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2017 to 2018. We obtained data for 2013 to 2014 from Amos et al. (2018) and data from 2015 to 2016 from Ross et al. (2021).

### III. Trends in section 1915(c) waiver program participation and expenditures, by LTSS target group (2018)

**Number and type of section 1915(c) waiver programs.** In 2018, 267 section 1915(c) waiver programs were active across 47 states, representing a net decline of seven waiver programs relative to 2017.<sup>10</sup> In all, 10 section 1915(c) waiver programs ended, and 3 new programs were newly active in waiver program year 2018, as shown in Table III.1.

**Table III.1. Section 1915(c) waiver program changes during 2017 and 2018**

Waiver programs ended in waiver program year 2017	Waiver programs newly active in waiver program year 2018
<i>Autism Waiver</i> (MO 0698)	<i>Family Supports Waiver</i> (MD 1466)
<i>Community Care Waiver</i> (NJ 0031)	<i>Community Supports Waiver</i> (MD 1506)
<i>Transitions DD Waiver Renewal</i> (OH 0383)	<i>Community Living Waiver</i> (PA 1486)
<i>Pervasive Developmental Disorder Waiver</i> (SC 0456)	
<i>San Francisco Community Living Support Benefit Waiver</i> (CA 0855)	
<i>Assisted Living Facility Home and Community Based Services Waiver</i> (WY 0369)	
<i>Home and Community Based Services Waiver for Individuals with HIV/AIDS and Related Illnesses</i> (AL 40382)	
<i>Project AIDS Care</i> (FL 0194)	
<i>Pediatric Palliative Care Waiver</i> (CA 0486)	
<i>Technology Assisted Waiver</i> (VA 4149)	

Missouri, New Jersey, Ohio, and South Carolina ended a total of four waiver programs serving people with autism spectrum disorder (ASD), intellectual disabilities (ID), or developmental disabilities (DD) (MO 0698, NJ 0031, OH 0383, and SC 0456). California and Wyoming ended two waiver programs serving the older adult and people with physical disabilities (PD) or other disabilities (OD) target group (CA 0855 and WY 0369). Two additional states—Alabama and Florida—ended waiver programs serving the HIV/AIDS target group (AL 40382 and FL 0194), and California and Virginia (CA 0486 and VA 4149) ended waiver programs serving people who were medically fragile or technology dependent (TD).

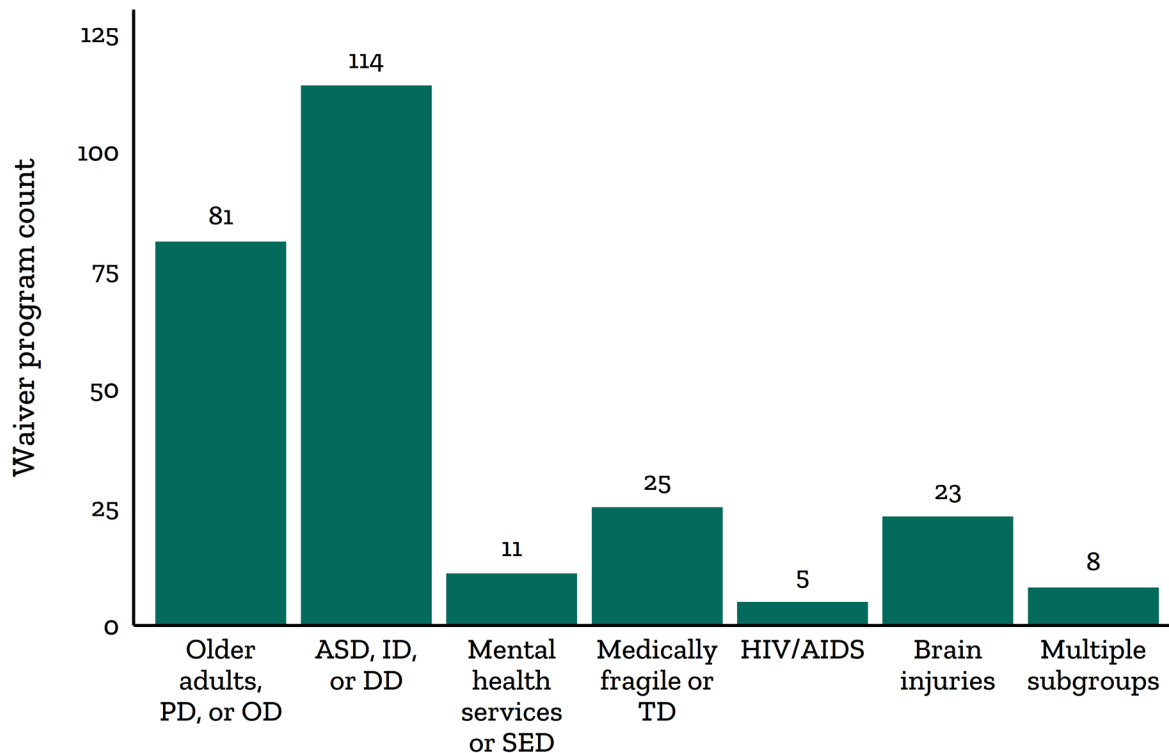
This reduction in the total number of section 1915(c) waiver programs was partially offset by the introduction of three newly active waiver programs in 2018, all serving people with ASD, ID, or DD. Maryland had two new waiver programs, *Family Supports Waiver* (MD 1466) and *Community Supports Waiver* (MD 1506), and in Pennsylvania the *Community Living Waiver* (PA 1486) was newly active in waiver program year 2018.

Finally, between 2017 and 2018, the *Elderly or Disabled with Consumer Direction Waiver* in Virginia (VA 0321) expanded from serving the older adult, PD, or OD target group to also include people who are TD, and the state renamed it the *Commonwealth Coordinated Care Plus Waiver*. As a result of this change, this waiver program was recategorized as serving multiple subgroups in 2018.

<sup>10</sup> Although Ross et al. 2021 reports 278 waiver programs in 2017, we found that four waivers in fact had not been active during the 2017 program year based upon this year’s analysis.

After accounting for these changes, about 73.0 percent of the 267 section 1915(c) waiver programs active in 2018 served either the ASD, ID, or DD target group (114 programs) or older adult, PD, or OD target group (81 programs) (Figure III.1).

Figure III.1. Total active section 1915(c) waiver programs in 2018, by LTSS target group



Source: Mathematica’s analysis of Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

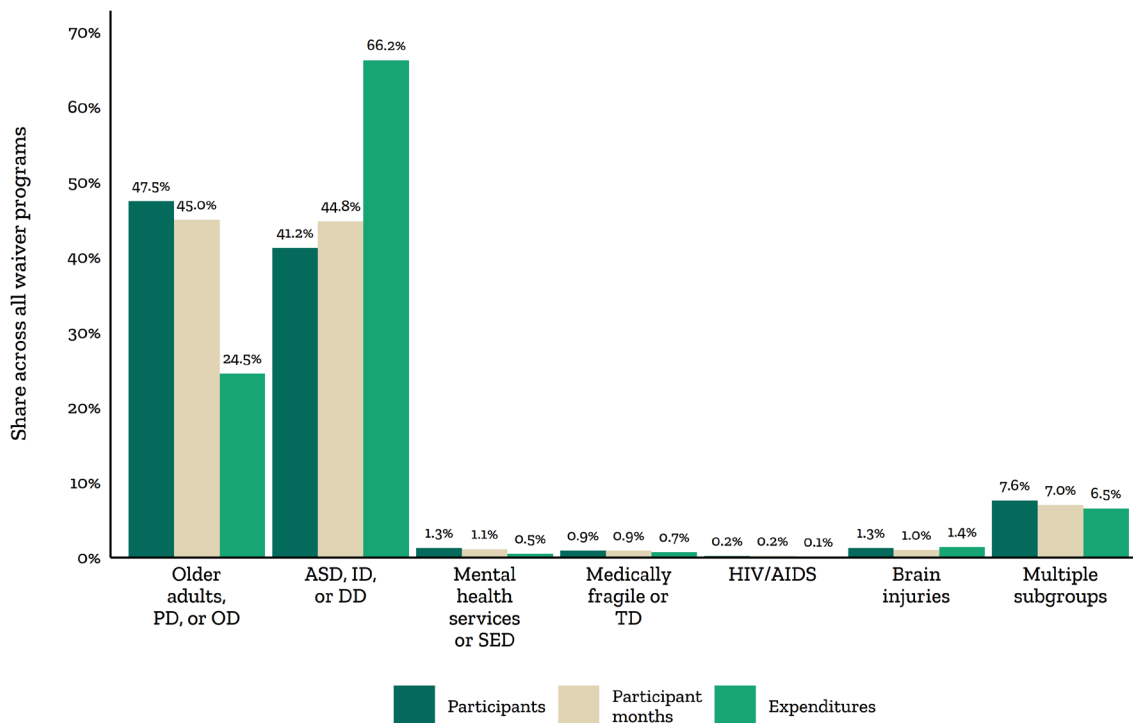
ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; LTSS = long-term services and supports; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbances; TD = technology dependent.

**Number of section 1915(c) waivers programs serving only children.** In 2018, of the 267 section 1915(c) waiver programs active across 47 states, 14 served only children in various subgroups targeted by these waiver programs. This represents 5.2 percent of all active section 1915(c) waiver programs in 2018. Between 2017 and 2018, two ASD, ID, or DD waivers programs serving children only ended (MO 0698 – *Autism Waiver* and SC 0456 – *Pervasive Developmental Disorder*). This decreased the total number of waiver programs serving only children in select subgroups by two, from 16 in 2017 to 14 in 2018.

**Participants.** In 2018, two target groups—older adults, PD, or OD and ASD, ID, or DD—together included 1.59 million participants, representing 88.7 percent of all participants (47.5 percent and 41.2 percent, respectively) (Figure III.2). Waiver programs serving multiple subgroups had the third largest share, comprising 136,635 participants (7.6 percent of all section 1915(c) waiver program participants). Waiver programs serving people receiving mental health services or with serious emotional disturbances (SED) (1.3 percent), people with brain injuries (1.3 percent), people who are medically fragile or TD (0.9

percent), and people with HIV/AIDS (0.2 percent) were much smaller, ranging from 3,652 to 24,056 participants.

**Figure III.2. Distribution of section 1915(c) waiver program participants, participant months, and waiver program expenditures by LTSS target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

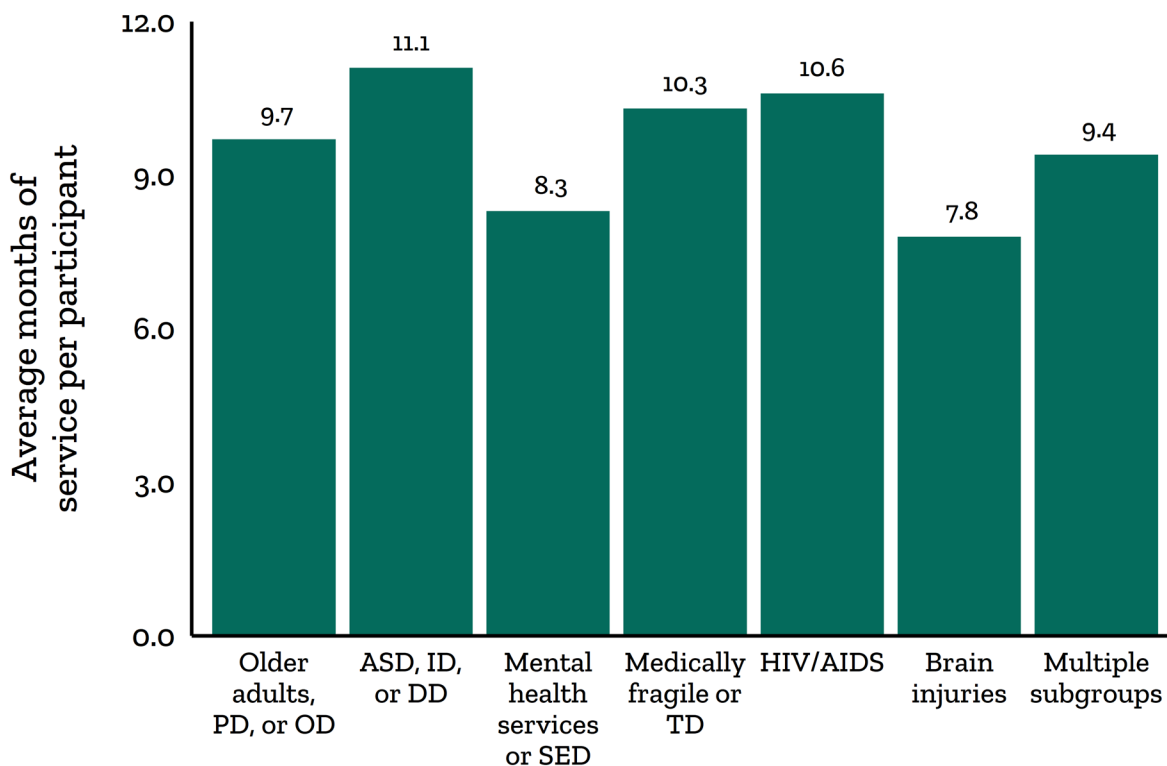
ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; LTSS = long-term services and supports; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technology dependent.

**Service use.** Nationwide, the average annual number of months that participants received section 1915(c) waiver program services during the year was 10.2 months in 2018, as noted in Chapter II. The average number of months of service use varied by target group and as a proportion of the total section 1915(c) waiver program participant months across target groups. For example, those enrolled in section 1915(c) waiver programs for people with brain injuries received waiver program services for an average of 7.8 months in 2018 compared with 11.1 months for the ASD, ID, or DD target group (Figure III.3). These groups represented 1.0 percent and 44.8 percent of all section 1915(c) waiver program participant months, respectively (Figure III.2).

Among the other target groups, waiver programs serving people with HIV/AIDS and those who were medically fragile or TD had average months of service relatively similar to the national average, at 10.6 months and 10.3 months. These groups represented 0.2 percent and 0.9 percent of all section 1915(c) waiver program participant months, respectively, in 2018. Waiver programs serving the older adults, PD, or OD target group had slightly fewer months of service, at an average of 9.7 months, as did the multiple

subgroups target group, at an average of 9.4 months. These programs accounted for 45.0 percent and 7.0 percent of all section 1915(c) waiver program participant months, respectively. Waiver programs serving people receiving mental health services or with SED had an average of 8.3 months of service use. These programs accounted for 1.1 percent of all section 1915(c) waiver program participant months.

**Figure III.3. Average annual number of participant months among people receiving section 1915(c) waiver program services by target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technology dependent.

**Expenditures.** In 2018, annual average waiver program expenditures per participant were \$29,453, representing 72.1 percent of total annual average Medicaid spending (\$40,835), as noted in Chapter II. Across target groups, however, average waiver program expenditures varied markedly in terms of absolute spending and as a proportion of total Medicaid spending and of all section 1915(c) waiver program expenditures. In 2018, section 1915(c) waiver program expenditures per participant were highest for the ASD, ID, or DD target group at about \$47,388 in 2018, followed by brain injuries (\$32,425), multiple subgroups (\$25,232), medically fragile or TD (\$22,934), older adults, PD, or OD (\$15,211), mental health services or SED (\$11,677), and HIV/AIDS (\$7,554) (Figure III.4). As a proportion of total Medicaid spending by target group, average waiver program expenditures ranged from 23.7 percent in the medically fragile or TD target group to 82.2 percent for waiver programs serving individuals with brain injuries (Figure III.4).

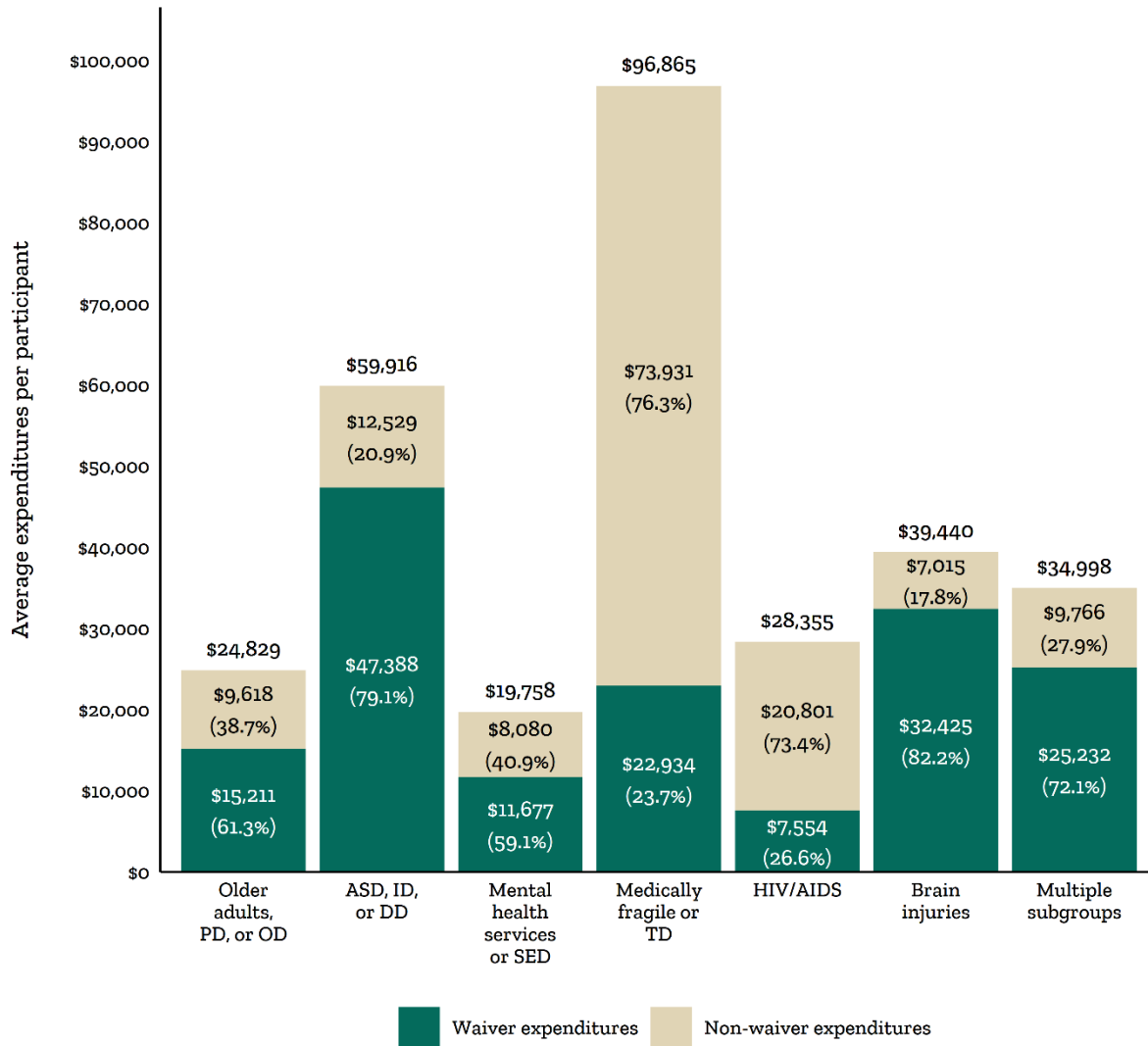
As a proportion of all section 1915(c) waiver program expenditures across target groups, the distribution of total expenditures by target group varied slightly. The people with ASD, ID, or DD target group had the highest share of total waiver program expenditures at 66.2 percent, and the older adults, PD, or OD target group had the next highest share of total waiver program expenditures (24.5 percent), followed by the multiple subgroups target group (6.5 percent) (Figure III.2). While the older adults, PD, or OD target group had the greatest number of participants, the ASD, ID, or DD target group had the highest share of total waiver program expenditures in 2018. Individuals in the ASD, ID, or DD target group had a higher average annual number of participant months (11.1 months) (Figure III.3), compared with that of the older adults, PD, or OD target group (9.7 months), which may contribute in part to the higher total observed expenditures for this target group. In 2018, the remaining target groups (brain injuries, medically fragile or TD, mental health services or SED, and HIV/AIDS) each had 1.4 percent or less share of total expenditures.

In terms of average non-waiver expenditures per participant, in 2018, the national average was \$11,382 per participant.<sup>11</sup> Again, target groups substantially varied. The medically fragile or TD target group had the highest non-waiver program expenditures at about \$73,931 in 2018. The target groups with the next highest average annual non-waiver expenditures were the HIV/AIDS target group (\$20,801) and the ASD, ID, or DD target group (\$12,529). The average non-waiver program expenditures among the multiple subgroups and older adults, PD, or OD populations, were quite similar, at \$9,766 and \$9,618, respectively, in 2018. The mental health services or SED and brain injuries target groups had the lowest average non-waiver program expenditures at \$8,080 and \$7,015, respectively (Figure III.4). In addition, although non-waiver expenditures comprised more than 70 percent of total Medicaid spending for waiver programs serving people who are medically fragile or TD and people with HIV/AIDS target groups, this category of expenditures makes up less than half of total expenditures among the remaining target groups.

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<sup>11</sup> Non-waiver program expenditures reflect the estimated annual average per capita Medicaid cost for all services (including state plan and services required under the Early and Periodic Screening, Diagnostic and Treatment [EPSDT] benefit when a waiver program serves children) that are furnished in addition to waiver program services while the individual is participating in the waiver program.

Figure III.4. Average annual waiver, non-waiver, and total Medicaid expenditures per section 1915(c) waiver program participant by LTSS target group, for waiver program year ending in 2018



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.  
 ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; LTSS = long-term services and supports; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technology dependent.

## IV. State variation in section 1915(c) waiver program participation and expenditures 2018

Section 1915(c) waiver programs vary across states because states differ in how they use these programs to serve different LTSS target groups that have diverse needs. States also design the waiver programs to provide different services to different groups, and these can vary considerably across states, and across waiver programs within a state. In this section, we describe state-level variation in section 1915(c) waiver program participation and expenditures for 2018 overall as well as for each of the seven LTSS target groups during this same time period.

To understand differences in section 1915(c) waiver program participants across states and to enable comparisons that account for state-level differences in population size, we calculated the number of section 1915(c) waiver program participants per 1,000 total residents in each state with at least one active waiver program with available 372 data. We obtained information on total residents per state from the U.S. Census Bureau (Appendix A). Similar to Chapters II and III for expenditures, we calculated average waiver expenditures per section 1915(c) waiver program participant for each state.

### 1. State-level variation among all LTSS target groups

**Participants.** In 2018, the total number of section 1915(c) program participants ranged from about 1 per 1,000 state residents (Tennessee and Delaware) to 16 (Wisconsin), and the U.S. total across all 47 states was 5.8 participants per 1,000 state residents (Figure IV.1; Appendix Table B.3).<sup>12</sup> Of the 47 states with section 1915(c) waiver programs, 25 (53 percent) had higher rates than the national rate. Those in the lowest quartile of section 1915(c) waiver program participants per 1,000 state residents (with fewer than 3.5 participants per 1,000 residents) were Tennessee, Delaware, Texas, Nevada, Hawaii, New Mexico, Michigan, North Carolina, Utah, Alabama, and California.<sup>13</sup> Among those in the highest quartile of section 1915(c) waiver program participants per 1,000 state residents (in which participants per 1,000 state residents fell between 8.4 and 16.1) were Washington, Wyoming, Iowa, Mississippi, Ohio, Kansas, Pennsylvania, Idaho, Illinois, Oregon, Minnesota, and Wisconsin.

Although these state differences provide insight into how expansive section 1915(c) waiver programs are across states, it is important to keep in mind the larger policy context and other authorities states could be using to provide similar services. For example, although Tennessee and Delaware had the fewest section 1915(c) waiver program participants per 1,000 residents, these states only operate waiver programs for the ASD, ID, or DD LTSS target group, and managed LTSS are provided to additional Medicaid beneficiaries via these states' section 1115(a) demonstrations.

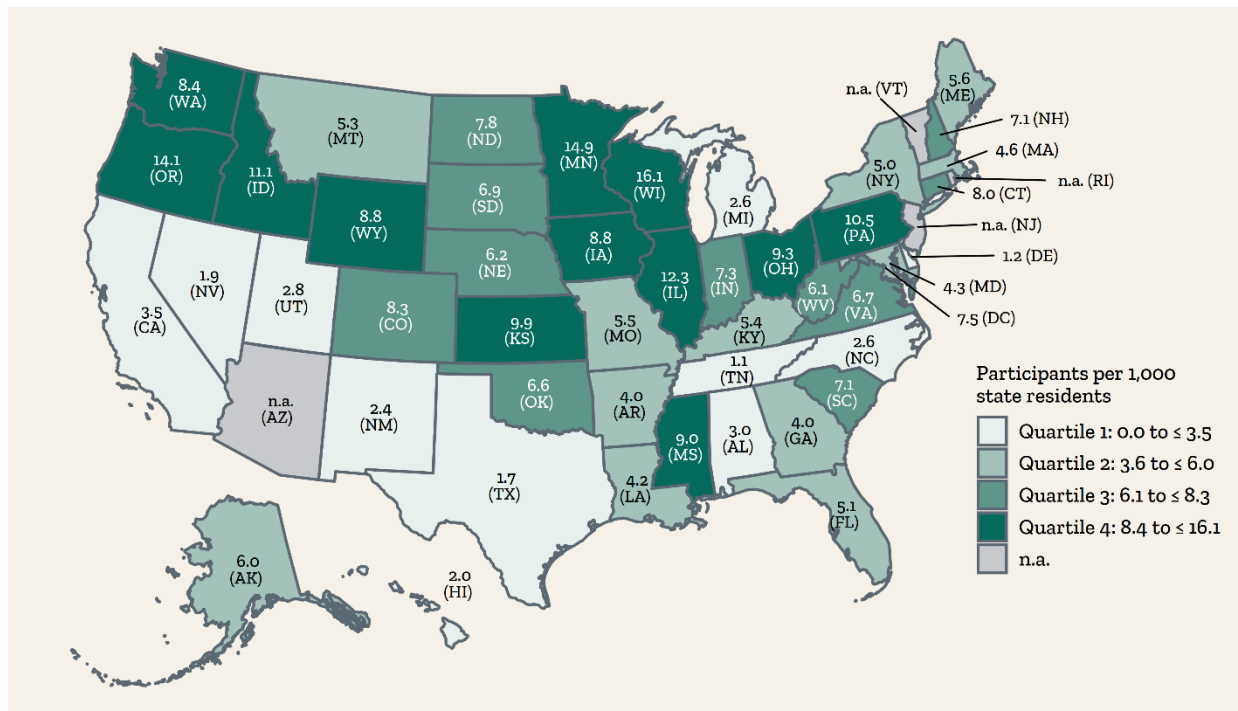
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<sup>12</sup> As we describe in Chapter I, Arizona, New Jersey, Rhode Island, and Vermont did not operate any section 1915(c) waiver programs in 2018, so we did not include these states in totals in this section.

<sup>13</sup> To determine quartiles and categorize states into quartiles, we used unrounded values. Rounded values are displayed in all output. Unless otherwise noted, states are listed in order of lowest to highest value.



**Figure IV.1. Section 1915(c) waiver program participants per 1,000 state residents, for waiver program year ending in 2018**

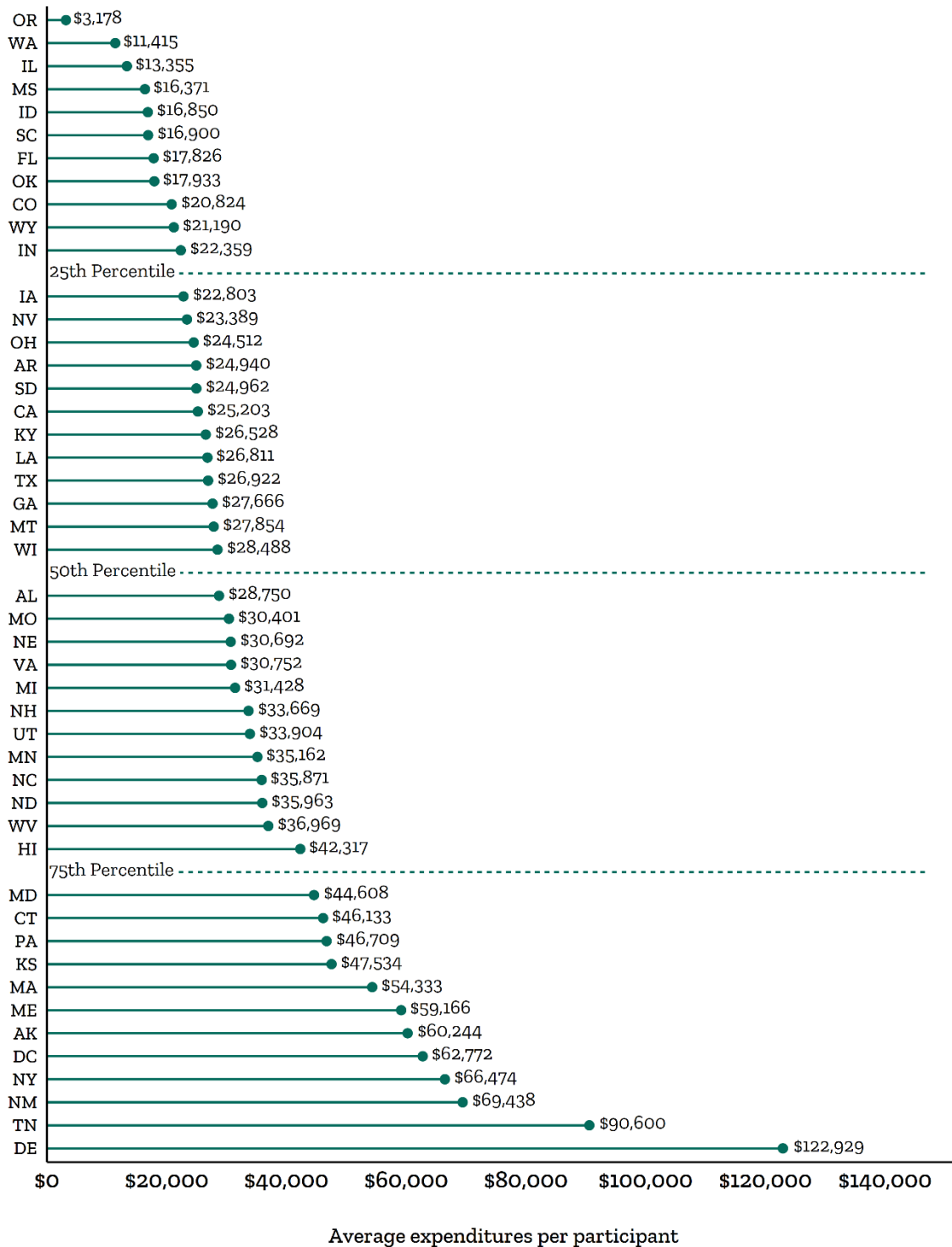


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data from 2018.  
n.a. = not applicable.

**Waiver expenditures.** As we describe in Chapter II, in 2018, the U.S. total annual average waiver expenditures per waiver program participant was \$29,453, but this average masks considerable state variation (Figure IV.2; Appendix Table B.1). The average in each state ranged from \$3,178 in Oregon to \$122,929 in Delaware. These two states were extremes at the low and high range of per participant average waiver expenditures. Specifically, Washington, which had the second lowest average expenditures, spent \$8,237 more per participant on average than Oregon in 2018 (or a total of \$11,415 per waiver program participant). Tennessee, which had the second highest average expenditures, spent \$32,329 less per participant on average than Delaware in 2018 (or a total of \$90,600 per participant). Oregon had particularly low expenditures because it provided a substantial proportion of HCBS to eligible Medicaid beneficiaries through the Community First Choice section 1915(k) State Plan option (Oregon Department of Human Services n.d.). In contrast, Delaware has particularly high expenditures because there was only one waiver program in 2018 (DE 0009 – *DDDS Lifespan Waiver*) serving a small number (1,147) of people with ASD, ID, or DD who had relatively high average waiver program expenditures.

Of the 47 states with section 1915(c) waiver programs, 23 (49 percent) had higher average waiver expenditures than the U.S. total average (\$29,453) in 2018. States in the lowest quartile of average expenditures per participant in 2018 were Oregon, Washington, Illinois, Mississippi, Idaho, South Carolina, Florida, Oklahoma, Colorado, Wyoming, and Indiana. Among those in the highest quartile of average expenditures were Maryland, Connecticut, Pennsylvania, Kansas, Massachusetts, Maine, Alaska, District of Columbia, New York, New Mexico, Tennessee, and Delaware.

Figure IV.2. Average waiver expenditures per section 1915(c) waiver program participant, for waiver program year ending in 2018



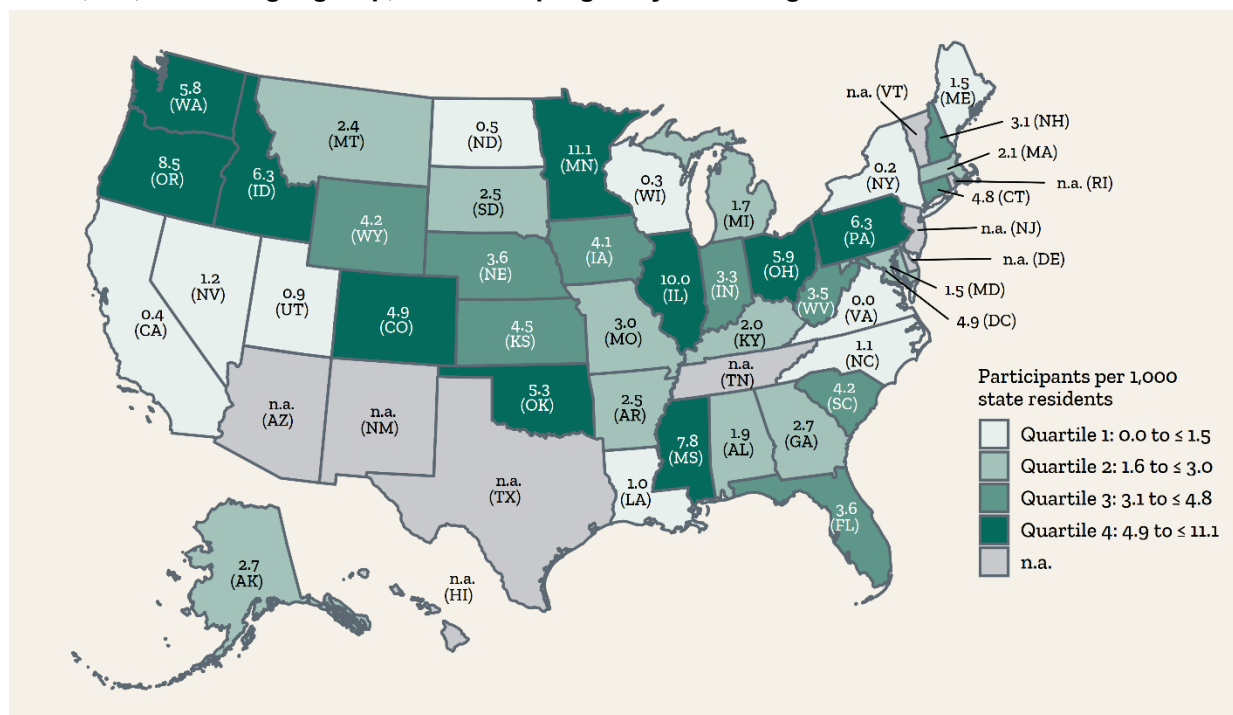
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018 and Waiver Management System Finder file.

## 2. State-level variation for older adults, PD or OD target group

**Participants.** Of the 47 states with section 1915(c) waiver programs in 2018, 42 (89 percent) had at least one section 1915(c) waiver program for the older adults, PD, or OD target group. Delaware, Hawaii, New Mexico, Tennessee, and Texas did not operate any waiver programs for this LTSS target group in 2018.<sup>14</sup> The number of older adult, PD, or OD waiver program participants per 1,000 state residents ranged from less than 1 in several states (Virginia serving the fewer than 0.0) to 11.1 (Minnesota), and the U.S. rate across all 42 states was 2.8 per 1,000 state residents (Figure IV.3; Appendix Table B.3). A total of six states served fewer than one section 1915(c) waiver program participant who was an older adult or had PD or OD per 1,000 state residents (Virginia, New York, Wisconsin, California, North Dakota, and Utah). Of the 42 states, 22 (52 percent) had higher rates than the U.S. rate (2.8) in 2018.

States in the lowest quartile of section 1915(c) waiver participants per 1,000 residents were Virginia, New York, Wisconsin, California, North Dakota, Utah, Louisiana, North Carolina, Nevada, and Maine. Those in the highest quartile (in which the number of participants was greater than or equal to 4.9 per 1,000 residents) were District of Columbia, Colorado, Oklahoma, Washington, Ohio, Idaho, Pennsylvania, Mississippi, Oregon, Illinois, and Minnesota.

**Figure IV.3. Section 1915(c) waiver program participants per 1,000 state residents for the older adults, PD, or OD target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

Note: We rounded the quartile ranges and state values to one decimal place in the figure, but states were grouped into quartiles based on unrounded values. Because of rounding, the range for quartile one appears to contain Maryland, but Maryland is actually part of quartile two based on its unrounded value.

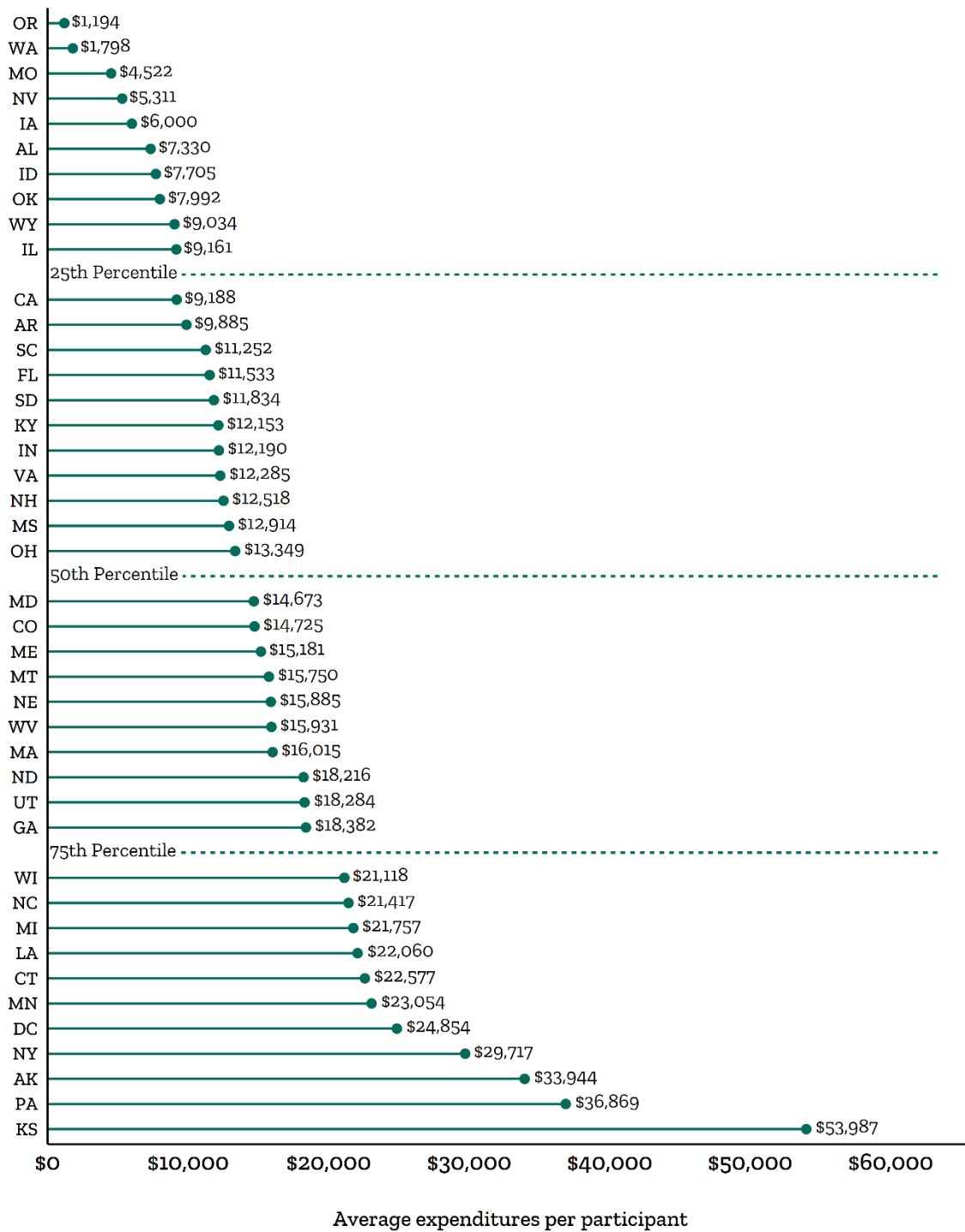
n.a. = not applicable; OD = other disabilities; PD = physical disabilities.

<sup>14</sup> These states use other Medicaid program authorities and delivery systems to provide LTSS to this target group.

**Waiver expenditures.** In 2018, the U.S. total average waiver expenditures per waiver program participant that was an older adult or had PD or OD was \$15,211. Average waiver expenditures per section 1915(c) waiver program participant for this LTSS target population ranged from \$1,194 in Oregon to \$53,987 in Kansas (Figure IV.4; Appendix Table B.3).

States in the lowest quartile of average waiver expenditures per waiver program participant were Oregon, Washington, Missouri, Nevada, Iowa, Alabama, Idaho, Oklahoma, Wyoming, and Illinois. Of 42 states, 18 (43 percent) had average waiver expenditures greater than the U.S. total average. Among those in the highest quartile of average waiver expenditures were Wisconsin, North Carolina, Michigan, Louisiana, Connecticut, Minnesota, District of Columbia, New York, Alaska, Pennsylvania, and Kansas.

Figure IV.4. Average waiver expenditures per section 1915(c) waiver program participant for the older adults, PD, or OD target group, for waiver program year ending in 2018



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

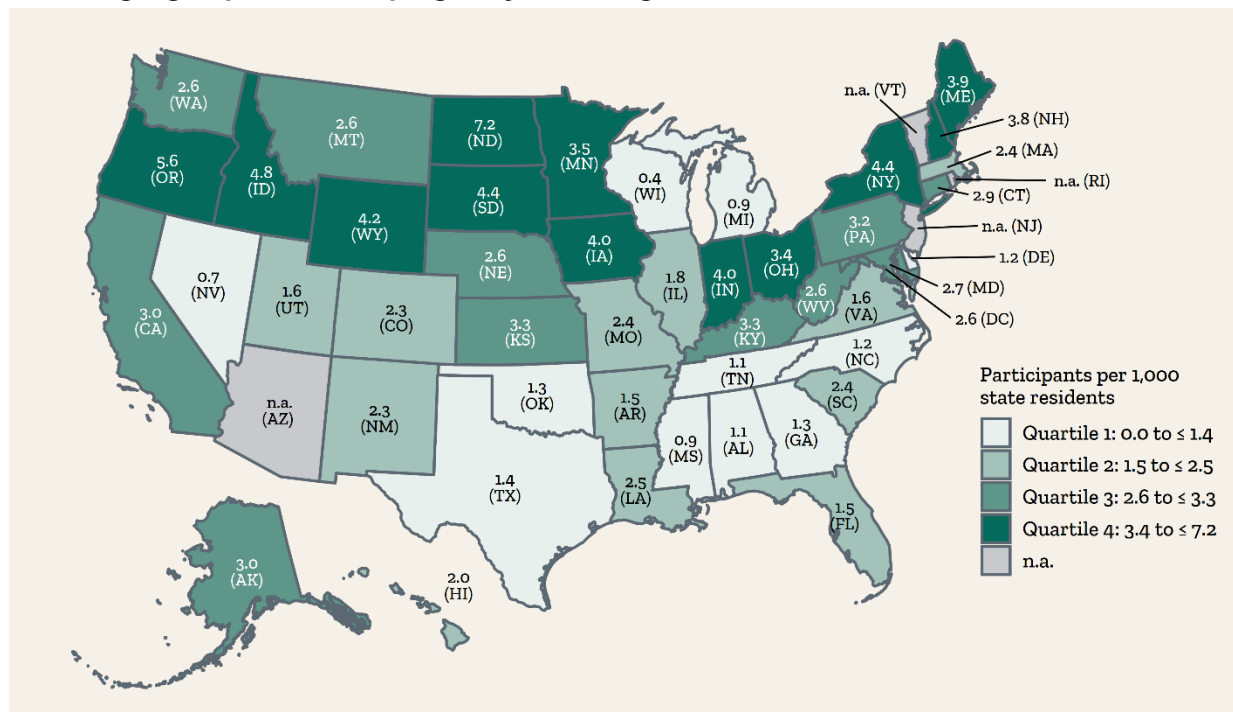
OD = other disabilities; PD = physical disabilities.

### 3. State-level variation for the ASD, ID, or DD target group

**Participants.** All 47 states with active section 1915(c) waiver programs in 2018 had waivers for the ASD, ID, or DD target group. The number of participants per 1,000 state residents for this LTSS target group ranged from 0.4 (Wisconsin) to 7.2 (North Dakota), and the U.S. rate across all states was 2.4 waiver program participants per 1,000 state residents (Figure IV.5; Appendix Table B.3). Of the 47 states, 28 (60 percent) had higher rates than the U.S. rate in 2018.

States in the lowest quartile of waiver program participants with ASD, ID, or DD per 1,000 state residents (fewer than 1.4 participants per 1,000 residents) were Wisconsin, Nevada, Michigan, Mississippi, Alabama, Tennessee, Delaware, North Carolina, Georgia, Oklahoma, and Texas. Those in the highest quartile (greater than or equal to 3.4 participants per 1,000 residents) were Ohio, Minnesota, New Hampshire, Maine, Indiana, Iowa, Wyoming, New York, South Dakota, Idaho, Oregon, and North Dakota.

**Figure IV.5. Section 1915(c) waiver program participants per 1,000 state residents for the ASD, ID, or DD target group, for waiver program year ending in 2018**



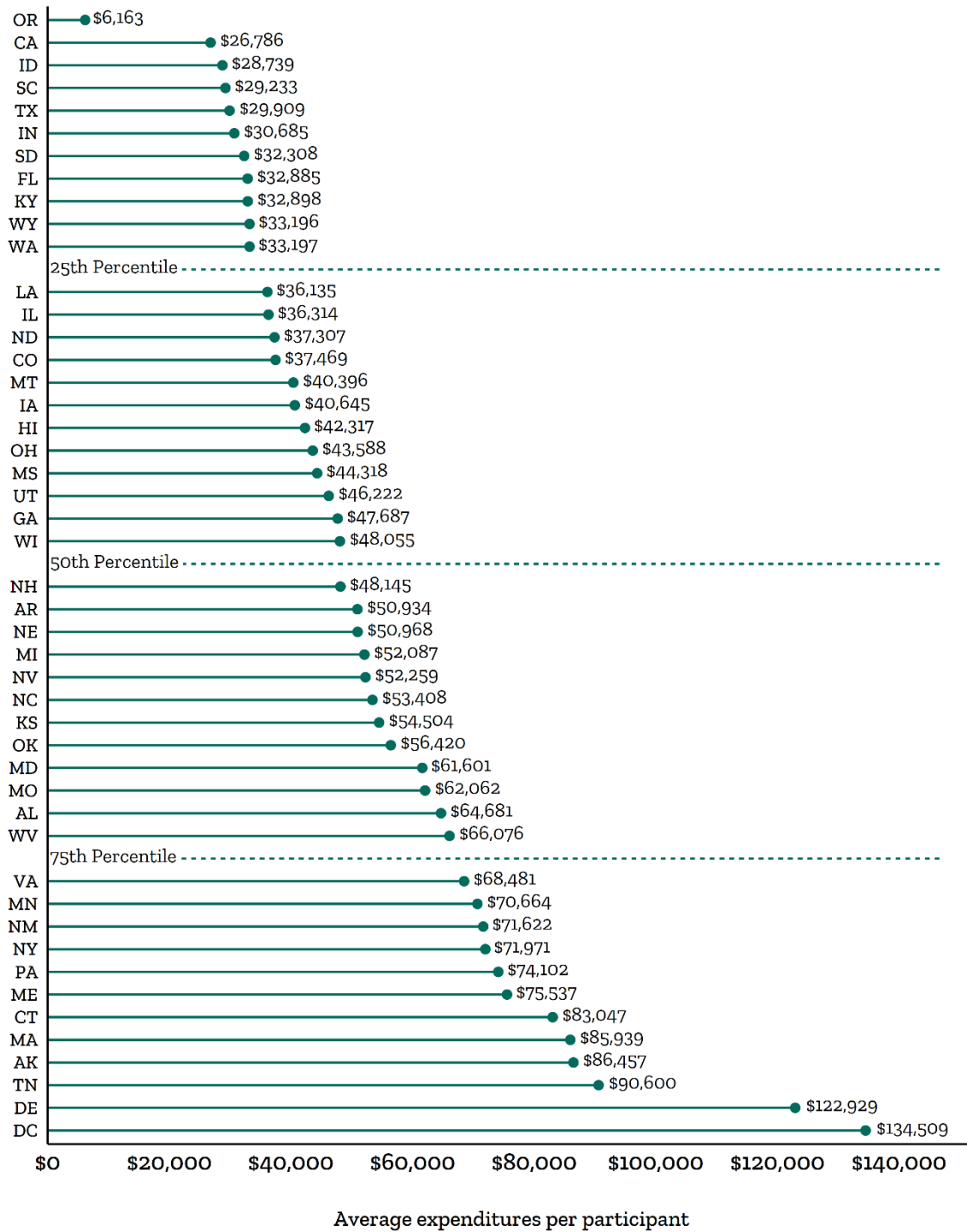
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data. ASD = autism spectrum disorder; DD = developmental disabilities; ID = intellectual disabilities; n.a. = not applicable.

**Waiver expenditures.** In 2018, U.S. total annual average waiver expenditures per waiver program participant with ASD, ID, or DD was \$47,388. Of 47 states, 26 (55 percent) had average waiver expenditures greater than the U.S. total average (Figure IV.6; Appendix Table B.3). Annual average waiver expenditures per section 1915(c) waiver program participant for this LTSS target group ranged from \$6,163 in Oregon to \$134,509 in the District of Columbia. Similar to the patterns for overall average expenditures, Oregon had disproportionately low average waiver expenditures for this LTSS target group

relative to other states at the lowest end of the distribution. The state with the second lowest average waiver expenditures for this LTSS target group was California at \$26,786.

States in the lowest quartile of average waiver expenditures per waiver program participant with ASD, ID, or DD were Oregon, California, Idaho, South Carolina, Texas, Indiana, South Dakota, Florida, Kentucky, Wyoming, and Washington. Those in the highest quartile of average waiver expenditures included Virginia, Minnesota, New Mexico, New York, Pennsylvania, Maine, Connecticut, Massachusetts, Alaska, Tennessee, Delaware, and District of Columbia.

**Figure IV.6. Average waiver expenditures per section 1915(c) waiver program participant for the ASD, ID, or DD target group, waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age files.

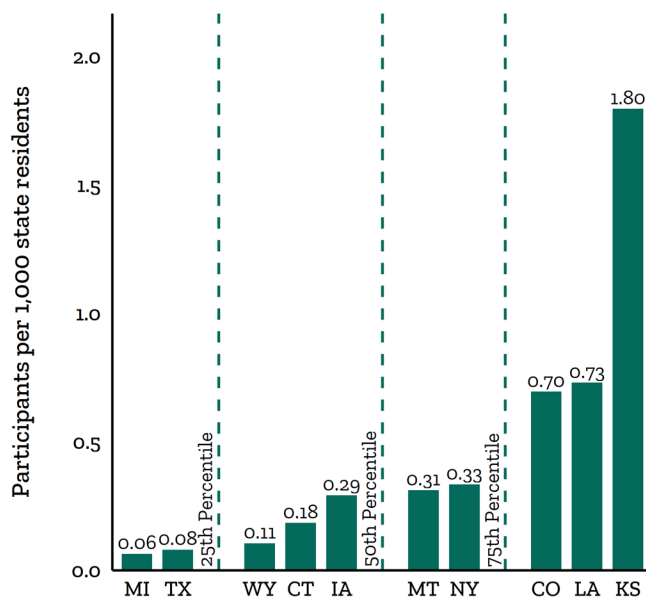
ASD = autism spectrum disorder; DD = developmental disabilities; ID = intellectual disabilities.



#### 4. State-level variation for the mental health services or SED target group

**Participants.** In 2018, 10 of the 47 states (21 percent) with section 1915(c) waiver programs had waiver programs for the mental health services or SED LTSS target group. In most states, these waiver programs served a relatively small population. The U.S. rate across all states was 0.08 waiver program participants per 1,000 state residents. Kansas was the only state that served more than 1 section 1915(c) waiver program participant per 1,000 state residents for this target population (Figure IV.7; Appendix Table B.3). Michigan and Texas were at the lowest end of the distribution for waiver program participants receiving mental health services or with SED per 1,000 state residents, and Colorado, Louisiana, and Kansas were at the highest end.

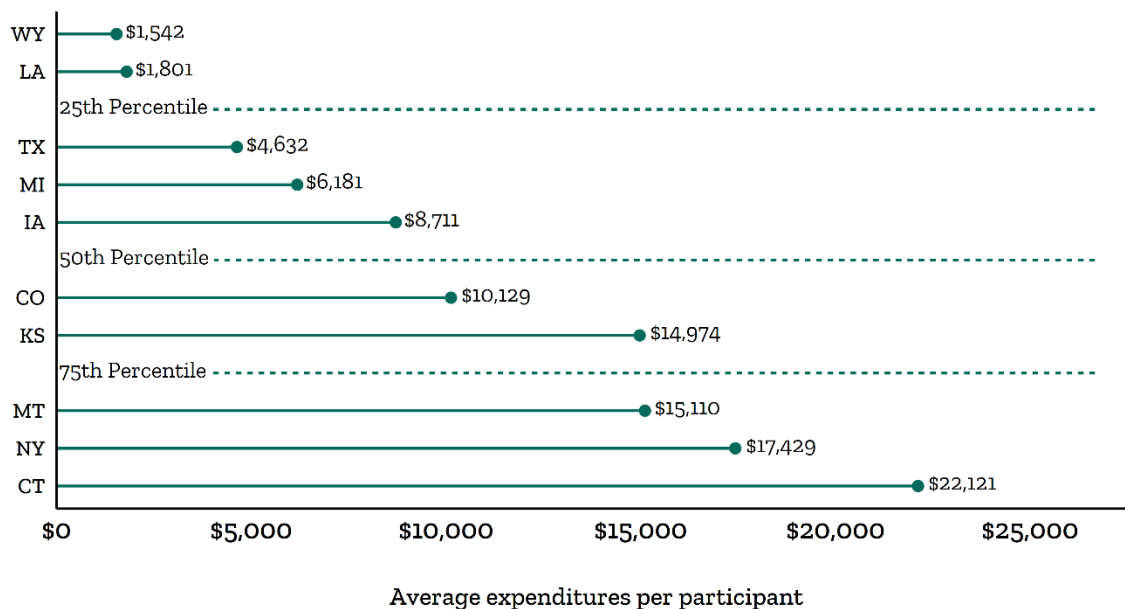
**Figure IV.7. Section 1915(c) waiver program participants per 1,000 state residents for the mental health services or SED target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data. SED = serious emotional disturbances.

**Waiver expenditures.** For the mental health services or SED LTSS target group, U.S. annual total average waiver expenditures per waiver program participant in 2018 was \$11,677 and ranged from \$1,542 in Wyoming to \$22,121 in Connecticut (Figure IV.8, Appendix Table B.3). Of the 10 states with section 1915(c) waiver programs for this LTSS target group, 4 (40 percent) had average waiver expenditures greater than the U.S. total average in 2018. States at the lowest end of the distribution were Wyoming (\$1,542), Louisiana (\$1,801), and Texas (\$4,632), and states at the highest end of the distribution were Montana (\$15,110), New York (\$17,429), and Connecticut (\$22,121).

**Figure IV.8. Average waiver expenditures per section 1915(c) waiver program participant for the mental health services or SED target group, for waiver program year ending in 2018**



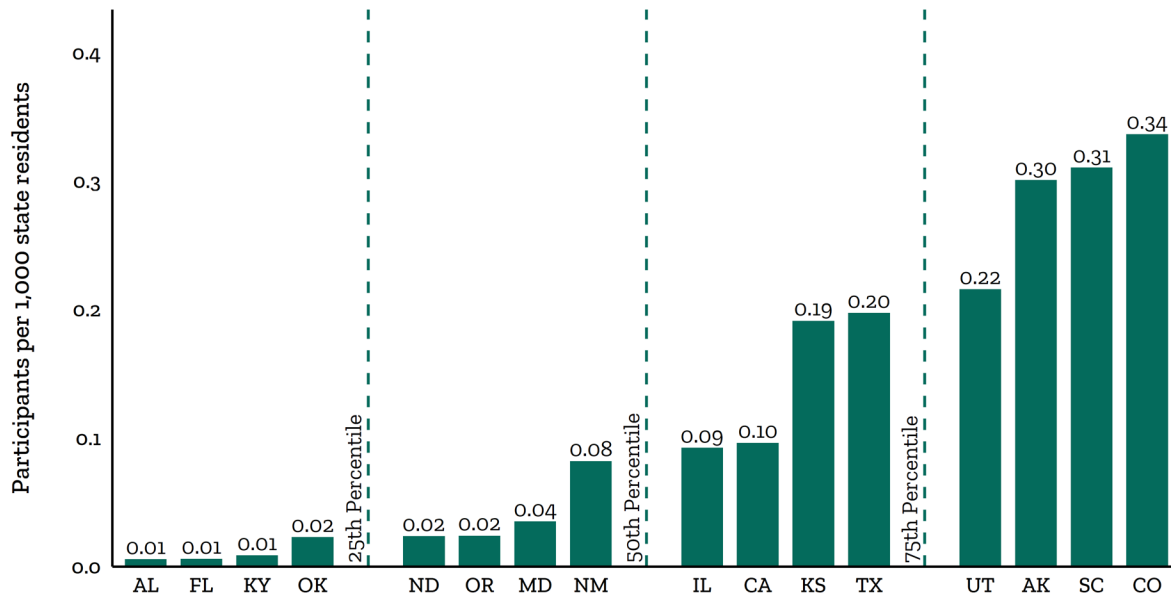
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

SED = serious emotional disturbances.

### 5. State-level variation for the medically fragile or TD target group

**Participants.** Of the 47 states with section 1915(c) waiver programs in 2018, 17 (36 percent) served the medically fragile or TD target group. Georgia’s *Georgia Pediatric Program (GAPP)* waiver (GA 4116), however, had no 372 reports with an accepted status within the past four years and could not be included in these analyses. All of the remaining states served fewer than 1 participant per 1,000 state residents, ranging from 0.01 to 0.34 (Figure IV.9; Appendix Table B.3). Of those 16 states, 9 (56 percent) had higher rates than the U.S. rate in 2018 of 0.05. The range across states was small. States in the lowest quartile for waiver program participants who are medically fragile or TD per 1,000 state residents were Alabama, Florida, Kentucky, and Oklahoma, and those in the highest quartile were Utah, Alaska, South Carolina, and Colorado.

**Figure IV.9. Section 1915(c) waiver program participants per 1,000 state residents for the medically fragile or TD target group, for waiver program year ending in 2018**

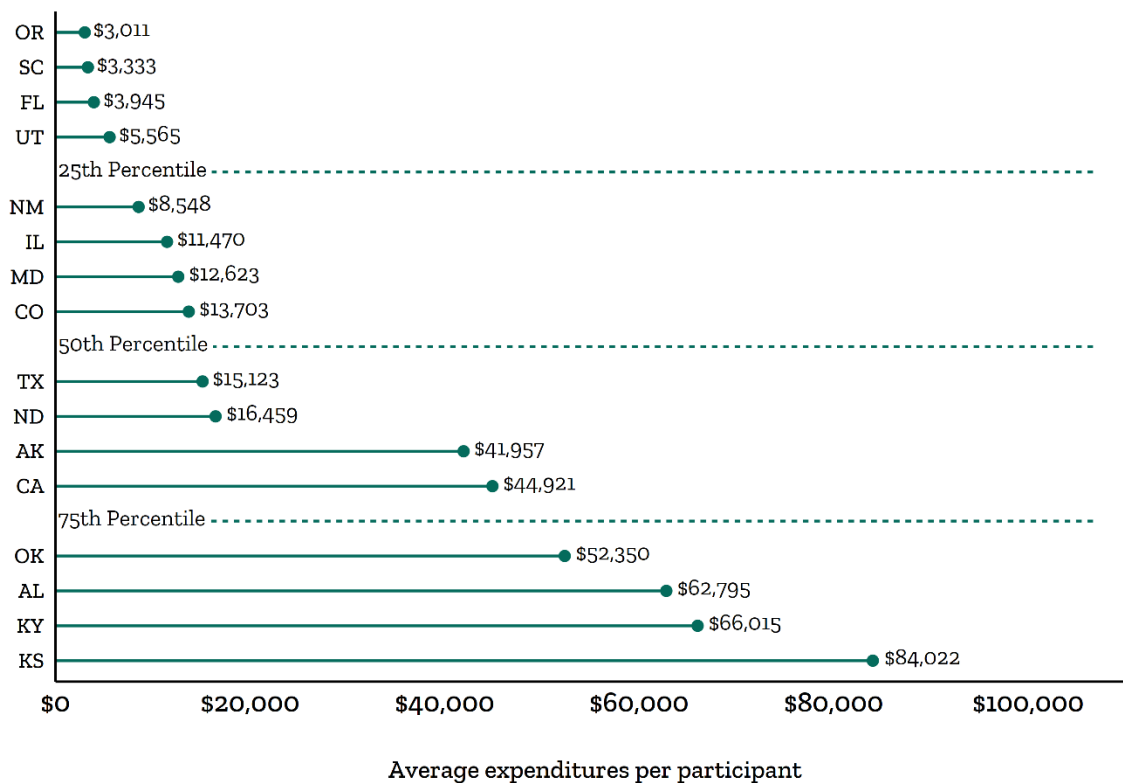


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

TD = technology dependent.

**Waiver expenditures.** For the medically fragile or TD LTSS target group, U.S. total average waiver expenditures per section 1915(c) waiver program participant in 2018 was \$22,934, ranging from \$3,011 in Oregon to \$84,022 in Kansas (Figure IV.10; Appendix Table B.3). Of the 16 states with waiver programs for this target group, 6 (38 percent) had average waiver expenditures greater than the U.S. average. States in the lowest quartile of average expenditures per waiver program participant who is medically fragile or TD were Oregon, South Carolina, Florida, and Utah, and states in the highest quartile included Oklahoma, Alabama, Kentucky, and Kansas.

**Figure IV.10. Average waiver expenditures per section 1915(c) waiver program participant for the medically fragile or TD target group, for waiver program year ending in 2018**

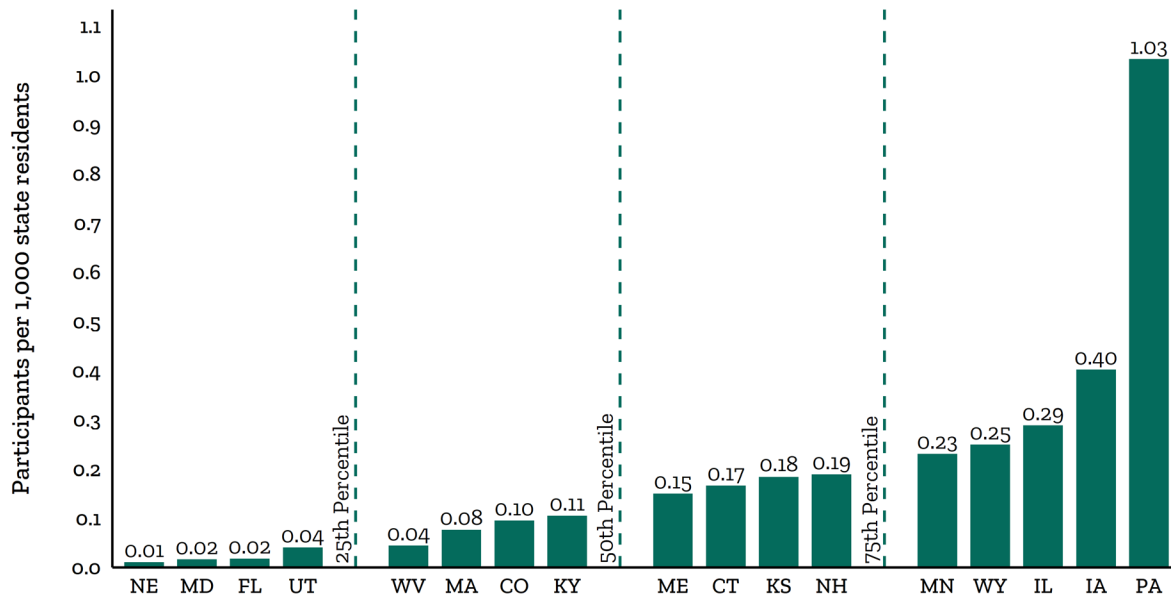


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services Subgroups, and Age file.  
 TD = technology dependent.

## 6. State-level variation for the brain injuries target group

**Participants.** In 2018, 19 of 47 states (40 percent) with section 1915(c) waiver programs served the brain injuries LTSS target group. Indiana’s *Traumatic Brain Injury Waiver* program (IN 4197) and New York’s *TBI Waiver* program (NY 0269), however, had no 372 reports with an accepted status within the past four years and could not be included in these analyses. Among the remaining states, the U.S. total was 0.08 participants per 1,000 state residents, and all states except Pennsylvania served fewer than 1 section 1915(c) waiver program participant per 1,000 state residents for this LTSS target group (Figure IV.11; Appendix Table B.3). The range across states was 0.01 (in Nebraska) to 1.03 (in Pennsylvania) participants per 1,000 state residents. Pennsylvania’s *COMMCARE Waiver* (PA 0386) served 13,221 people with brain injuries in 2018, which is more than three times the size of the population served by next highest state (Illinois, with 3,672 people).

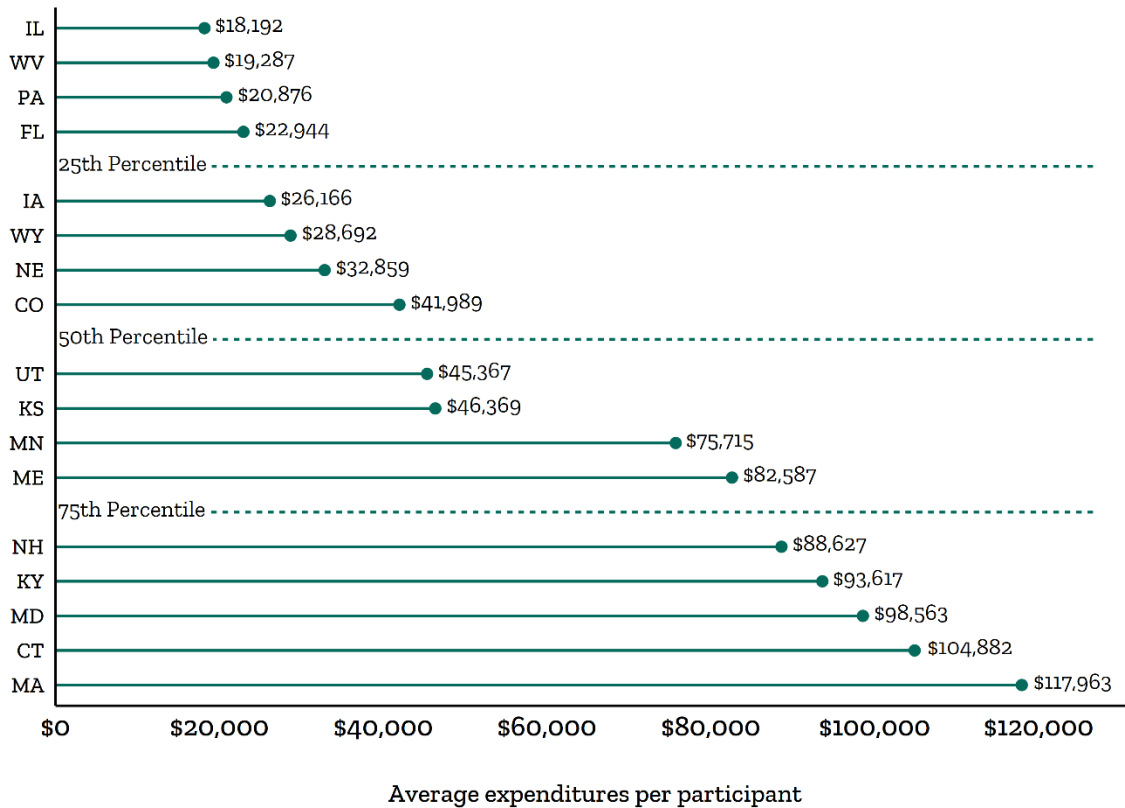
**Figure IV.11. Section 1915(c) waiver program participants per 1,000 state residents for the brain injuries target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

**Waiver expenditures.** For the brain injuries LTSS target group, U.S. annual average total waiver expenditures per section 1915(c) waiver program participant in 2018 was \$32,425. It ranged from \$18,192 in Illinois to \$117,963 in Massachusetts (Figure IV.12; Appendix Table B.3). Of the 17 states with active section 1915(c) waiver programs and available data for this target group, 11 (65 percent) had average waiver expenditures greater than the U.S. total average in 2018 (\$32,425). States at the lowest end of the distribution were Illinois, West Virginia, Pennsylvania, and Florida, and states at the highest end of the distribution were New Hampshire, Kentucky, Maryland, Connecticut, and Massachusetts.

**Figure IV.12. Average waiver expenditures per section 1915(c) waiver program participant for the brain injuries target group, for waiver program year ending in 2018**

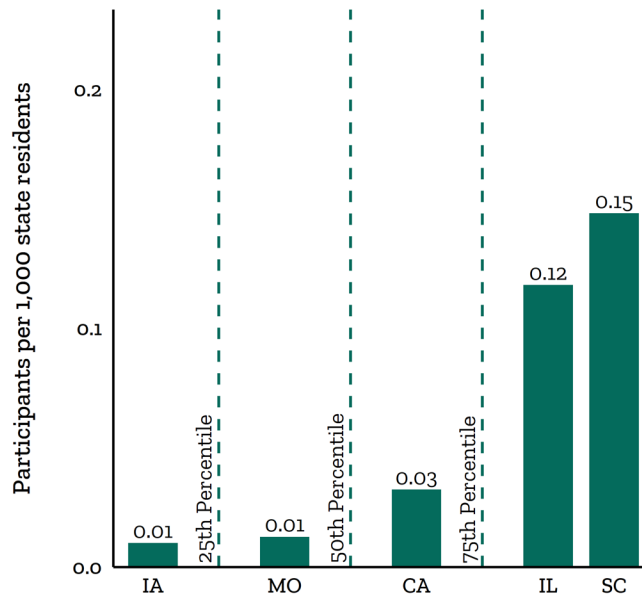


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

### 7. State-level variation for the HIV/AIDS target group

**Participants.** In 2018, 5 of 47 states (11 percent) with section 1915(c) waiver programs served the HIV/AIDS LTSS target group. The U.S. total was 0.01 per 1,000 state residents, and all states served fewer than 1 section 1915(c) waiver program participant per 1,000 state residents for this LTSS target group (Figure IV.13; Appendix Table B.3). The range across the five states was 0.01 (in Iowa and Missouri) to 0.15 (in South Carolina) participants per 1,000 state residents.

**Figure IV.13. Section 1915(c) waiver program participants per 1,000 state residents for the HIV/AIDS target group, for waiver program year ending in 2018**

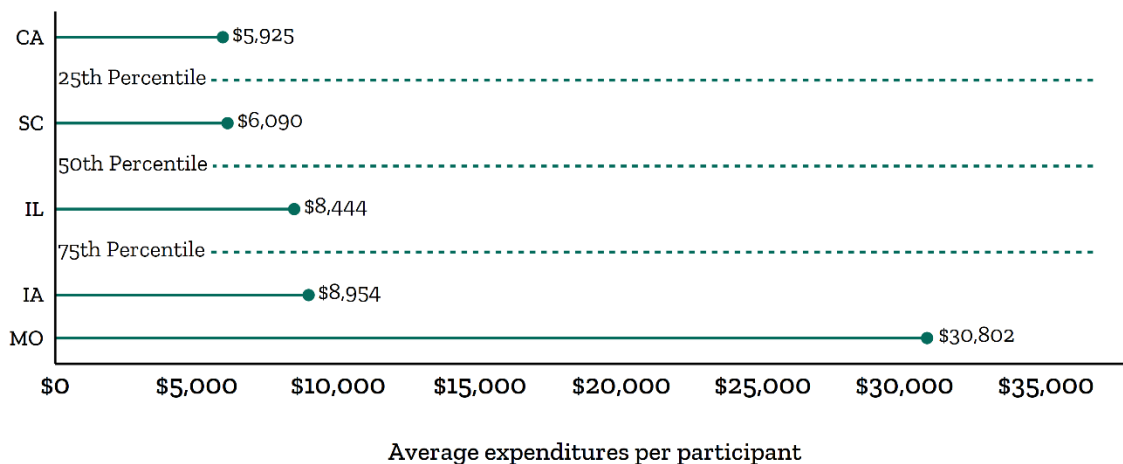


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome.

**Waiver expenditures.** In 2018, the U.S. annual average waiver expenditures per waiver program participant with HIV/AIDS was \$7,554. This ranged from \$5,925 in California to \$30,802 in Missouri (Figure IV.14; Appendix Table B.3). Missouri had high per-participant waiver program expenditures relative to the other four states that served this LTSS target group. Specifically, Missouri spent an average of \$21,848 more per participant than Iowa in 2018, which was the state with the second highest expenditures per waiver program participant (with a total of \$8,954 per participant).

**Figure IV.14. Average waiver expenditures per section 1915(c) waiver program participant for the HIV/AIDS target group, for waiver program year ending in 2018**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder, and Waiver Target Group, Subgroups, and Age file.

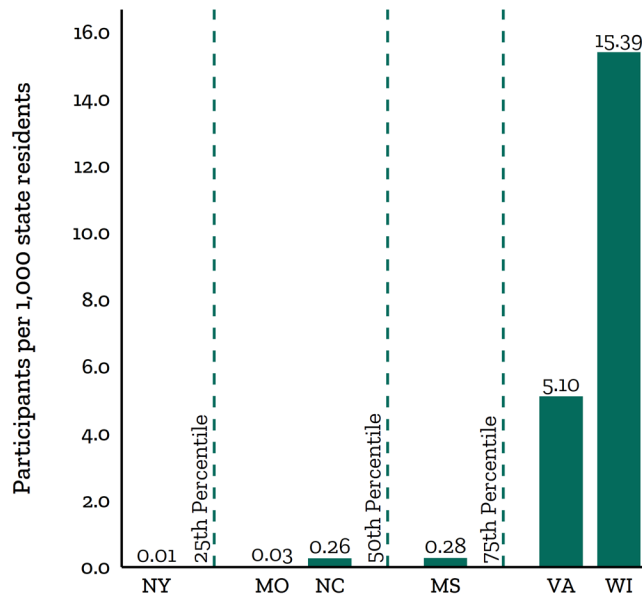
HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome

## 8. State-level variation for the multiple subgroups target group

**Participants.** In 2018, 6 of 47 states (13 percent) with section 1915(c) waiver programs served the multiple subgroups target group. The U.S. total was 0.44 per 1,000 state residents, but the number of participants differed substantially across the six states with waiver programs for this LTSS target group. Four states (New York, Missouri, North Carolina, and Mississippi) served fewer than 1 section 1915(c) waiver program participant per 1,000 state residents (Figure IV.15; Appendix Table B.3). Among the remaining two states, Virginia served 5.1 and Wisconsin served 15.4 participants per 1,000 state residents. More than 95 percent of section 1915(c) waiver program participants in Wisconsin are enrolled in one of the state’s three waiver programs serving multiple subgroups, which accounts for Wisconsin’s considerably higher number of participants per 1,000 state residents than the other states with waiver programs for this LTSS target group.



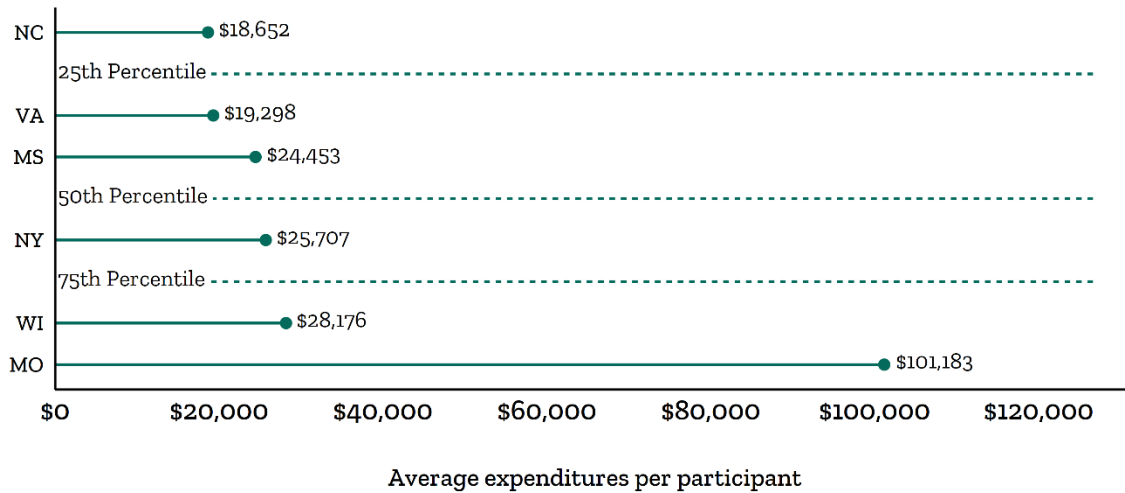
**Figure IV.15. Section 1915(c) waiver program participants per 1,000 state residents for the multiple subgroups target group, for waiver program year ending in 2018**



Source: Mathematica's analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

**Waiver expenditures.** For the multiple subgroups LTSS target group, U.S. total average waiver expenditures per section 1915(c) waiver program participant in 2018 was \$25,232 and ranged from \$18,652 in North Carolina to \$101,183 in Missouri (Figure IV.16; Appendix Table B.3). Missouri had high per-participant waiver program expenditures relative to the other five states that served this LTSS target group, spending an average of \$73,007 more per participant than Wisconsin, which was the state with the second highest expenditures per waiver program participant.

**Figure IV.16. Average waiver expenditures per section 1915(c) waiver program participant for the multiple subgroups target group, for waiver program year ending in 2018**



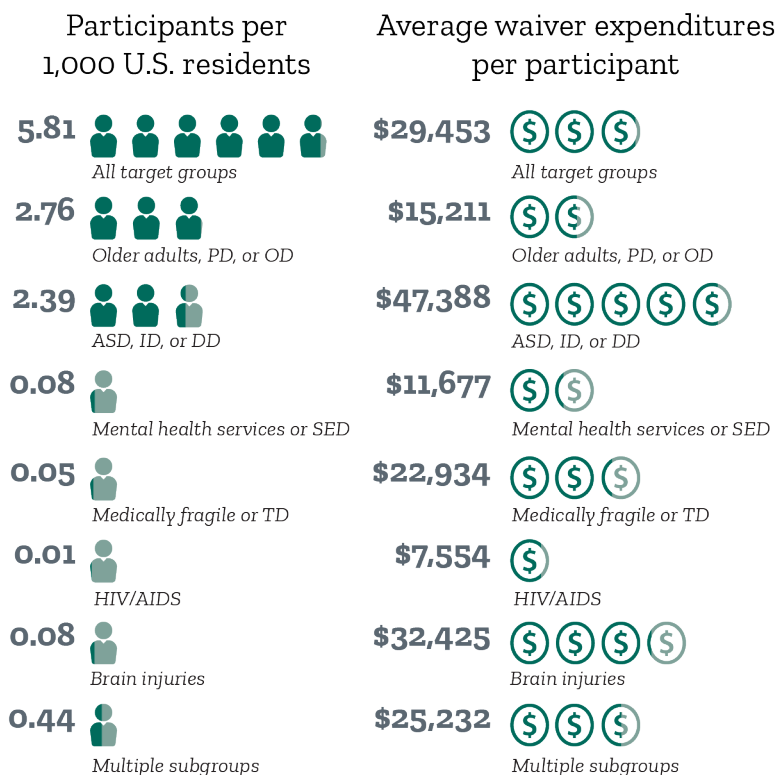
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

## V. Conclusion

In this report, we provide important insights into section 1915(c) waiver program participants, service use, and expenditures based on annual 372 reports submitted by states for 2018. Similar to the previous five years, national participation in section 1915(c) waiver programs increased during 2018, rising to 1.8 million participants, representing an increase of 4.9 percent relative to 2017. As a proportion of the U.S. population, about 5.81 of every 1,000 residents used section 1915(c) waiver program services in 2018. In parallel with the increase in participation observed from 2017 to 2018, annual average waiver program expenditures also grew: in 2018, waiver program expenditures averaged \$29,453 per participant, up from \$28,044 in 2017 (Figure V.1).

In addition to these national year-over-year changes, our analyses reveal important variation in section 1915(c) waiver program participation and expenditures by LTSS target group and by state. In 2018, waiver programs serving the older adults, PD, or OD target group, and those for people with ASD, ID, or DD, had the highest proportion of participants per 1,000 residents and comprised about 89 percent of total waiver program participants. There were 2.76 participants in section 1915(c) waiver programs per 1,000 residents for older adults, PD, or OD populations, and 2.39 for people with ASD, ID, or DD, respectively, in 2018. Waiver programs focusing on the other five LTSS target groups served fewer than 1 participant per 1,000 U.S. residents in these years. Among these five smaller target groups, the waiver programs serving multiple subgroups had the highest proportion of participants per 1,000 residents, followed by people receiving mental health services or with SED, people with brain injuries, people who are medically fragile or TD, and people with HIV/AIDS.

**Figure V.1. Key 2018 statistics for section 1915(c) waiver program participants**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports for 2018, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbances; TD = technology dependent.

For these two largest waiver program types, participation is similar but average expenditures differ markedly. Although average waiver program expenditures per participant for the older adults, PD, and OD target group was \$15,211 in 2018, average waiver expenditures for the ASD, ID, or DD target group were about three times as much at \$47,388. Among the smaller target groups, the lowest observed average section 1915(c) waiver program expenditures were reported for the HIV/AIDS target group (\$7,554), and people with brain injuries had the highest average waiver expenditures in 2018 (\$32,425). This variation may be due to differences in the type and intensity of services required by individuals in these different target groups.

States also varied markedly in the types of section 1915(c) waiver programs offered, number of participants served, use of services, and waiver and non-waiver expenditures. Although there were 267 total waiver programs offered by states in 2018, all 47 states offered waiver programs for the ASD, ID, or DD target group, and 42 of 47 (89.4 percent) offered waiver programs for the older adult, PD, or OD target group. For the remaining five target groups, 17 states (36.2 percent) offered waiver programs for people with brain injuries, 16 states (34.0 percent) served the medically fragile or TD population, 10 (21.3 percent) served people receiving mental health services or with SED, 5 were for people with HIV/AIDS (10.6 percent), and 6 served multiple subgroups (12.8 percent).

The results in this report underscore the utility of 372 annual reports for understanding national trends and state variation in section 1915(c) waiver program participation, service use, and expenditures for all participants and across the different LTSS population target groups. They are, however, subject to several important limitations. First, although Chapter II of this report presents five-year national trends, our analyses focus on waiver program year 2018. We obtained national data from 2012, 2013, and 2014 from prior reports analyzing 372 annual report data and did not verify them for accuracy in our analyses; we also did not update our analyses of the 2015 and 2016 372 annual report data from the previous year's report. We recalculated results for 2017 for this report, which will serve as the final analysis of 2017 372 annual report data. Second, to provide a complete picture of section 1915(c) waiver programs, we estimate missing data using prior accepted 372 annual reports. These data, however, might not be reasonable proxies for the year in which there were missing data. To limit the risk of making inaccurate assumptions, we imposed a restriction of four years on any estimation using prior year reports. Finally, the accuracy of these analyses is at least partially a reflection of the validity of the underlying data, which are the responsibility of states, CMS, and the U.S. Census Bureau. Nonetheless, these analyses provide important insights on section 1915(c) waiver programs, which comprise an important component of LTSS delivery systems in most states.

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## **Appendix A. Data sources, methods, and limitations**

This appendix presents details about the data sources, key variables, and methods used to produce the results contained in this report, as well as analytic limitations.

### 1. Data sources and key variables

The **CMS 372 Reports by Year (rptWvr372Base.csv)** files available from the Waiver Management System (WMS) are the foundation for most analyses in this report. Files for waiver program years 2013 – 2018 were downloaded on April 27, 2021. We calculated section 1915(c) waiver program participants, service use, and expenditures during 2018 and 2017 to produce the majority of analyses in this report. When no accepted annual 372 report was available for the year of interest, we used information from the most recently available annual accepted 372 report during the prior four years. Annual 372 reports are due 18 months after the close of a given waiver program year, which can occur as late as December 31. Therefore, the final possible due date for each year’s annual 372 report is June 30, as shown in Table A.1. In this table, we list the number of days between the 2018 and 2017 waiver program year reporting deadlines and data download, which were 311 days or more for waiver program years analyzed in this report.

**Table A.1. CMS 372 waiver program reporting deadlines for waiver program years ending in 2018 and 2017**

Waiver year	Last possible waiver year date	Latest possible reporting date deadline	Time between reporting deadline and data download
2018	December 31, 2018	June 30, 2020	311 days
2017	December 31, 2017	June 30, 2019	1 year, 311 days



In the CMS 372 Reports by Year files, we used the following key variables, as shown in Table A.2.

**Table A.2. Key variables in the CMS 372 Reports by Year file**

Variable name	Description
State	Section 1915(c) waiver program state
Begin Date	Start date for period covered by report
End Date	End date for period covered by report
Base Waiver Number	4-5 digits reflecting the number associated with the overall waiver, held constant when revisions are made over time
Report Status	Indicating whether the report was accepted, submitted, unlocked, unsubmitted, or unaccepted. The meaning of each report status is described further in Step 2 of the Methods section.
Report Type	Indicating whether a “Lag” or “TE” report. The meaning of each report type is described further in Step 2 of the Methods section.
Unduplicated Participants	Number of unduplicated individuals participating in the program during the waiver year
Days of Waiver Enrollment	Total number of days of waiver coverage for all waiver participants
Total Waiver Expenditures	Total amount expended for all 1915(c) waiver program services for all waiver participants
D	Estimated annual average per capita Medicaid cost for HCBS services for all waiver participants
D'	Estimated annual average per capita Medicaid cost for all other services (i.e., non-waiver services) provided to all waiver participants <sup>a</sup>
D + D'	Estimated annual average per capita Medicaid costs for all HCBS and other services for all waiver participants

Note: TE = temporary extension; HCBS = home and community-based services.

<sup>a</sup>Non-waiver program expenditures reflect the estimated annual average per capita Medicaid cost for all services (including state plan and services required under the Early and Periodic Screening, Diagnostic and Treatment [EPSDT] benefit when a waiver program serves children) that are furnished in addition to waiver program services while the individual is participating in the waiver program.

We obtained the **WMS Finder file (INC0760617\_WaiversDataRequest.xlsx)** from the WMS Help Desk on January 19, 2021, replacing IBM’s **Section 1915(c) Waiver List** used in the analysis for Ross et al. (2021). The **WMS Finder file** contained information on every new section 1915(c) waiver submission, renewal, or amendment contained within the WMS system, including application status, approved effective date, expiration date, and, if applicable, termination date.

Because the annual CMS 372 Reports by Year files only reflect section 1915(c) waiver programs for which a state submitted the annual 372 report, the WMS Finder file is an important source to draw upon to assess which section 1915(c) waiver programs were active and expected to report for a given year. We used the following key variables from this file, as shown in Table A.3.

**Table A.3. Key variables in the WMS Finder file**

Variable name	Description
State	State of the waiver program
Waiver Number	Finalized, full waiver number, containing two-character state acronym, four or five-digit base waiver number, renewal number, and amendment indicator (e.g., AK.0262.R03.01)
Program Type	Indicates either a section 1915(b) or 1915(c) waiver
Request Type	Waiver type application, indicating the submission is either new, a renewal, or an amendment
Program Title	Waiver program title, e.g., “Alaskans Living Independently”
Original Base Waiver Number	Four or five digit number that does not change with subsequent waiver renewals or amendments (e.g., 0262)
Approved Effective Date	MM/DD/YYYY when the waiver took effect
Date of Termination	MM/DD/YYYY of waiver termination
Date of Expiration	MM/DD/YYYY after which waiver is no longer in effect

Note: WMS = Waiver Management System.

For each section 1915(c) waiver new submission, renewal, or amendment, we obtained information about the specified **Waiver Target Group, Subgroups, and Ages (INC0537136\_Queries.xlsx)** from the WMS Help Desk on May 29, 2020. This file contained all current and historical information about the target groups, subgroups, and ages included in each waiver as of May 2020, allowing us to characterize section 1915(c) waiver program populations through 2018. We used the information in this file to assign target groups and subgroups, and determine if the waiver served only children during our periods of interest (i.e., waiver program year 2017 or 2018). Unlike the **Waiver Characteristics Data files** used in Ross et al. (2021), the **Waiver Target Group, Subgroups, and Ages file** allowed us to more precisely determine the LTSS populations served by the waiver program during the waiver program years examined in this report, using the key variables shown in Table A.4.

**Table A.4. Key variables in the WMS Target Group, Subgroups and Ages file**

Variable name	Description
CMSID	Finalized, full waiver number, containing two-character state acronym, four or five-digit base waiver number, renewal number, and amendment indicator (e.g., AK.0262.R03.01). Identical to the Waiver Number variable in Table A.3.
PLAN_WVR_FLD_MPNG_DESC	Indication of whether a given LTSS population subgroup (e.g., autism, aged, brain injury, etc.): Was included in the waiver Any minimum age criteria Any maximum age criteria
SYS_DTL_VAL_TXT_1	“True” if an LTSS population was included in the waiver, and “False” if not Numeric value of any minimum age criteria, “False” if no minimum age criteria Numeric value of any maximum age criteria, and “False” if no maximum age criteria

The **WMS Target Group, Subgroups, and Age** file information was used to categorize LTSS populations as shown in Table A.5.

**Table A.5. Section 1915(c) waiver subgroups**

Subgroup Label	Report Subgroup Label
Autism	Autism Spectrum Disorder (ASD)
Developmental Disability	Developmental disability (DD)
Mental Retardation	Intellectual disability (ID)
Aged	Older adults
Disabled (Physical)	Physical disability (PD)
Disabled (Other)	Other disability (OD)
Mental Illness	Mental health services
Serious Emotional Disturbance	Serious Emotional Disturbance (SED)
Medically Fragile	Medically fragile
Technology Dependent	Technology dependent (TD)
HIV/AIDS	HIV/AIDS
Brain Injury	Brain injuries

HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome.

The **U.S. Census Bureau State Population Totals and Components of Change (nst-estYYYY-01.xlsx)** file was also used for this report to produce estimates of section 1915(c) waiver program participants per 1,000 residents. This file includes state- and national-level population estimates calculated as of July 1 of each year and are derived using the standard Census Bureau methodology (U.S. Census Bureau 2019). To calculate the estimates, the Census Bureau starts with the base population from the most recent decennial census (in this case, 2010) and adjusts for population changes, such as births, deaths, and net migrations (both international and domestic).<sup>15</sup> We downloaded the annual population table that includes yearly estimates for all states and the District of Columbia from 2010 to 2019.

We downloaded the 2010–2019 file on May 3, 2021, and utilized the following key variables, as shown in Table A.6.

**Table A.6. Key variables in the U.S. Census Bureau state population totals and components of change**

Variable name	Description
State	Numerical value indicating state number
Name	Either United States, region, or state name
Poestimate2017	2017 population, estimated as a projection of 2010 Census
Poestimate2018	2018 population, estimated as a projection of 2010 Census

<sup>15</sup> For detailed methodology on how the Census Bureau estimates annual population, see “Methodology for the United States Population Estimates: Vintage 2019,” available at: <https://www2.census.gov/programs-surveys/popest/technical-documentation/methodology/2010-2019/natstcopr-methv2.pdf>.

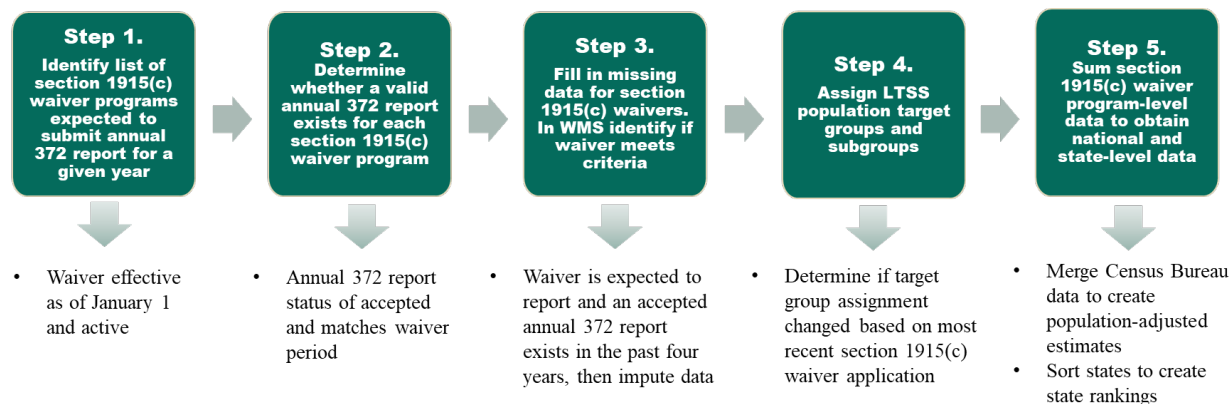
## 2. Methods

Overall, our analytic approach comprised five main steps:

1. Identify the section 1915(c) waiver programs active and expected to have annual 372 reports in 2017 and 2018.
2. Determine whether there was a valid annual 372 report for each section 1915(c) waiver program.
3. Fill in missing data for section 1915(c) waiver programs without an annual 372 report for given waiver program year using the most recent valid, accepted report within the prior four years, if available.
4. Assign LTSS population target groups and subgroups.
5. Sum section 1915(c) waiver program-level data to obtain state and national-level data, merge Census Bureau data to create population-adjusted demographic and expenditures statistics, and sort states by statistics to create state rankings.

We provide additional detail regarding each of these steps below, which are also illustrated in Figure A.1.

**Figure A.1. Data flow diagram**



**Step 1. Identify list of section 1915(c) waiver programs expected to have annual 372 reports in 2017 and 2018.** As noted previously, annual 372 reports are generally required of all section 1915(c) waiver programs within 18 months of the close of their “waiver program year.” A waiver program year may begin and end on any day of the calendar year. The start of the section 1915(c) waiver program year generally corresponds to the anniversary of the historical effective or current effective date, with the end date falling 365 or 366 days later.

To determine whether a state was expected to submit an annual 372 report in 2017 and 2018 for a section 1915(c) waiver program, we first compared the historical effective and current effective dates of the section 1915(c) waiver program to the first day of the calendar year (for example, January 1, 2018). If the section 1915(c) waiver program was effective as of January 1 of a given year, then the state was expected to submit an annual 372 report for that year. If, however, a section 1915(c) waiver program took effect on the first day of the calendar year (for example, the waiver programs effective date is January 1, 2018), then the state is not expected to submit a report until the anniversary of the waiver program effective date in the subsequent year. For the section 1915(c) waiver programs that started during the calendar year

(after January 1), the states are not expected to report for that year (Personal communications between S. Cummins and K. Liao, April 17, 2020).

Generally, it is expected that each annual 372 report submission represents a full year of data; that is, a waiver with an effective date of March 26 reporting for waiver program year ending in 2018 should reflect the period of March 26, 2017 through March 25, 2018. However, if the waiver had a termination date prior to the end of the calendar year (for example, December 31, 2017), CMS guidance requires that states submit an annual 372 report in the months leading up to the termination for that year. For example, if a waiver with an effective date of December 26, 2017, was terminated on November 20, 2018, the state would submit data for report year 2018 for the period between the anniversary of the waiver effective date and waiver termination date (that is, from December 26, 2017–November 20, 2018).

**Step 2. Determine whether there was a valid annual 372 report for each section 1915(c) waiver program.** We analyzed the CMS 372 Reports by Year file to determine if there was a valid, submitted report for the relevant year for each section 1915(c) waiver program we identified in Step 1. An annual 372 report was considered valid if it had a report status of “Accepted,” indicating CMS review of the annual 372 report is complete and reporting requirements were met (Personal communications between S. Cummins and K. Liao, January 21, 2020).<sup>16</sup>

We then reviewed all accepted annual 372 reports for section 1915(c) waiver programs expected to report and identified those (1) with duplicate entries, (2) reflecting partial year data based on the report Begin Date and End Date fields, or (3) reflecting greater than one year of data based on the report Begin Date and End Date. Following this review, we excluded annual 372 reports with Begin and End Dates that did not align with the Effective, Expiration, and Termination dates of the section 1915(c) waiver application that was in effect during the waiver program year of interest (i.e., 2017 or 2018).

If there were obvious data entry errors, such as recording the report end date as January 12, 2006, instead of January 12, 2016, in the 2016 annual 372 report file, we corrected and included the record. Anomalous annual 372 report entries that did not correspond to an active waiver program, such as those with a state of “ZZ” were also removed.

**Step 3. Fill in missing data for section 1915(c) waiver programs expected to have an annual 372 report in a given year but did not have a report.** After applying the criteria in Step 2, some waiver programs that we expected to report in a given year did not have a valid report. To provide a reasonable approximation of participation, service use, and expenditures for these section 1915(c) waiver programs, we used the most recent available accepted report meeting the Step 2 criteria to impute current year information. When there were no available accepted, valid reports within the past four years, we did not impute current year information and did not include the waiver program in the analysis. In the case of New Jersey section 1915(c) waiver program 0031, the most recently accepted, valid report was from 2011 and therefore did not use these data to estimate results for 2017. Unlike other states with waiver programs for which data are missing, there are no other section 1915(c) waiver programs in New Jersey. For this reason, we do not report any information for New Jersey in this report, and show the 2017 state- and waiver-level results as NR = Not reported in Appendix Table B.2.

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<sup>16</sup> Other possible report statuses include (1) Submitted: State has submitted the annual CMS 372 report for review and cannot make any changes; (2) Unaccepted: CMS review of the CMS 372 report is complete but report does not meet the reporting requirements; (3) Unlocked: Report was unlocked by CMS so the state can make edits; and (4) Unsubmitted: State has submitted the annual report, but later decided it was not ready for CMS review.

The proportion of active waivers in 2017 and 2018 for which data are estimated from prior year annual 372 reports is shown below in Table A.7. For these waivers, all of the key variables in Table A.2 are estimated using the most recently accepted prior annual 372 report available within the past four years. Individual waiver programs for which we estimated data from prior years are noted with a footnote in Appendix B tables.

**Table A.7. Annual 372 report data entry, by waiver program report year**

Waiver program year	Waivers expected to report	Waivers with no Accepted, Valid Annual 372 Report for current year, where prior year data were used	Waivers with no Accepted, Valid Annual 372 Report for current year or prior four years
2017	274	19	7
2018	267	43	6

**Step 4. Assign LTSS target groups and subgroups.** Creating appropriate groups of LTSS populations to facilitate cross-state analyses is a key component of this report. We utilized the WMS Target Group, Subgroups, and Age file to determine the LTSS target groups and subgroups included during the waiver program year of interest. In general, the LTSS population groups used in this report align with those used in past years. However, for a small number of section 1915(c) waiver programs that represented unique mixes of LTSS participants from different subgroups, which could not be easily categorized into the standard target groups, we created a new LTSS target group, entitled “Multiple Subgroups.” The use of a “Multiple Subgroups” group was first employed in Ross et al. (2021), and continued in this report. Waiver programs in this group might include a mix of section 1915(c) waiver program participants who are older adults, with physical disabilities, have brain injuries, or have HIV/AIDS, for example. Additional details are provided in the Table I.1.

**Step 5. Sum section 1915(c) waiver program-level data to obtain state and national-level data, merge Census Bureau Data to create population-adjusted demographic and expenditures statistics, and sort states by statistics to create state rankings.** Following Steps 1–4, we established the final dataset of section 1915(c) waiver programs for each year, including their actual or imputed annual 372 report data, and target group assignment. We used this dataset to create aggregated results including counts of unduplicated participants and total waiver program expenditures at the state and national levels, and for each of the seven LTSS target population subgroups. We then calculated the proportion of section 1915(c) waiver program participants per 1,000 residents for each year using the Census Bureau national and state- level population estimates for 2017 and 2018. We ranked states from highest to lowest for all key results. These results can be found in Appendix B.

### 3. Limitations

The analyses in this report are meant to provide useful information regarding national and state-level trends in section 1915(c) waiver program participation, service use, and expenditures. The information presented is nonetheless subject to important limitations. First, the accuracy of these analyses is a reflection of the validity of the underlying data, which are the responsibility of states, CMS, and the U.S. Census Bureau. Second, Chapter II of this report uses national data from 2012 through 2016, which was obtained from prior reports analyzing annual 372 report data, and we did not attempt to update or validate

those results. As a result, differences between results for these earlier years and the current years of analysis (2018 and 2017) may be due in part to updates to data sources and analytic approach. Third, we analyze changes in expenditures from year to year, but in alignment with past reports, do not adjust for inflation. Fourth, to provide a complete picture of trends in section 1915(c) waiver programs, we estimate missing data using the most recently accepted annual 372 report in the four years prior to the waiver program report year of interest. However, these data may not be reasonable proxies for the actual waiver program report year in which there was missing data. We imposed a restriction of four years on any estimation of current year data to mitigate this potential risk. Fifth, to avoid overcounting or undercounting, annual 372 report submissions with partial year data or more than 12 months of data were compared to the waiver program effective period to ensure they aligned. It is important to note that in some cases, an annual 372 report representing more or less than 12 months of data may represent a legitimate early expiration or extension of a waiver program year, due to a revision that resets the effective date.

## **Appendix B. Data tables Excel workbook attachment**