

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

**ANALYSIS OF CMS 372 ANNUAL REPORTS, 2018–2019**

**June 9, 2023**



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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

SED = serious emotional disturbance

TD = technology dependent

TE = temporary extension

WMS = Waiver Management System

## Executive Summary

**Purpose of this report.** Section 1915(c) of the Social Security Act enlarged the scope of the Medicaid program to allow for comprehensive long-term services and supports (LTSS) in home and community-based settings as an alternative to institutional care. Enacted as part of the Omnibus Budget Reconciliation Act of 1981, states' use of section 1915(c) waiver programs grew slowly but steadily since its inception. 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) that (1) demonstrates they met assurances on cost neutrality; (2) details the type, amount, and costs of services provided; and (3) assesses other aspects of the waiver programs including health and welfare, and other quality assurance requirements (CMS 2018). CMS and its contractors have produced summary reports of these data in most years. This is the ninth 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 waiver program year 2019. To determine changes in the number of section 1915(c) waiver program participants and their use of services and expenditures for 2019, we also recalculate results for 2018. We obtained prior year results from previous reports and did not recalculate them.

Because states have flexibility under the Social Security Act in how they design their HCBS programs, the types of section 1915(c) waiver programs offered vary markedly. As in past years, Arizona, New Jersey, 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. Thus, we include 46 states and the District of Columbia in this report and reference them as the 47 states with active section 1915(c) waiver programs. Though states are required to submit a separate 372 report annually for each waiver program they operate, CMS sometimes does not receive or cannot accept a 372 report for active waiver programs. Hence, our analyses only includes waiver programs that have a 372 report with an accepted status within the past four years.<sup>1</sup>

**Findings.** Nationally, about 1.9 million beneficiaries participated in section 1915(c) waiver programs in 2019, representing a 5.2 percent increase from the prior year. When normalized to the overall U.S. population, there were about 6.11 section 1915(c) waiver program participants per 1,000 total U.S. residents in 2019 (Figure ES.1).<sup>2</sup> Similar to observed increases in participation from 2018 to 2019, average waiver program and total Medicaid (waiver and non-waiver program) expenditures per participant also increased during this time period. In 2018, average section 1915(c) waiver program expenditures per participant per year were \$29,743, and, in 2019, they were \$30,063. In both years,

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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.

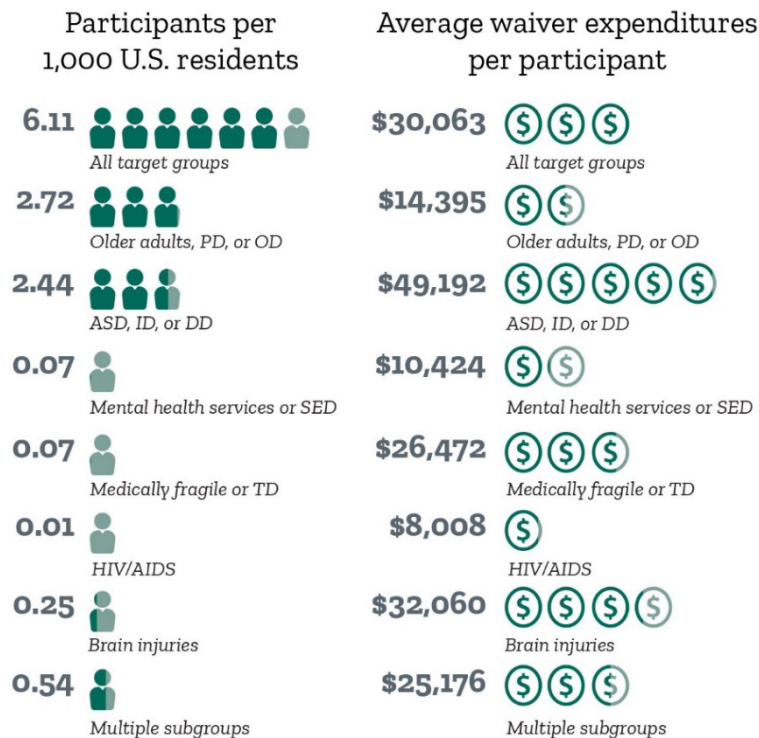
<sup>2</sup> To determine the national number of section 1915(c) waiver program participants per 1,000 residents, we divided the total number of participants by the sum of the Census Bureau population estimate for all states, excluding Arizona, New Jersey, Rhode Island, and Vermont. In addition, although we round most results in this report to one decimal place, we use two decimal places 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 disturbance, with brain injuries, or with HIV/AIDS).



waiver program expenditures constituted around 71.3 percent of total Medicaid 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 LTSS target group populations: (1) older adults, people with physical disabilities, or people with other disabilities; (2) people with autism spectrum disorder (ASD), intellectual disabilities (ID), or developmental disabilities (DD); (3) people receiving mental health services or with serious emotional disturbance (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) people with program waivers in multiple subgroups.<sup>3,4</sup>

**Figure ES.1. Key 2019 statistics for section 1915(c) waiver program participants**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports for 2019, Waiver Management System Waiver Finder System file, Waiver Target Group, Subgroups, and Age file and Census Bureau data. We calculated the number of participants and average waiver expenditures per waiver program year.

ASD = people with autism spectrum disorder; DD = people with developmental disabilities; HIV/AIDS = people with human immunodeficiency virus/acquired immunodeficiency syndrome; ID = people with intellectual disabilities; OD = people with other disabilities; PD = people with physical disabilities; SED = people with serious emotional disturbance; TD = people who are 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 waiver programs with unique or rare combinations of subgroups that are not necessarily comparable to other waiver programs. For example, Colorado’s *Elderly, Blind and Disabled (HCBS-EBD) Waiver* (#0006) includes older adults, people with physical disabilities, or people with HIV/AIDS, which effectively combines the older adults, people with physical disabilities, or people with other disabilities target group with the people with HIV/AIDS target group. Likewise, Wisconsin’s *Family Care Waiver* (#0367) includes older adults, people with physical disabilities, people with other disabilities, DD, or ID, incorporating both the older adults, people with physical disabilities, or people with other disabilities target group and the ASD, ID, or DD target group.

<sup>4</sup> In January 2014, CMS published a final rule (CMS 2249-F/2296-F) that permits, but does not require, states to combine target groups within one HCBS waiver. Prior to that change, a single section 1915(c) HCBS waiver could only serve one of the following three target groups: older adults, individuals with disabilities, or both; individuals with intellectual disabilities, developmental disabilities, or both; or individuals with mental illness. This regulatory change removed a barrier for states that wish to design a waiver program that meets the needs of more than one target population (CMS 2014).

In 2019, the target groups with the highest participation were those serving (1) older adults, people with physical disabilities, or people with other disabilities and (2) people with ASD, ID, or DD. There were 2.72 participants in section 1915(c) waiver programs per 1,000 residents for older adults, people with physical disabilities, or people with other disabilities and 2.44 per 1,000 residents for people with ASD, ID, or DD in 2019. Waiver programs focusing on the other five LTSS target groups served less than 1 participant per 1,000 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 with brain injuries, people receiving mental health services or with SED, people who are medically fragile or TD, and people with HIV/AIDS.

Average annual section 1915(c) waiver program expenditures in 2019 also ranged markedly across the seven target groups. Waiver programs serving people with HIV/AIDS had much lower average expenditures per person than those of other groups at \$8,008. In contrast, section 1915(c) waiver programs serving people with ASD, ID, or DD had the highest average expenditures per person at \$49,192, which was about six times higher than waiver programs serving people with HIV/AIDS. Average per-person expenditures for the remaining five target groups ranged from \$10,424 (mental health services or SED) to \$32,060 (people with brain injuries) in 2019.

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. Listed from highest to lowest, Wisconsin, Minnesota, Pennsylvania, Oregon, Illinois, and Idaho all had more than 10 total section 1915(c) waiver program participants per 1,000 residents in 2019. Among the remaining states, Kansas, Ohio, Mississippi, Washington, Wyoming, Iowa, Colorado, Connecticut, and North Dakota had more than 8 total section 1915(c) waiver program participants per 1,000 residents, and Tennessee had about 1 participant per 1,000 residents.

For section 1915(c) waiver programs serving older adults, people with physical disabilities, or people with other disabilities, Minnesota, Illinois, Oregon, Mississippi, Washington, Idaho, and Ohio served the greatest number of participants as a proportion of their populations, exceeding 6 per 1,000 residents in 2019 (11.7 in Minnesota and 6.1 in Idaho and Ohio). North Dakota, Oregon, Idaho, South Dakota, New York, Wyoming, Indiana, Maine, 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. Yet in these two LTSS population groups (older adults, people with physical disabilities, or people with other disabilities as well as and people with ASD, ID, or DD), states with the highest participation rates did not necessarily have the highest average waiver program expenditures. Only Minnesota appeared among the states with the highest average section 1915(c) waiver program expenditures for the older adults, people with physical disabilities, or people with other disabilities populations, ranking 6th. Among states with the highest participation in ASD, ID, or DD waiver programs per 1,000 residents, Maine and New York ranked highest for average waiver program expenditures at 6th and 10th place, respectively; the remainder were in the bottom 50 percent of states.

For the waiver programs serving the other five target groups, different states generally had the greatest participation per 1,000 residents. In 2019, Kansas, Colorado, and Louisiana 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 Minnesota had the highest participants per 1,000 residents for their waiver programs serving people with brain injuries (0.22 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 2019 (0.13 and 0.11 per 1,000 residents,

respectively), which was more than three times that of the next highest state (California). Colorado, South Carolina, Alaska, North Carolina, and Utah each served 0.23 or more medically fragile or TD participants per 1,000 residents in 2019, and Wisconsin had the highest participation rates for its waiver programs for multiple subgroups (16.4 per 1,000 residents). Similar to the patterns overall and for the two waiver program types serving the largest number of beneficiaries (older adults, people with physical disabilities, or people with other disabilities 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 the delivery system for LTSS in most states. Nationally in 2019, about 1.9 million beneficiaries participated in section 1915(c) waiver programs and average section 1915(c) waiver program expenditures per participant per year were \$30,063. Similar to previous years, beneficiary participation and average expenditures varied meaningfully by state and across the section 1915(c) waiver programs. The results in this report underscore the utility of 372 annual reports for understanding national trends and states' variation in section 1915(c) waiver program participation, service use, and expenditures for all participants as well as by specific target groups for LTSS.

## I. Introduction

**Background.** Section 1915(c) of the Social Security Act enlarged the scope of the Medicaid program to allow for comprehensive long-term services and supports (LTSS) in home and community-based settings as an alternative to institutional care. Enacted as part of the Omnibus Budget Reconciliation Act of 1981, states' use of section 1915(c) waiver programs grew slowly but steadily since its inception. 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 people 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 (1) demonstrates states met their assurances on cost neutrality; (2) details the type, amount, and cost of services provided; and (3) assesses other aspects of the waiver programs including health and welfare, and other quality assurance requirements (CMS 2018). States submit this information in CMS Form 372(S), hereafter referred to as annual 372 reports, via the Waiver Management System (WMS). The WMS is a web-based system, managed by CMS and its contractors, whereby states submit section 1915(c) waiver program forms for CMS review and approval. Waiver applications housed in WMS contain information about the waiver including eligible target groups and subgroups, and 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.<sup>5</sup>

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 after the end of the waiver program year to submit a 372 report for the financial reporting requirements.<sup>6</sup> For example, a waiver program year that began on March 26, 2018, and ended on March 25, 2019, would be considered active for waiver program year 2019, and the corresponding annual 372 report with financial reporting would be due by September 24, 2020. 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 2019.<sup>7</sup> CMS has published eight reports to date using annual 372 data to analyze section 1915(c) waiver program trends, which cover 2009 to 2018 (Ross et al. 2021a; Ross et al. 2021b; Amos et al. 2018; Eiken 2017; Eiken 2016; Eiken 2015; Eiken 2014; Eiken and Lelchhook 2013).<sup>8</sup> This report continues the following changes made in the most recent report (Ross et al. 2021a) in (1) displaying national-, state-, and waiver-level results in an accompanying

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<sup>5</sup> Approved waiver submissions, amendments, and renewals are available on Medicaid.gov at <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>.

<sup>6</sup> States have six months after the end of each waiver program year to report on quality assurance requirements.

<sup>7</sup> To determine changes in section 1915(c) waiver program participants, service use, and expenditures for 2019, we also calculate results for 2018.

<sup>8</sup> Reports from prior years are available at <https://www.medicaid.gov/medicaid/long-term-services-supports/reports-evaluations/index.html>.

Appendix B Excel attachment for ease of stakeholder use; (2) omitting a comparison with Form CMS-64 expenditure data;<sup>9</sup> (3) updating the waiver program-level labels describing the populations of Medicaid beneficiaries and recategorizing some waiver programs to reflect the included target groups and subgroups in the section 1915(c) waiver program applications; and (4) identifying subgroups that include only children as opposed to adults only or a mixed population of adults and children in Appendix B. All dollar amounts included in this report are not adjusted for inflation.

Table I.1 presents the seven LTSS target groups served by the section 1915(c) waiver programs analyzed in this report, and the groups appear in the same order throughout the report.<sup>10</sup> In Appendix B, the waiver program-level tables for 2018 and 2019 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). 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, people with physical disabilities, or people with other disabilities	Aged, Disabled (Physical), or Disabled (Other)
2. ASD, ID, or DD	Autism, Developmental Disability, or Intellectual Disability
3. Mental health services or SED <sup>a</sup>	Mental Illness or Serious Emotional Disturbance <sup>a</sup>
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.

<sup>a</sup> These programs might include people with substance use disorder.

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

<sup>9</sup> We omitted this comparison because of significant differences in reporting periods between the 372 and Form CMS-64 data sources. As of the time of this report, 2019 was the most recent year for which all section 1915(c) waiver programs were required to have 372 reports. The 2019 waiver program year, however, covers a range of possible reporting periods from January 2, 2018, to December 31, 2019, 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 2020 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. 2023).

<sup>10</sup> Although we show the section 1915(c) waiver programs serving the most participants first and second, respectively, we do not necessarily present the report results from the highest to lowest number of participants per 1,000 residents for every target group.

The accuracy of this report reflects the completeness and quality of annual 372 reports for 2018 and 2019. Although the report focuses primarily on section 1915(c) waiver programs active in 2019, we also recalculated results for programs active in 2018. This serves as the second and final analysis of 372 reports for 2018. During these years, four states (Arizona, New Jersey, 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. The remaining 46 states and the District of Columbia had one or more section 1915(c) waiver programs for which they had to submit a 372 report. Not all section 1915(c) waiver programs, however, had an accepted report at the time of this analysis. Submission for some of the reports due in this timeframe have been delayed because of flexibilities granted during the COVID-19 public health emergency. 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, Indiana operated the *Traumatic Brain Injury Waiver* (IN 4197) section 1915(c) waiver program during 2019 but submitted its last accepted 372 report in 2013. Because those data are more than four years old, we did not use that 2013 report to estimate participants, service use, or expenditures for the state’s 2019 waiver program year. Consequently, we did not use data for Indiana to calculate the 2019 estimates for waiver programs serving people with brain injuries, and we present waiver–level results as Not Reported in Appendix Table B.1. 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 estimated or absent current year data in Appendix B.

Results in this report on non-waiver services reflect Medicaid services only. Many beneficiaries receiving HCBS such as those in section 1915(c) waiver programs are dually eligible for Medicare and Medicaid benefits (Kim et al. 2022). For these dually eligible beneficiaries, Medicare is the first payer for most if not all non-waiver services. Hence, the non-waiver spending amounts included in this report are less than total government outlays for non-waiver services because they reflect only Medicaid spending amounts. In addition, some of the variation in non-waiver spending across target groups could reflect differences in Medicare enrollment rates across target groups.

**Number and type of section 1915(c) waiver programs.** In 2019, 262 section 1915(c) waivers were active across 47 states, representing a net decline of five section 1915(c) waivers relative to 2018. As Table I.2 shows, 9 section 1915(c) waivers ended, and 4 section 1915(c) waivers were newly active in waiver year 2019.

Colorado, Connecticut, and Wisconsin ended a total of three section 1915(c) waivers serving people with autism spectrum disorder (ASD), intellectual disabilities (ID), or developmental disabilities (DD) (CO 0434, CT 1040, and WI 0229). Virginia and Wisconsin ended two section 1915(c) waivers serving the older adults, people with physical disabilities, or people with other disabilities target group (VA 40206 and WI 0154). Two states, Florida and Wyoming, ended section 1915(c) waivers serving people with brain injuries (FL 0342 and WY 0370). Florida and Georgia (FL 0392 and GA 4116) ended section 1915(c) waivers serving people who were medically fragile or technology dependent (TD). With CMS approval, states transitioned individuals served through these waiver programs to state plan services or other waiver programs.

The reduced number of section 1915(c) waivers in 2019 was partially offset by four newly active waivers. In 2018, Alaska and California implemented new section 1915(c) waivers serving people with ASD, ID, or DD (AK 1566 and CA 1166). North Carolina started a section 1915(c) waiver in 2018 serving people

with brain injuries (NC 1326). From November 1, 2018 until it was terminated on January 1, 2019, California renewed a waiver program serving people who were medically fragile or TD (CA 0486).

**Table I.2. Section 1915(c) waiver changes between 2018 and 2019**

Section 1915(c) waivers ended in waiver year 2018	Section 1915(c) waivers newly active in waiver year 2019
HCBS Children With Autism Waiver (CO 0434)	Individualized Supports Waiver (AK 1566)
Early Childhood Autism Waiver (CT 1040)	Pediatric Palliative Care Waiver (CA 0486)
Traumatic Brain and Spinal Cord Injury Waiver (FL 0342)	California Self-Determination Program Waiver for Individuals with Developmental Disabilities (CA 1166)
Adults with Cystic Fibrosis (FL 0392)	TBI Waiver (NC 1326)
Georgia Pediatric Program (GAPP) Renewal Waiver (GA 4116)	
Alzheimer's Assisted Living (AAL) Waiver (VA 40206)	
Community Options Program (COP) Waiver (WI 0154)	
Community Integration Program (CIP-1) – DD Renewal Waiver (WI 0229)	
Acquired Brain Injury Waiver (WY 0370)	

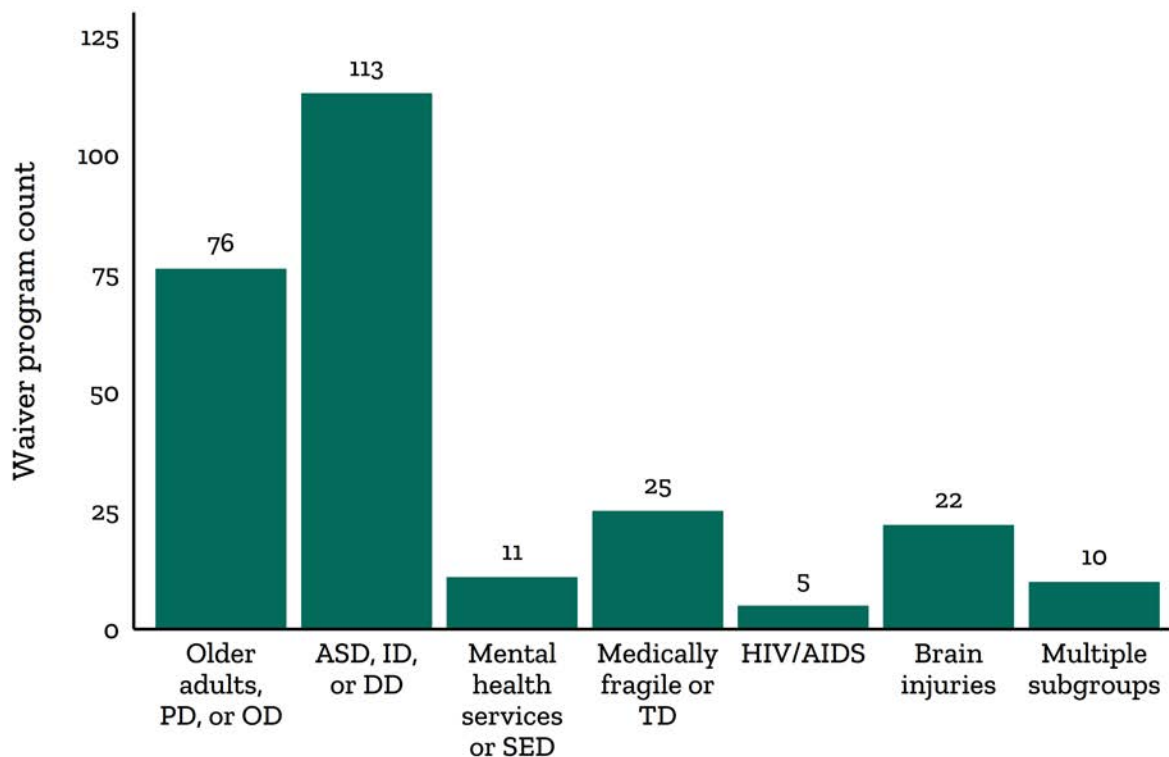
HCBS = home and community-based services; TBI =people with traumatic brain injury.

Finally, we recategorized a few section 1915(c) waivers that adjusted their target groups between 2018 and 2019. The *Elderly, Blind and Disabled (HCBS-EBD) Waiver* in Colorado (CO 0006), *MFP Community Living (MFP-CL) Waiver* in Massachusetts (MA 1027), and *MFP Residential Supports (MFP-RS) Waiver* in Massachusetts (MA 1028) expanded their target groups and were consequently recategorized as serving multiple subgroups.

After accounting for these changes, about 72.1 percent of the 262 section 1915(c) waivers active in 2019 served the ASD, ID, or DD target group (113 programs) or the older adults, people with physical disabilities, or people with other disabilities target group (76 programs) (Figure I.1).



Figure I.1. Total active section 1915(c) waiver programs in 2019, by LTSS target group



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

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

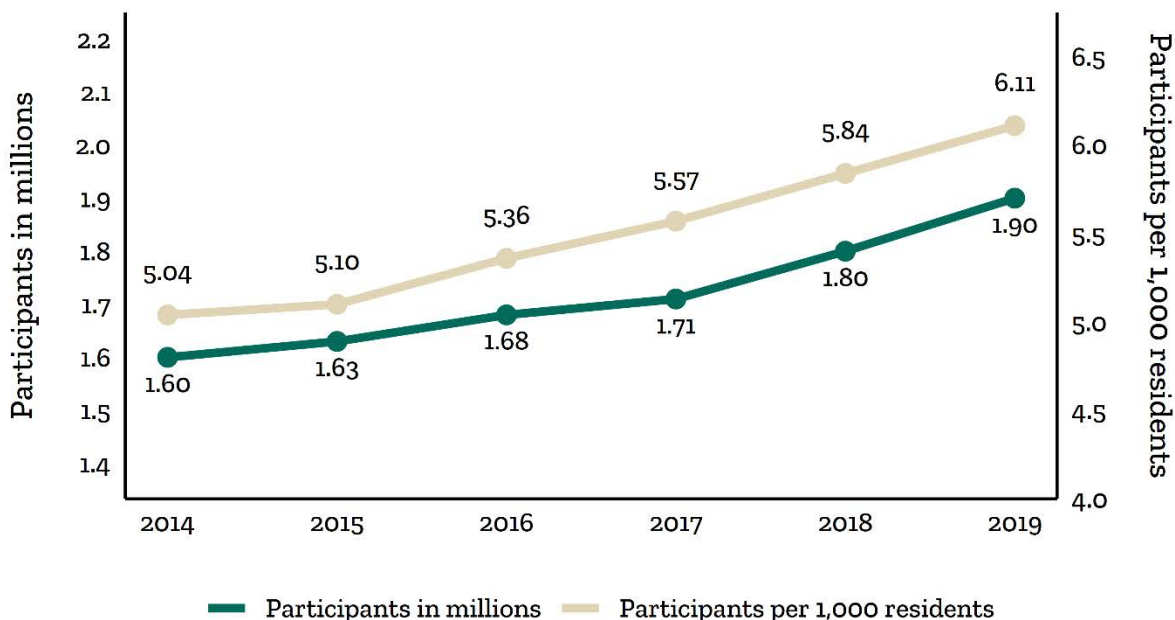
**Overview of report.** In the remaining sections of this report, we summarize information about section 1915(c) waiver program participants, service use, and expenditures for the 2019 waiver program year. In Chapter II, we examine national-level trends for 2019 and the most recent six years (2014 to 2019). We present more detailed national information for 2019 in Chapter III for the seven section 1915(c) waiver program target groups. Chapter IV includes an analysis of section 1915(c) waiver program participation and expenditures by state. And in Chapter V, we present our conclusions.



## II. National Trends in Section 1915(c) Waiver Program Participation and Expenditures, 2014 to 2019

**Participants.** National participation in section 1915(c) waiver programs increased during 2019 relative to 2018, continuing a trend of annual increases observed in the prior five years (Figure II.1). In 2019, the total number of waiver program participants was about 1.9 million, representing an increase of 5.2 percent relative to 2018 (Figure II.2).

**Figure II.1. Section 1915(c) waiver program participants, waiver program years ending in 2014–2019**

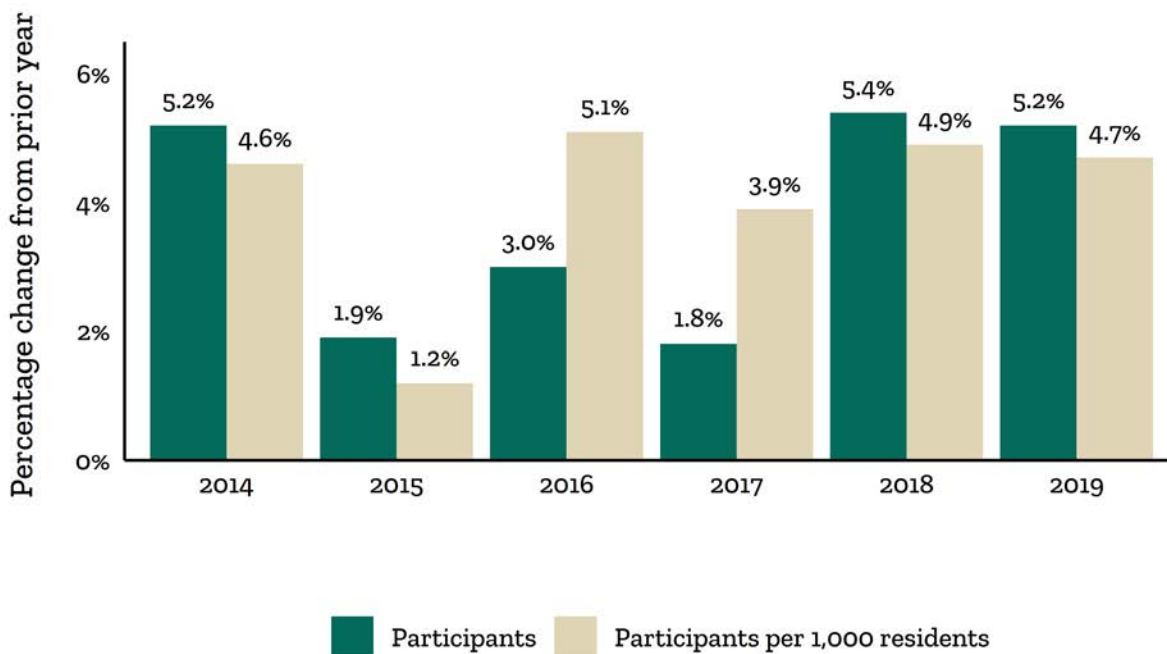


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data from 2018 to 2019. We obtained data for 2014 from Amos et al. (2018), data for 2015 to 2016 from Ross et al. (2021b), and data for 2017 from Ross et al. (2021a).

Note: Data reported on participants per 1,000 residents for 2015 and 2016 differs from Ross et al. (2021b) 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 a relatively consistent pattern over the five-year period. For every 1,000 U.S. residents, 6.11 were section 1915(c) waiver program participants in 2019 (Figure II.1), representing an increase of 4.7 percent from the prior year (Figure II.2), when the proportion of residents using section 1915(c) waiver program services was 5.84 per 1,000. Though waiver program participation grew over the five-year period, the growth varied somewhat year to year (Figure II.2). Participants per 1,000 U.S. residents increased by less than 4.0 percent in 2015 and 2017 and exceeded 4.5 percent in 2014, 2016, 2018, and 2019.

Figure II.2. Change in section 1915(c) waiver program participants, waiver program years ending in 2014–2019



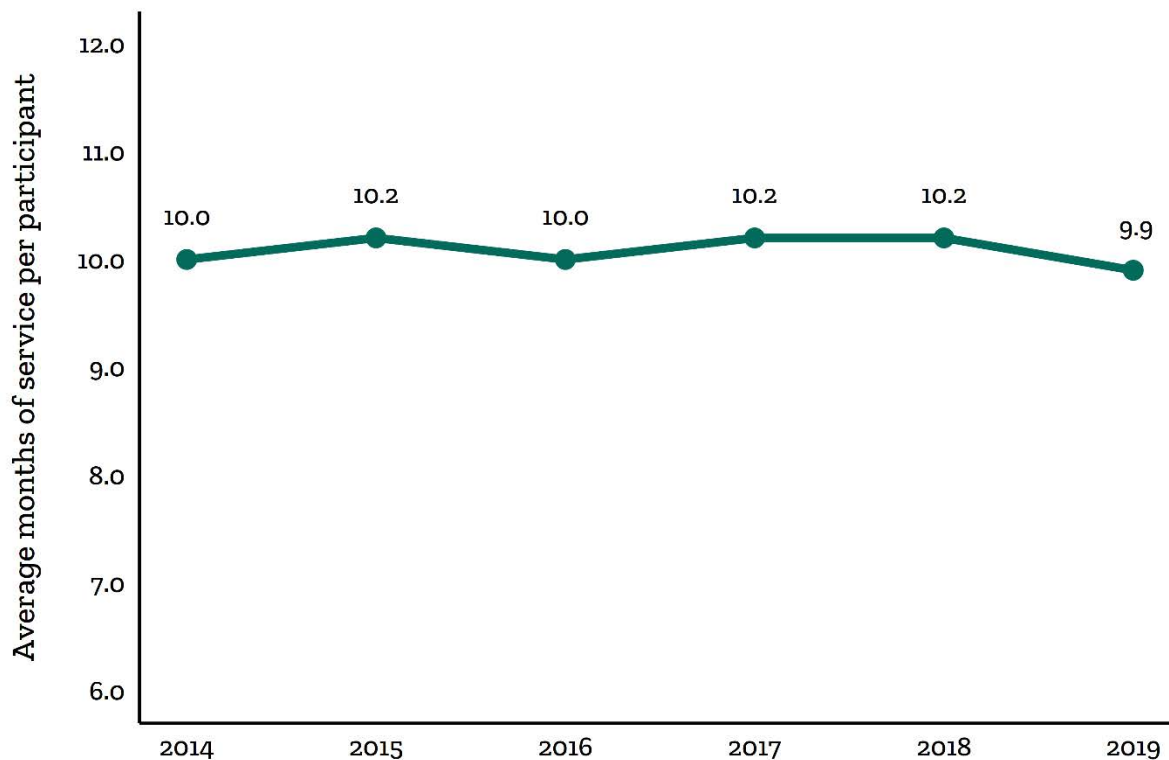
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data 2018 to 2019. We obtained data for 2014 from Amos et al. (2018), data for 2015 to 2016 from Ross et al. (2021b), and data for 2017 from Ross et al. (2021a).

Note: Data reported on participants per 1,000 residents for 2015 and 2016 differs from Ross et al. (2021b) 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.** The average months of section 1915(c) waiver program service use per participant fluctuated between 9.9 and 10.2 average months from 2014 to 2019, aligning with trends from 2012 and earlier years (Figure II.3).<sup>11</sup> In 2019, the average participant used section 1915(c) waiver program services for 9.9 months, the slightly-lower-than-average duration of service use reported in 2018. We explore how average months of service use varies across different target groups of section 1915(c) waiver program participants in Chapter III.

<sup>11</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 2014–2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports 2018 to 2019. We obtained data for 2013 to 2014 from Amos et al. (2018), data for 2015 to 2016 from Ross et al. (2021b), and data for 2017 from Ross et al. (2021a).

**Expenditures.** Nationally, average annual total Medicaid expenditures (including waiver and non-waiver expenditures) for section 1915(c) waiver program participants reached \$42,182 in 2019 (Figure II.4). This expenditure amount represents a 2.2 percent increase in average annual total Medicaid spending from 2018 (\$41,284) and continues the pattern of growth over the past five years.

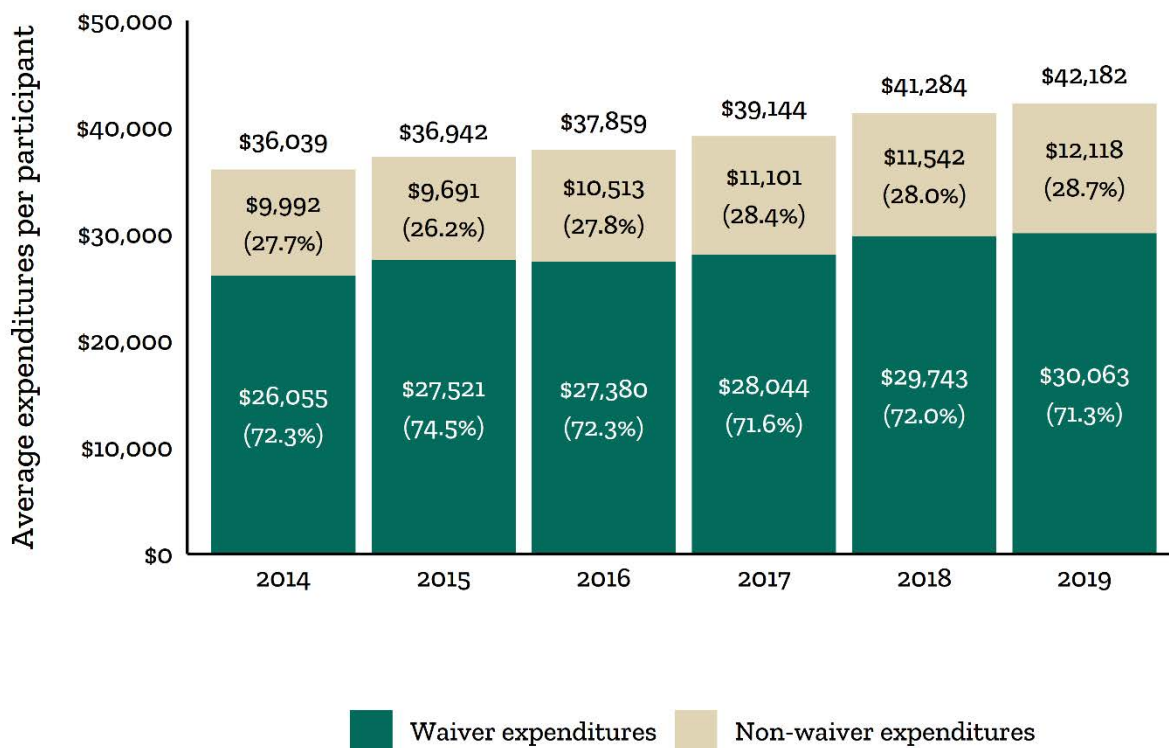
Annual waiver program expenditures per section 1915(c) waiver program participant grew from 2014 to 2019, with most years experiencing annual positive increases relative to the prior year. From 2014 to 2015, average waiver program expenditures grew by 5.6 percent to an average of \$27,521 per participant 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 6.1 percent to reach \$29,743. The average increased again in 2019 by 1.1 percent to \$30,063.

Average annual per-person waiver program expenditures remained a fairly stable proportion of total annual per-person Medicaid spending during 2014 to 2019. Depending on the year, average annual per-participant waiver program spending ranged from about 71 percent to nearly 75 percent of total per-participant Medicaid expenditures. We observed a slight downward trend from 2016 to 2019 relative to 2014 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. This proportion increased to 72.0 percent in 2018 and then decreased to 71.3 percent in 2019 (Figure II.4).

During the same period, we observed increases in annual average Medicaid non-waiver expenditures among section 1915(c) waiver program participants in every year except 2015. Average annual non-waiver program Medicaid expenditures increased by 8.5 percent to \$10,513 in 2016 and continued to grow from 2017 to 2019, reaching \$11,101, \$11,542, and \$12,118 respectively (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 2014–2019**

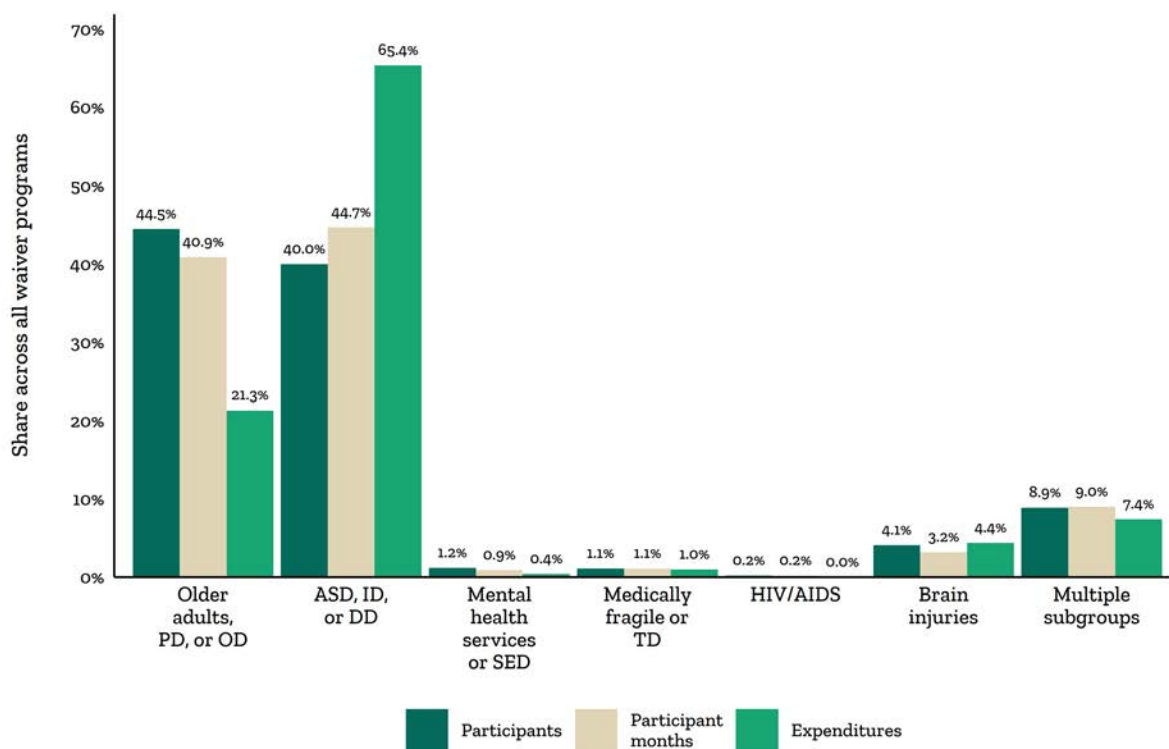


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2018 to 2019. We obtained data for 2014 from Amos et al. (2018), data for 2015 to 2016 from Ross et al. (2021b), and data for 2017 from Ross et al. (2021a). Dollar amounts are not adjusted for inflation.

### III. Trends in Section 1915(c) Waiver Program Participation and Expenditures, by LTSS Target Group, 2019

**Participants.** In 2019, two target groups—(1) older adults, people with physical disabilities, or people with other disabilities and (2) ASD, ID, or DD—together included 1.6 million participants, representing 84.5 percent of all waiver program participants (44.5 percent and 40.0 percent, respectively) (Figure III.1). Waiver programs serving multiple subgroups had the third largest share, comprising 168,664 participants (8.9 percent of all section 1915(c) waiver program participants). Waiver programs serving people with brain injuries (4.1 percent), people receiving mental health services or with SED (1.2 percent), people who are medically fragile or TD (1.1 percent), and people with HIV/AIDS (0.2 percent) were much smaller, ranging from 3,416 to 78,686 participants.

**Figure III.1. Distribution of section 1915(c) waiver program participants, participant months, and waiver program expenditures by LTSS target group, for waiver program year ending in 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

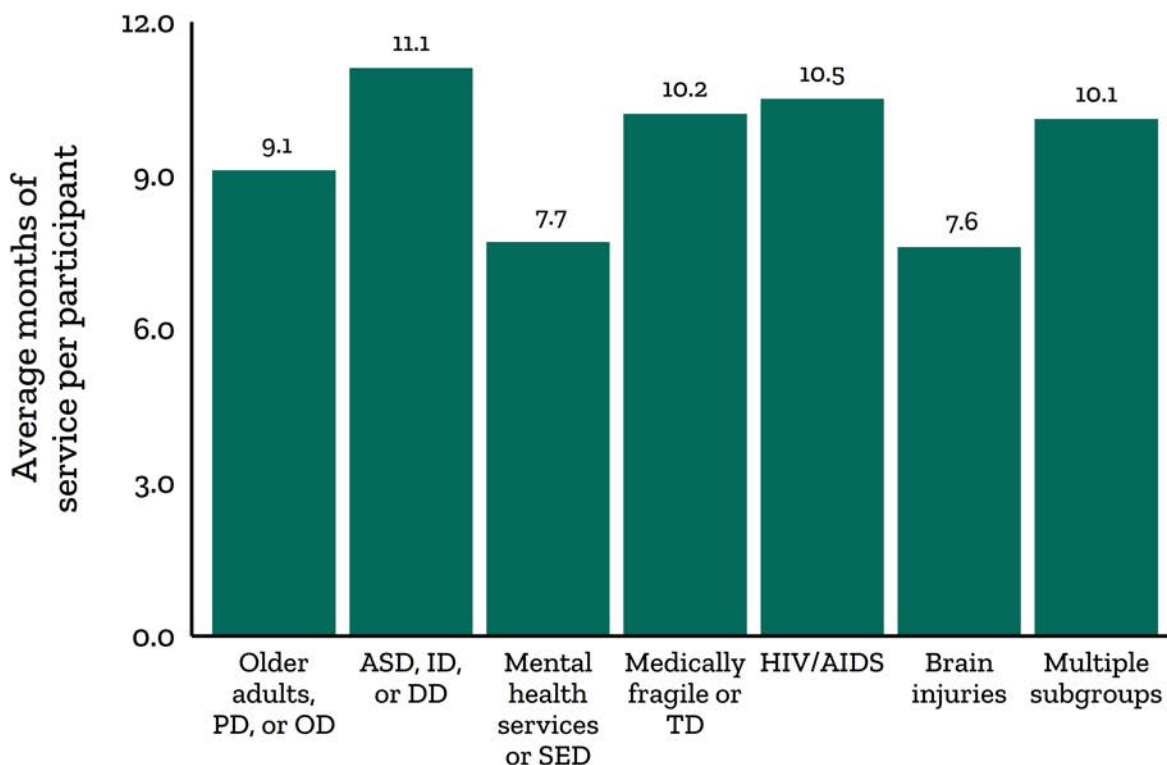
ASD = people with autism spectrum disorder; DD = people with developmental disabilities; HIV/AIDS = people with human immunodeficiency virus/acquired immunodeficiency syndrome; ID = people with intellectual disabilities; LTSS = long-term services and supports; OD = people with other disabilities; PD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

**Service use.** Nationwide, the average annual number of months that participants received section 1915(c) waiver program services during the year was 9.9 months in 2019, as we note 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 7.6 months in 2019 compared with 11.1 months for the ASD, ID, or DD target group (Figure III.2), representing 3.2 percent and 44.7 percent of all section 1915(c) waiver program participant months, respectively (Figure III.1).

Among the other target groups, waiver programs serving people with multiple subgroups and those who were medically fragile or TD had average months of service relatively similar to the national average, at 10.1 months and 10.2 months, representing 9.0 percent and 1.1 percent of all section 1915(c) waiver program participant months, respectively, in 2019. Waiver programs serving older adults, people with physical disabilities, or people with other disabilities had slightly fewer months of service, at an average of 9.1 months, accounting for 40.9 percent of all section 1915(c) waiver program participant months. Waiver programs serving people receiving mental health services or with SED had an average of 7.7 months of service use, and programs serving people with brain injuries had an average of 7.6 months of services use. These programs accounted for 0.9 and 3.2 percent of all section 1915(c) waiver program participant months, respectively.

**Figure III.2. Average annual number of participant months among people receiving section 1915(c) waiver program services by target group, for waiver program year ending in 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

ASD = people with autism spectrum disorder; DD = people with developmental disabilities; HIV/AIDS = people with human immunodeficiency virus/acquired immunodeficiency syndrome; ID = people with intellectual disabilities;

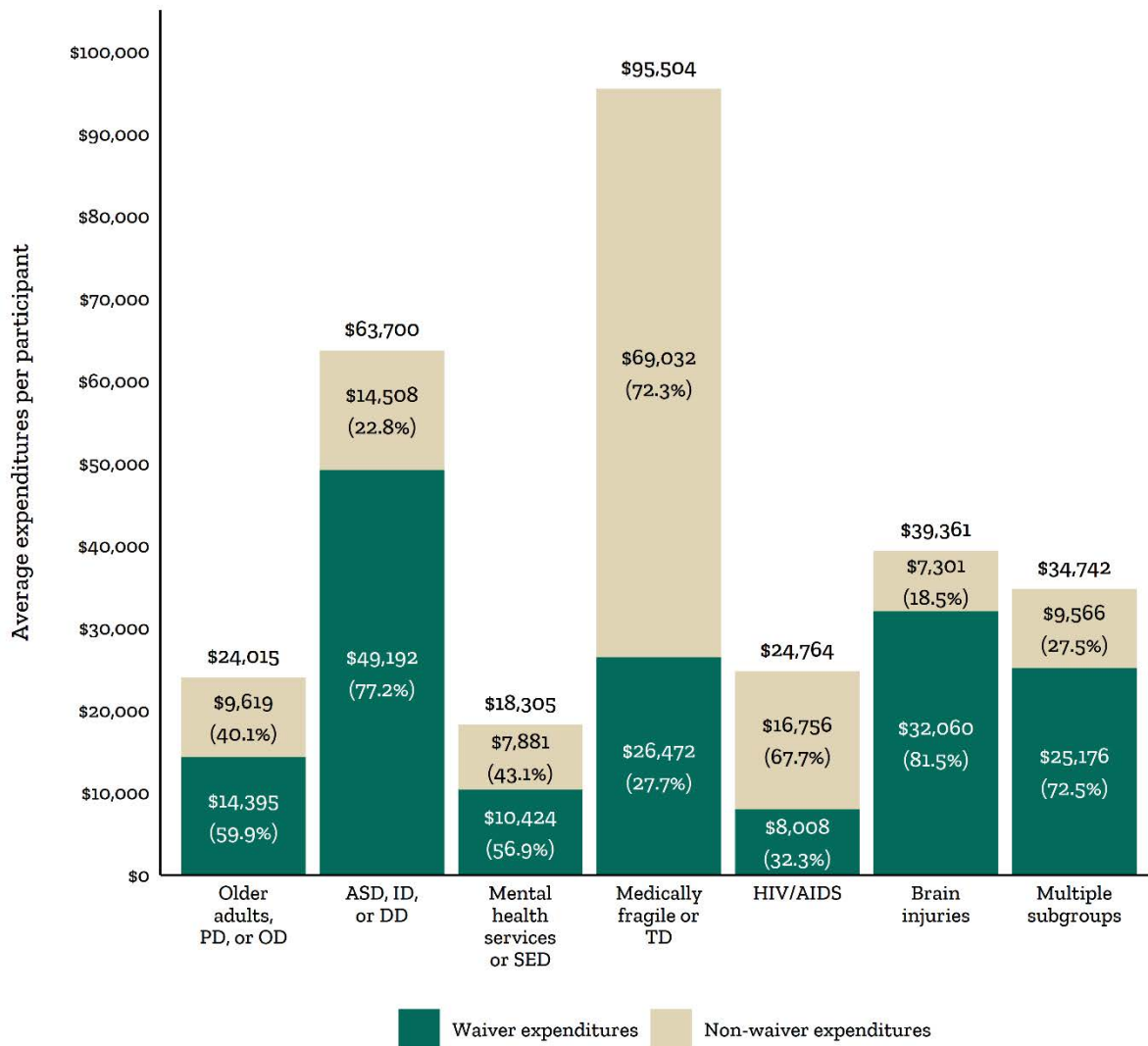
LTSS = long-term services and supports; OD = people with other disabilities; PD = people with physical disabilities; SED = people with serious emotional disturbance; TD = people who are technology dependent.

**Expenditures.** In 2019, annual average waiver program expenditures per participant were \$30,063, representing 71.3 percent of total annual average Medicaid spending (\$42,182), as we note 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 2019, section 1915(c) waiver program expenditures per participant were highest for the ASD, ID, or DD target group at about \$49,192 in 2019; followed by people with brain injuries (\$32,060); medically fragile or TD (\$26,472); multiple subgroups (\$25,176); older adults, people with physical disabilities, or people with other disabilities (\$14,395); mental health services or SED (\$10,424); and HIV/AIDS (\$8,008) (Figure III.3). As a proportion of total Medicaid spending by target group, average waiver program expenditures ranged from 32.3 percent for participants in waiver programs serving people with HIV/AIDS to 81.5 percent for participants in waiver programs serving people with brain injuries (Figure III.3).

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 65.4 percent, and the older adults, people with physical disabilities, or people with other disabilities target group had the next highest share of total waiver program expenditures (21.3 percent), followed by the multiple subgroups and people with brain injuries target groups (7.4 and 4.4 percent, respectively) (Figure III.1). These percentages reflect the relatively greater numbers of people served in these target groups. In 2019, the remaining target groups (medically fragile or TD, mental health services or SED, and HIV/AIDS) each had 1.0 percent or less of the share of total expenditures.

In terms of average non-waiver expenditures per participant, in 2019, the national average was \$12,118 per participant. Again, target groups substantially varied. The medically fragile or TD target group had the highest non-waiver program expenditures at about \$69,032 in 2019. The target groups with the next highest average annual non-waiver expenditures were the HIV/AIDS target group (\$16,756) and the ASD, ID, or DD target group (\$14,508). The average non-waiver program expenditures among the older adults, people with physical disabilities, or people with other disabilities and multiple subgroups populations were quite similar at \$9,619 and \$9,566, respectively, in 2019. The mental health services or SED and people with brain injuries target groups had the lowest average non-waiver program expenditures at \$7,881 and \$7,301, respectively (Figure III.3). In addition, although non-waiver expenditures comprised more than 67 percent of total Medicaid spending for waiver programs serving the 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.

**Figure III.3. 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 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file and Waiver Target Group, Subgroups, and Age file.

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



## IV. State Variation in Section 1915(c) Waiver Program Participation and Expenditures, 2019

Section 1915(c) waiver programs vary across states because states differ in how they use these programs to serve the different LTSS target groups that have diverse needs. States also design the waiver programs to provide different services to different groups, and these differences 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 2019 overall as well as for each of the seven LTSS target groups.

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 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.

### A. All LTSS target groups

**Participants.** In 2019, section 1915(c) program participants ranged from about 1 per 1,000 state residents (Tennessee) to 16 (Wisconsin), and the U.S. total across all 47 states was 6.1 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 less than 3.7 participants per 1,000 residents) were Tennessee, Delaware, Texas, Hawaii, Nevada, 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 (with 8.8 and 16.4 participants per 1,000 residents) were Iowa, Wyoming, Washington, Mississippi, Ohio, Kansas, Idaho, Illinois, Oregon, Pennsylvania, Minnesota, and Wisconsin.

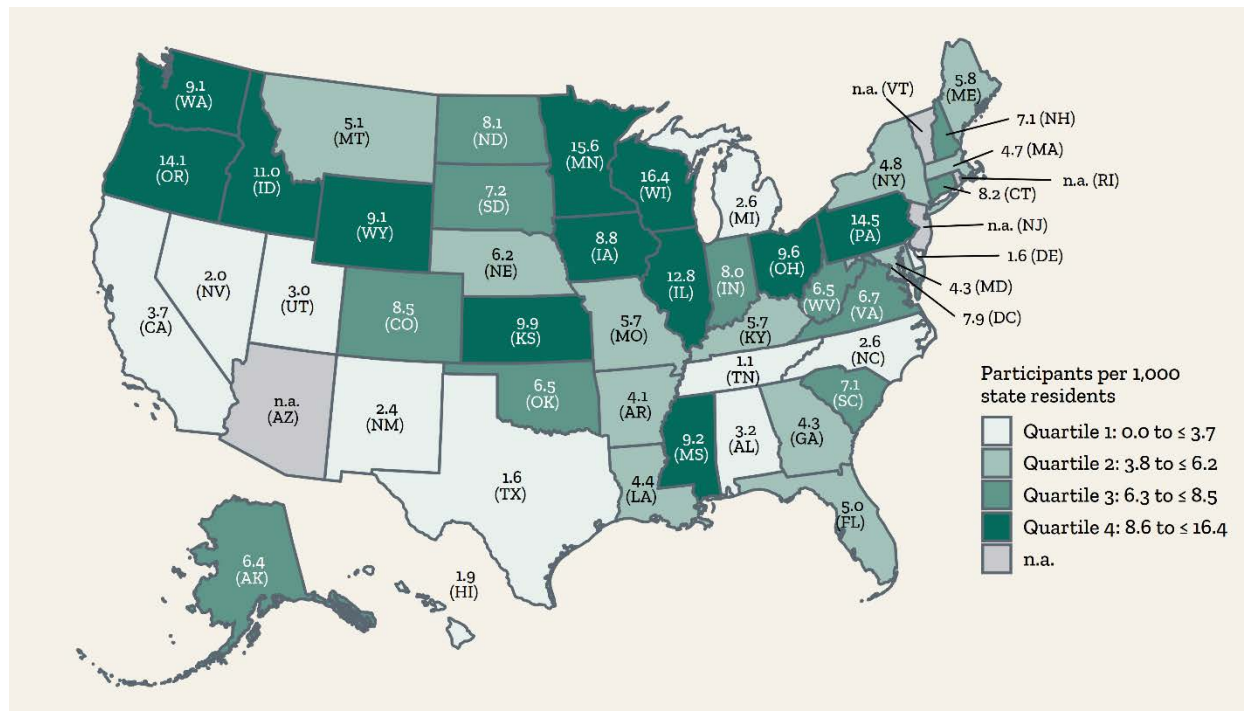
Although these state differences provide insight into how expansive section 1915(c) waiver programs are across states, it is important to consider the larger policy context and other authorities states could be using to provide similar services. For example, although Tennessee had the fewest section 1915(c) waiver program participants per 1,000 residents, this state only operates a waiver program for the ASD, ID, or DD LTSS target group, and managed LTSS are provided to additional Medicaid beneficiaries via the state's 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 2019, 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, we list states 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 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports and Census Bureau data from 2019.

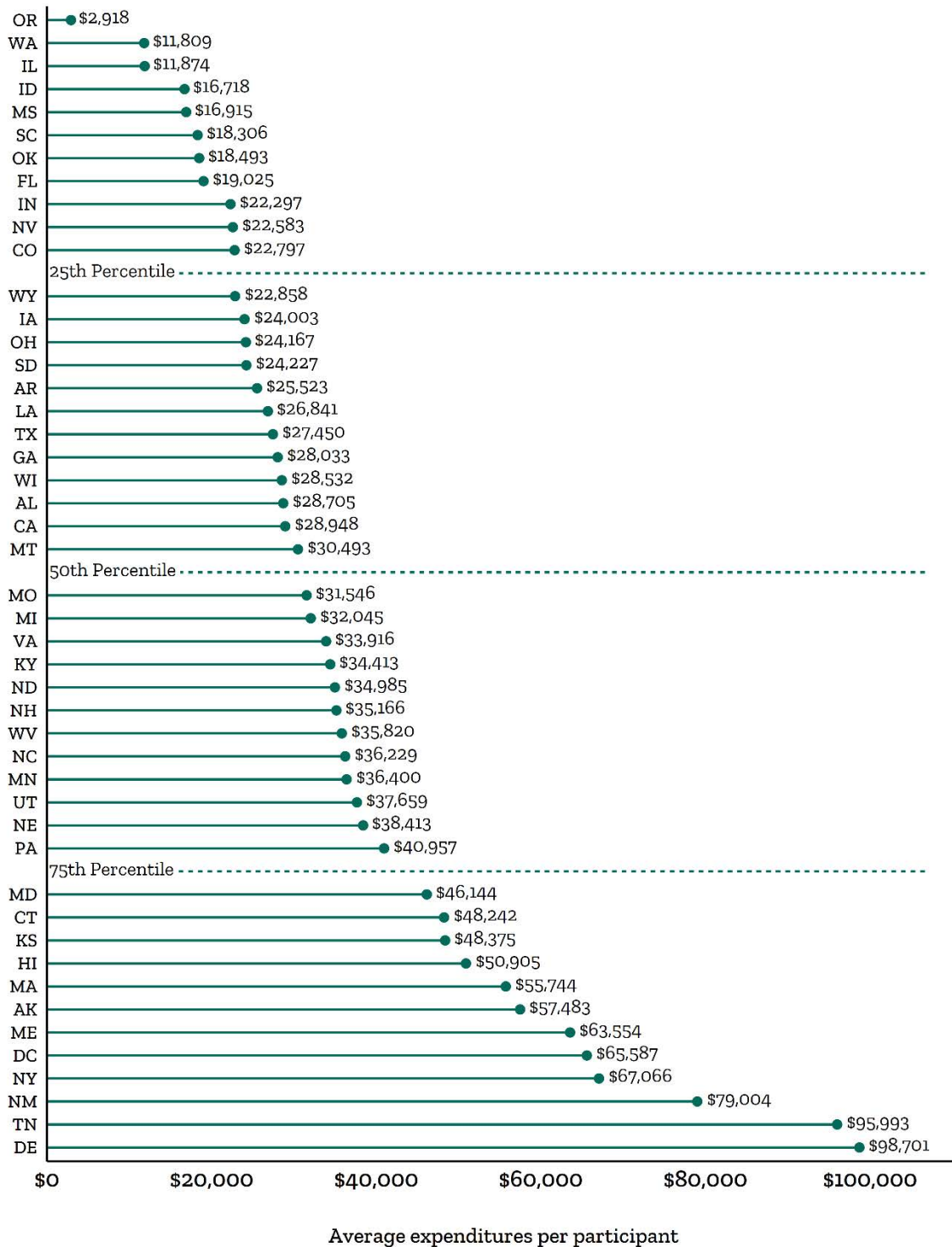
Note: We rounded the quartile ranges and state values to one decimal place in the figure, but states were grouped into quartiles based on unrounded values. Though this figure provides insight into variation in section 1915(c) waiver programs across states, it is important to consider that states might use authorities other than section 1915(c) waiver programs to provide similar services. For example, though Tennessee had the fewest section 1915(c) waiver program participants per 1,000 residents, it provided various LTSS to additional Medicaid beneficiaries through the state’s section 1115(a) demonstration.

n.a. = not applicable.

**Waiver expenditures.** As we describe in Chapter II, in 2019, the U.S. total annual average waiver expenditures per waiver program participant was \$30,063, but this average masks considerable variation across states (Figure IV.2; Appendix Table B.1). The average in each state ranged from \$2,918 in Oregon to \$98,701 in Delaware. Expenditures in Oregon were substantively lower than the per-participant waiver expenditures in other states. Washington, which had the second lowest average expenditures, spent \$8,891 more per participant on average than Oregon in 2019 (or a total of \$11,809 per waiver program 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.).

Of the 47 states with section 1915(c) waiver programs, 25 (53 percent) had higher average waiver expenditures than the U.S. total average (\$30,063) in 2019. States in the lowest quartile of average expenditures per participant in 2019 were Oregon, Washington, Illinois, Idaho, Mississippi, South Carolina, Oklahoma, Florida, Indiana, Nevada, and Colorado. Among those in the highest quartile of average expenditures were Maryland, Connecticut, Kansas, Hawaii, Massachusetts, Alaska, Maine, 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 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019 and Waiver Management System Finder file.

**Figure IV.2. (continued)**

Note: Though this figure provides insight into variation in section 1915(c) waiver programs across states, it is important to consider that states might use authorities other than section 1915(c) waiver programs to provide similar services. For example, Oregon had 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.

**B. Older adults, people with physical disabilities, or people with other disabilities target group**

**Participants.** Of the 47 states with section 1915(c) waiver programs in 2019, 40 (85 percent) had at least one section 1915(c) waiver program for the older adults, people with physical disabilities, or people with other disabilities target group.<sup>14</sup> Delaware, Hawaii, New Mexico, Tennessee, Texas, Virginia, and Wisconsin did not operate any waiver programs for this LTSS target group in 2019, though states might use authorities other than section 1915(c) waiver programs to provide similar services.<sup>15</sup> The number of older adults, people with physical disabilities, or people with other disabilities waiver program participants per 1,000 state residents ranged from less than 1 in several states to 11.7 (Minnesota), and the U.S. rate across all 40 states was 2.7 per 1,000 state residents (Figure IV.3; Appendix Table B.3). Five states served less than 1 section 1915(c) waiver program participant who was an older adult, had physical disabilities, or had other disabilities per 1,000 state residents (Colorado, New York, California, North Dakota, and Utah) and 24 (60 percent) had higher rates than the U.S. rate (2.7) in 2019.

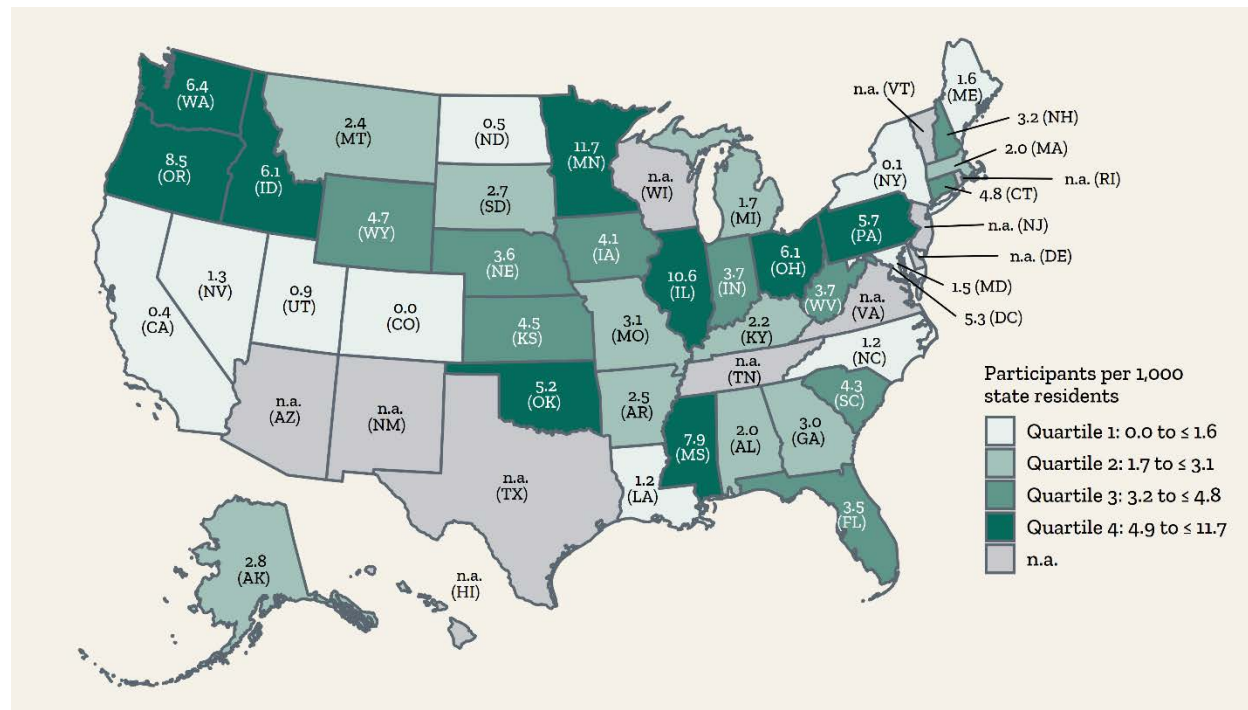
States in the lowest quartile of section 1915(c) waiver participants per 1,000 residents were Colorado, New York, California, North Dakota, Utah, Louisiana, North Carolina, Nevada, Maryland, and Maine. Those in the highest quartile (with 5.2 or more participants per 1,000 residents) were Oklahoma, District of Columbia, Pennsylvania, Ohio, Idaho, Washington, Mississippi, Oregon, Illinois, and Minnesota.

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<sup>14</sup> New York's *Nursing Home Transition and Diversion Medicaid Waiver* program (NY 0444) had no 372 reports with an accepted status within the past four years, so we could not include it in these analyses. New York's *Care at Home* program (NY 4125), however, did have a 372 report with an accepted status.

<sup>15</sup> Virginia and Wisconsin serve the older adults, people with physical disabilities, or people with other disabilities target group through a consolidated waiver program that provides services to multiple groups. Please see Section H of Chapter IV for more information about those waiver programs.

**Figure IV.3. Section 1915(c) waiver program participants per 1,000 state residents for the older adults, people with physical disabilities, or people with other disabilities target group, for waiver program year ending in 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, 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.

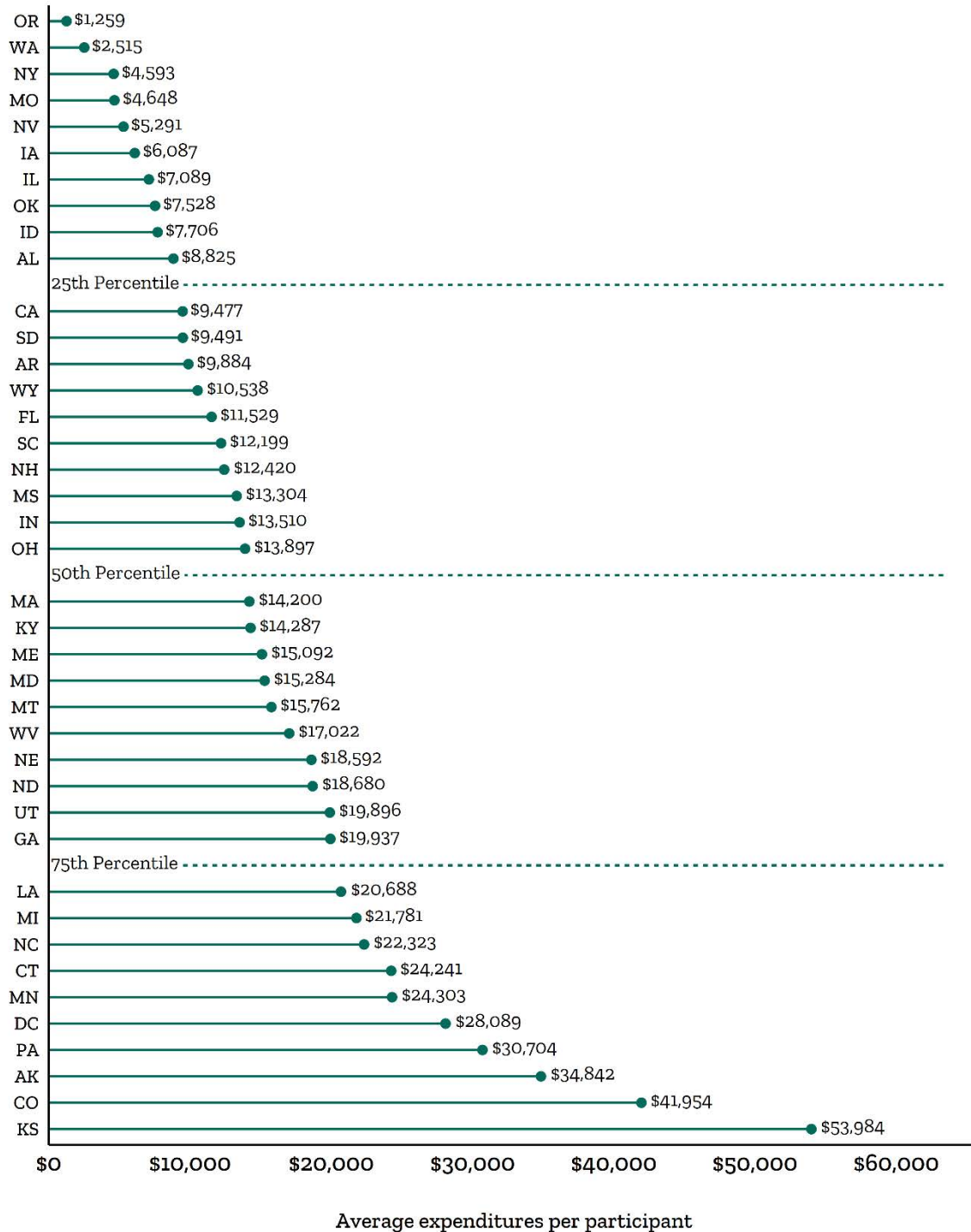
n.a. = not applicable.

**Waiver expenditures.** In 2019, the U.S. total average waiver expenditures per waiver program participant who was an older adult, had physical disabilities, or had other disabilities was \$14,395. Average waiver expenditures per section 1915(c) waiver program participant for this LTSS target group ranged from \$1,259 in Oregon to \$53,984 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, New York, Missouri, Nevada, Iowa, Illinois, Oklahoma, Idaho, and Alabama. Of the 40 states in this group, 18 (45 percent) had average waiver expenditures greater than the U.S. total average. Among those in the highest quartile of average waiver expenditures were Louisiana, Michigan, North Carolina, Connecticut, Minnesota, District of Columbia, Pennsylvania, Alaska, Colorado, and Kansas.



**Figure IV.4. Average waiver expenditures per section 1915(c) waiver program participant for the older adults, people with physical disabilities, or people with other disabilities target group, for waiver program year ending in 2019**



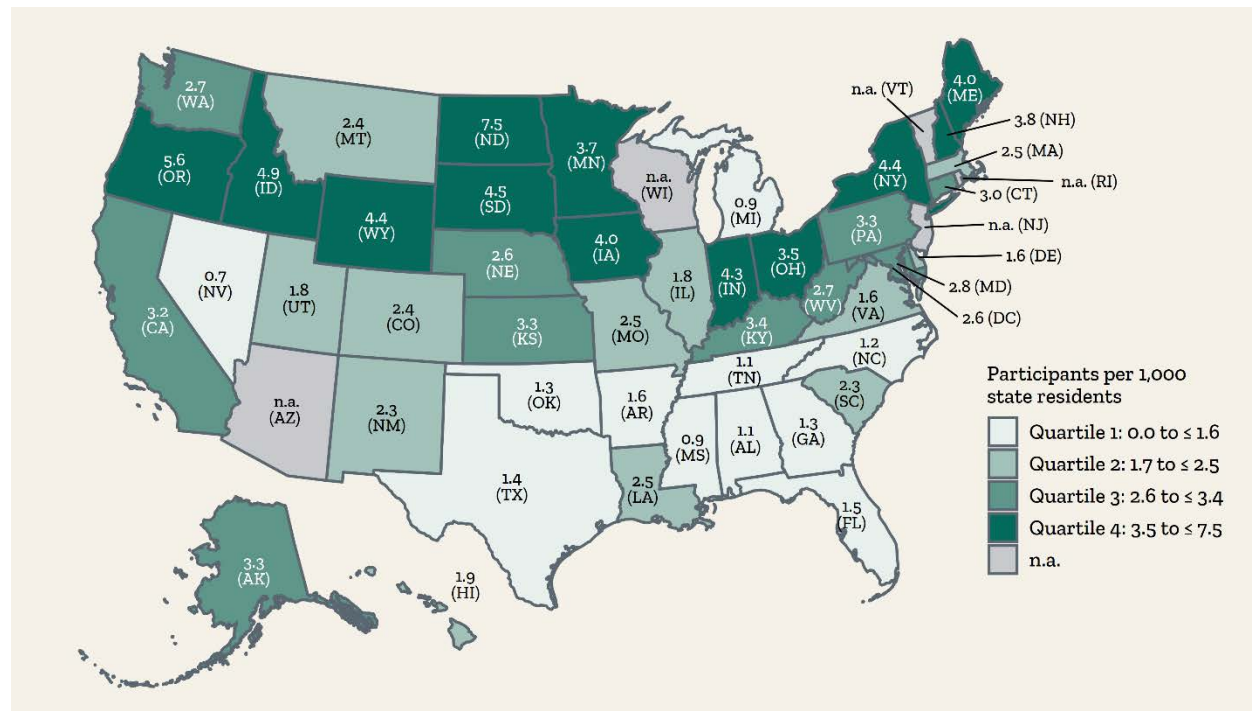
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

### C. ASD, ID, or DD target group

**Participants.** All states with active section 1915(c) waiver programs in 2019 except Wisconsin had waivers for the ASD, ID, or DD target group.<sup>16</sup> The number of participants per 1,000 state residents for this LTSS target group ranged from 0.7 (Nevada) to 7.5 (North Dakota), and the U.S. rate was 2.4 waiver program participants per 1,000 state residents (Figure IV.5; Appendix Table B.3). Of the 46 states, 26 (57 percent) had higher rates than the U.S. rate in 2019.

States in the lowest quartile of waiver program participants with ASD, ID, or DD per 1,000 state residents (with less than 1.5 participants per 1,000 residents) were Nevada, Michigan, Mississippi, Tennessee, Alabama, North Carolina, Georgia, Oklahoma, Texas, Florida, and Arkansas. Those in the highest quartile (with 3.5 or more participants per 1,000 residents) were Ohio, Minnesota, New Hampshire, Iowa, Maine, Indiana, 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 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, 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.

ASD = people with autism spectrum disorder; DD = people with developmental disabilities; ID = people with intellectual disabilities; n.a. = not applicable.

**Waiver expenditures.** In 2019, U.S. total annual average waiver expenditures per waiver program participant with ASD, ID, or DD was \$49,192. Of 46 states, 26 (57 percent) had average waiver

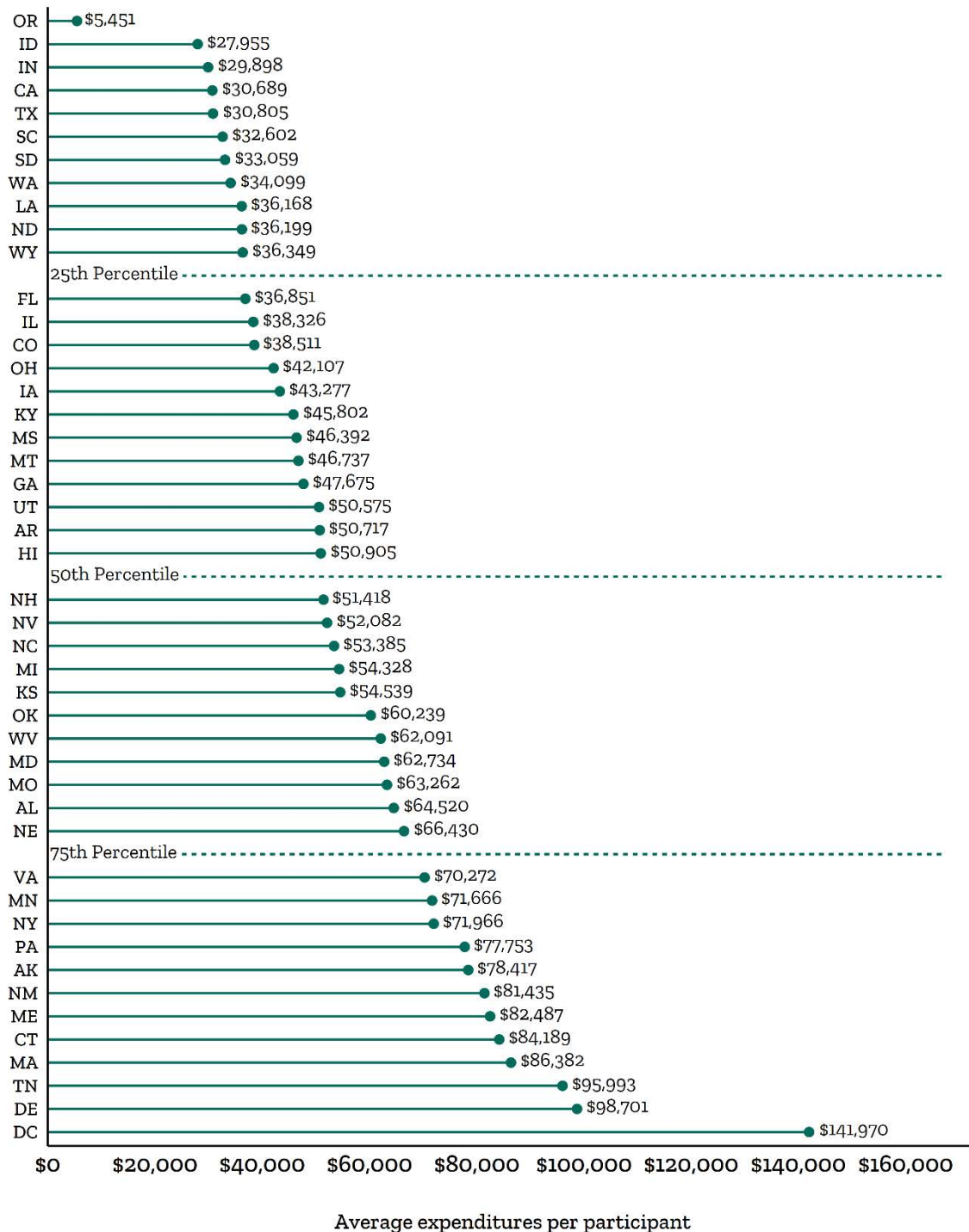
<sup>16</sup> Wisconsin serves the ASD, ID, or DD target group through a consolidated waiver program that provides services to multiple groups. Please see Section H of Chapter IV for more information about that waiver program.

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 \$5,451 in Oregon to \$141,970 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 Idaho at \$27,955.

States in the lowest quartile of average waiver expenditures per waiver program participant with ASD, ID, or DD were Oregon, Idaho, Indiana, California, Texas, South Carolina, South Dakota, Washington, Louisiana, North Dakota, and Wyoming. Those in the highest quartile of average waiver expenditures included Virginia, Minnesota, New York, Pennsylvania, Alaska, New Mexico, Maine, Connecticut, Massachusetts, 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 2019**



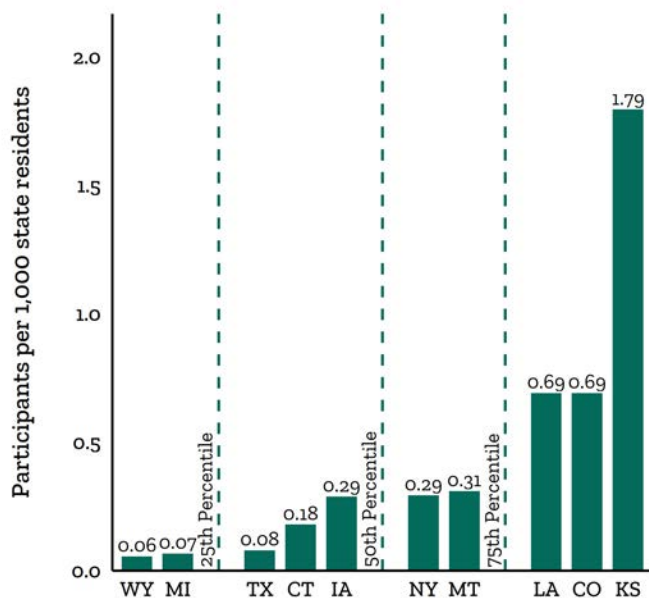
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age files.

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

### D. Mental health services or SED target group

**Participants.** In 2019, 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 0.07 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 group (Figure IV.7; Appendix Table B.3). Wyoming and Michigan 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 Louisiana, Colorado, 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 2019**



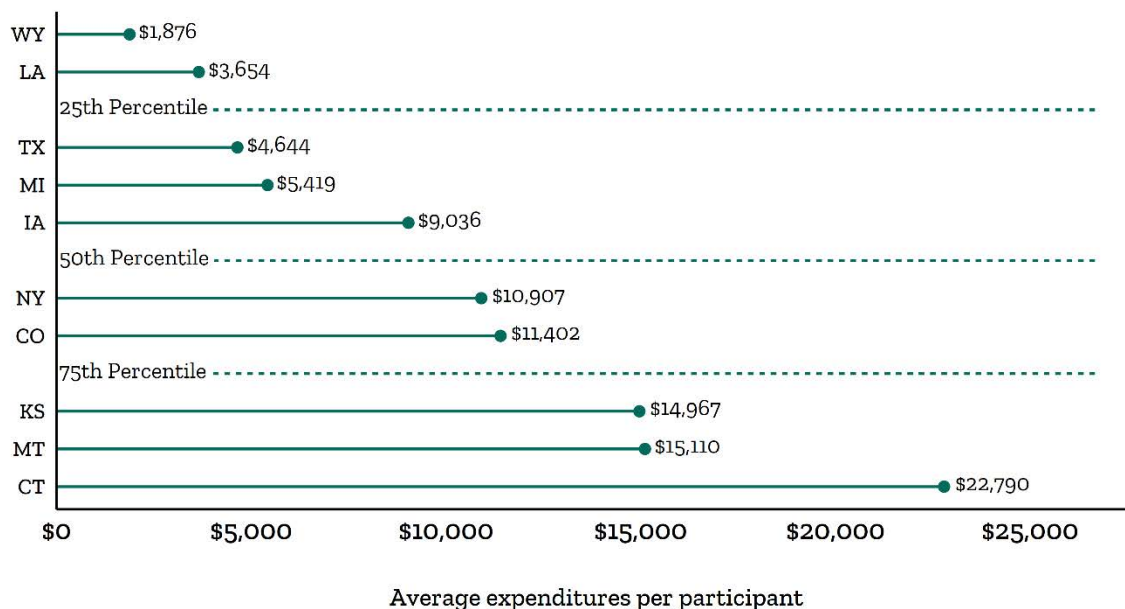
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

Note: We rounded the quartile ranges and state values to two decimal places in the figure, but states were grouped into quartiles based on unrounded values.

SED = people with serious emotional disturbance.

**Waiver expenditures.** For the mental health services or SED LTSS target group, U.S. annual total average waiver expenditures per waiver program participant in 2019 was \$10,424 and ranged from \$1,876 in Wyoming to \$22,790 in Connecticut (Figure IV.8, Appendix Table B.3). Of the 10 states with section 1915(c) waiver programs for this LTSS target group, 5 (50 percent) had average waiver expenditures greater than the U.S. total average in 2019. States at the lowest end of the distribution were Wyoming (\$1,876) and Louisiana (\$3,654), and states at the highest end of the distribution were Kansas (\$14,967), Montana (\$15,110), and Connecticut (\$22,790).

**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 2019**



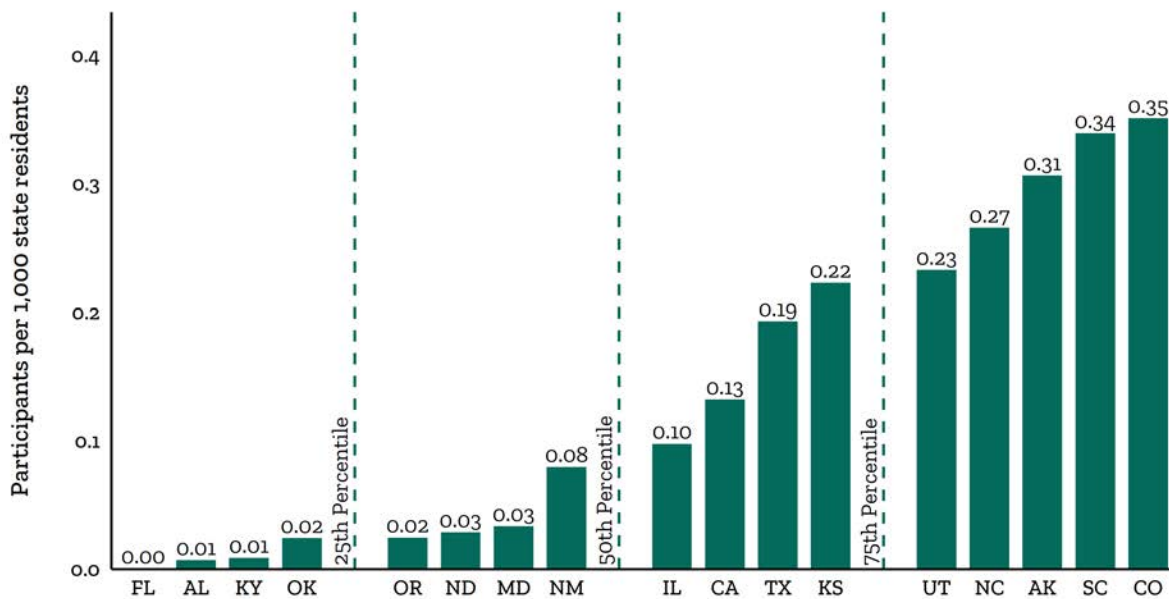
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

SED = people with serious emotional disturbance.

### E. Medically fragile or TD target group

**Participants.** Of the 47 states with section 1915(c) waiver programs in 2019, 17 (36 percent) served the medically fragile or TD target group. All 17 states served less than 1 participant per 1,000 state residents, ranging from 0.00 to 0.35 (Figure IV.9; Appendix Table B.3). Of those 17 states, 10 (59 percent) had higher rates than the U.S. rate in 2019 of 0.07. 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 Florida, Alabama, Kentucky, and Oklahoma, and those in the highest quartile were Utah, North Carolina, 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 2019**



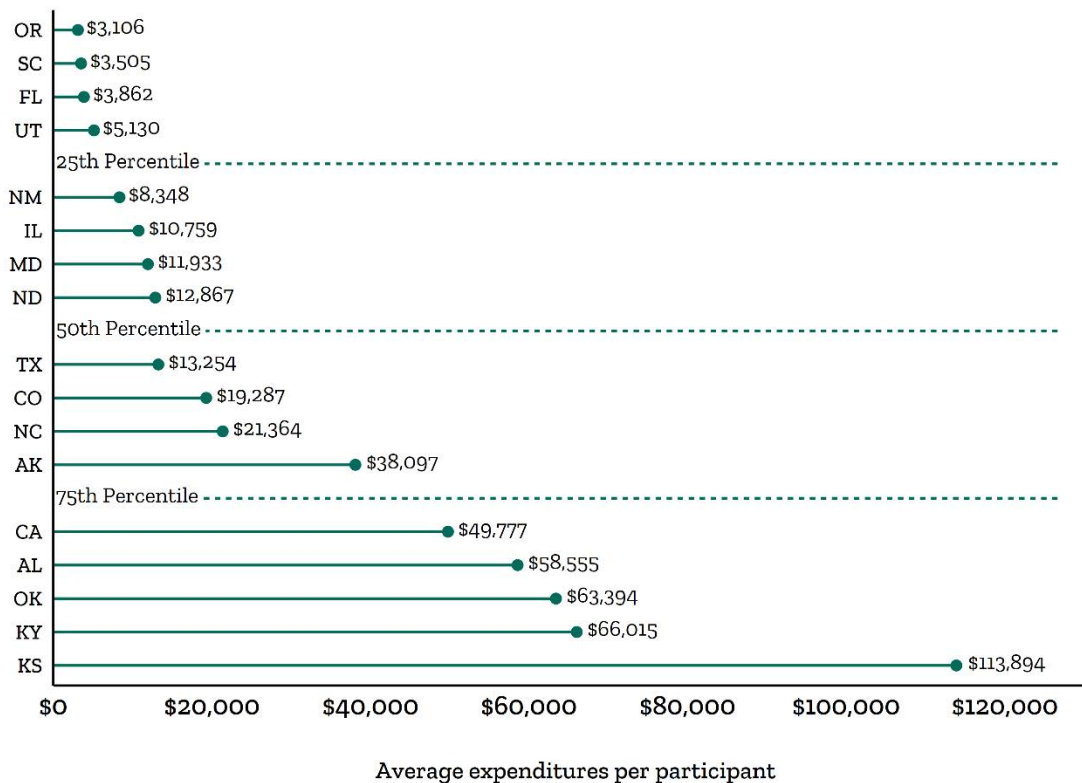
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

Note: We rounded the quartile ranges and state values to two decimal places in the figure, but states were grouped into quartiles based on unrounded values.

TD = people who are 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 2019 was \$26,472, ranging from \$3,106 in Oregon to \$113,894 in Kansas (Figure IV.10; Appendix Table B.3). Average expenditures in Kansas were substantively greater than average expenditures in other states for this target group. Kentucky, the state with the second-highest waiver expenditures, spent \$66,015 on average, which is \$47,879 less than the average for Kansas. Of the 17 states with waiver programs for this target group, 6 (35 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 were California, Alabama, Oklahoma, 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 2019**



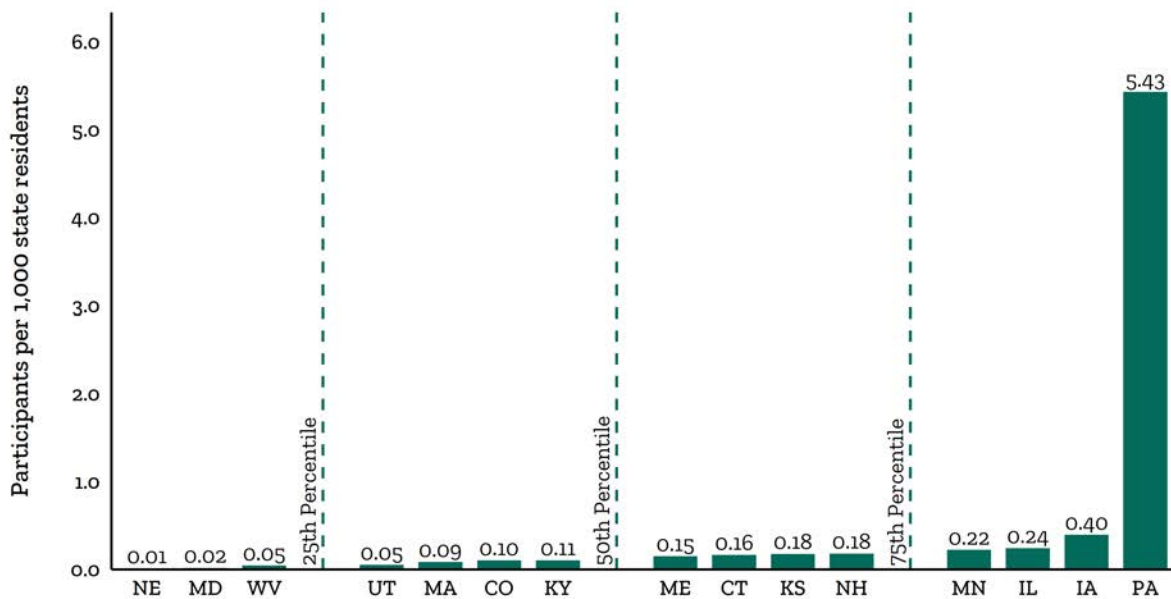
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services Subgroups and Age file.  
 TD = people who are technology dependent.

### F. People with brain injuries target group

**Participants.** In 2019, 18 of 47 states (38 percent) with section 1915(c) waiver programs served people with brain injuries target group. Waiver programs in 3 states did not have a recently accepted 372 report.<sup>17</sup> Among the remaining 15 states, the U.S. total was 0.25 participants per 1,000 state residents, and all states except Pennsylvania served less 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 5.43 (in Pennsylvania) participants per 1,000 state residents. Pennsylvania’s *COMM CARE Waiver* (PA 0386) served 13,221 people with brain injuries in 2019, which is more than three times the size of the population served by next highest state (Illinois, with 3,672 people).

<sup>17</sup> Indiana’s *Traumatic Brain Injury Waiver* program (IN 4197), New York’s *TBI Waiver* program (NY 0269), and North Carolina’s *Traumatic Brain Injury Waiver* program (NC 1326) had no 372 reports with an accepted status within the past four years, so we could not include them in these analyses.

**Figure IV.11. Section 1915(c) waiver program participants per 1,000 state residents for the people with brain injuries target group, for waiver program year ending in 2019**

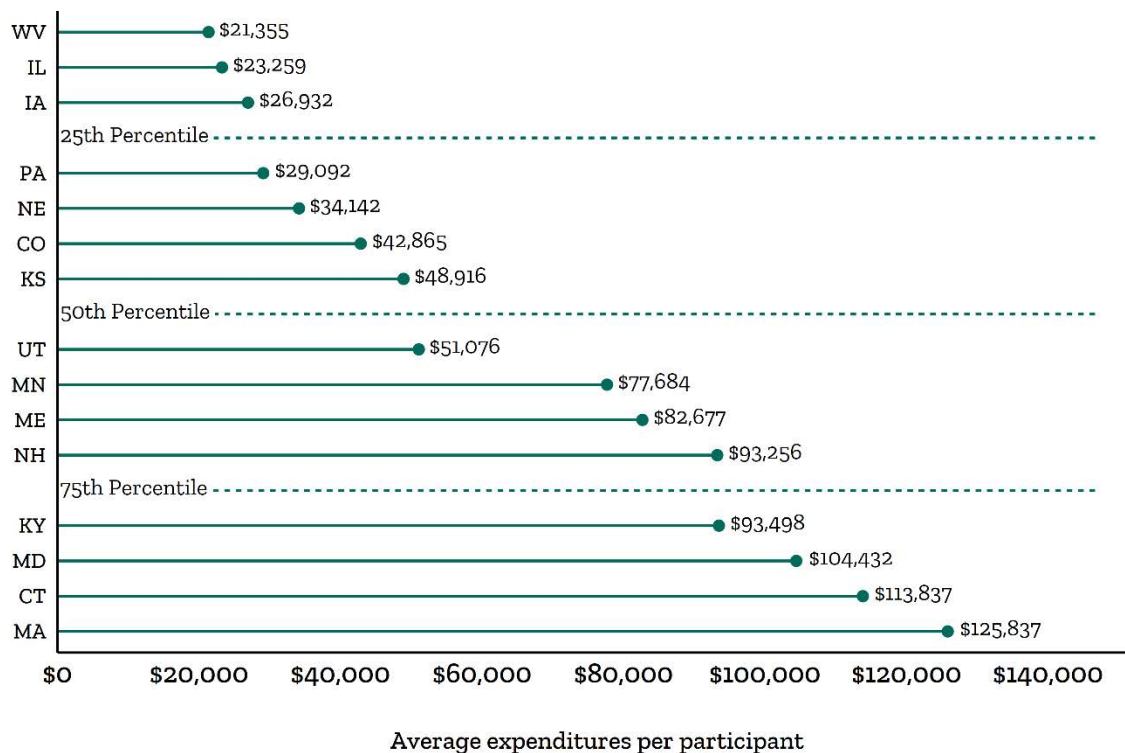


Source: Mathematica's analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

Note: We rounded the quartile ranges and state values to two decimal places in the figure, but states were grouped into quartiles based on unrounded values.

**Waiver expenditures.** For the people with brain injuries LTSS target group, U.S. annual average total waiver expenditures per section 1915(c) waiver program participant in 2019 was \$32,060. It ranged from \$21,355 in West Virginia to \$125,837 in Massachusetts (Figure IV.12; Appendix Table B.3). Of the 15 states with active section 1915(c) waiver programs and available data for this target group, 11 (73 percent) had average waiver expenditures greater than the U.S. total average in 2019 (\$32,060). States at the lowest end of the distribution were West Virginia, Illinois, and Iowa, and states at the highest end of the distribution were Kentucky, Maryland, Connecticut, and Massachusetts.

**Figure IV.12. Average waiver expenditures per section 1915(c) waiver program participant for the people with brain injuries target group, for waiver program year ending in 2019**

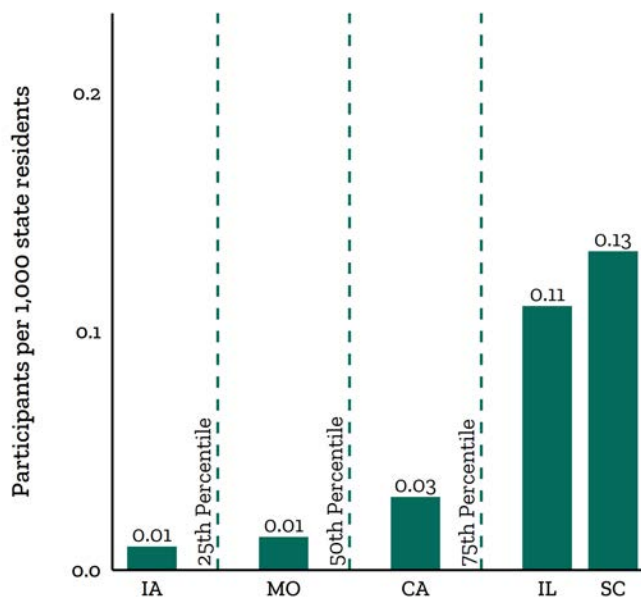


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

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

**Participants.** In 2019, 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 less 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 0.13 (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 2019**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

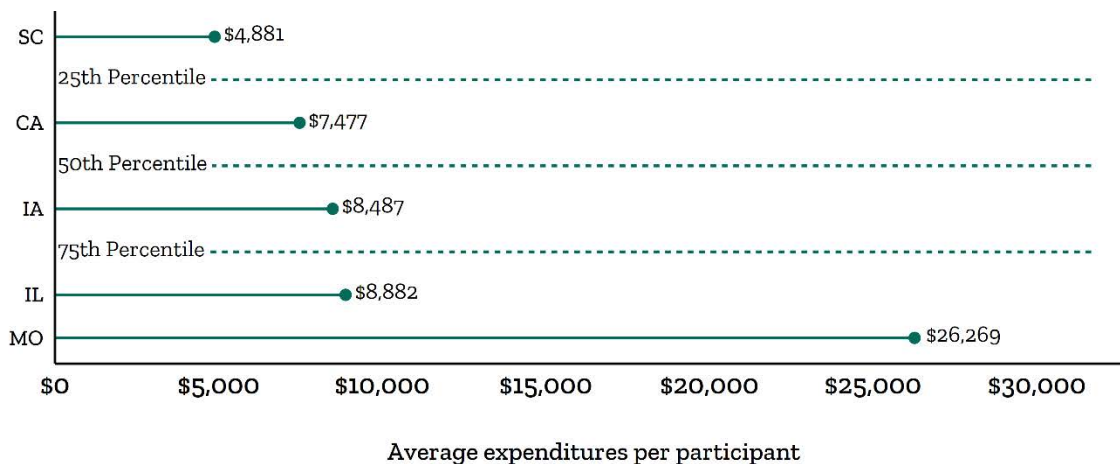
Note: We rounded the quartile ranges and state values to two decimal places in the figure, but states were grouped into quartiles based on unrounded values.

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

**Waiver expenditures.** In 2019, the U.S. annual average waiver expenditures per waiver program participant with HIV/AIDS was \$8,008. This ranged from \$4,881 in South Carolina to \$26,269 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 \$17,387 more per participant than Illinois in 2019, which was the state with the second-highest expenditures per waiver program participant (with a total of \$8,882 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 2019**



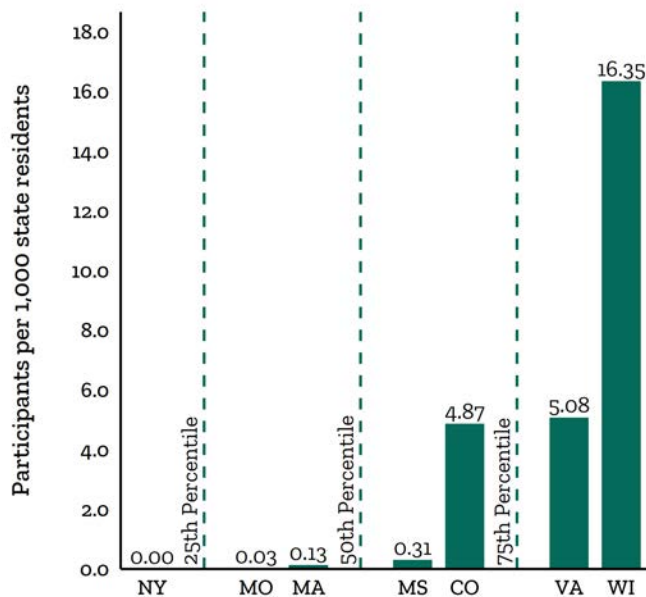
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder, and Waiver Target Group, Subgroups, and Age file.

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

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

**Participants.** In 2019, 7 of 47 states (15 percent) with section 1915(c) waiver programs served the multiple subgroups target group. For example, Missouri’s Medically Fragile Adult Waiver serves people with developmental disabilities and people who are medically fragile. The U.S. total was 0.54 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, Massachusetts, and Mississippi) served less than 1 section 1915(c) waiver program participant per 1,000 state residents (Figure IV.15; Appendix Table B.3). Among the remaining three states, Colorado served 4.9, Virginia served 5.1, and Wisconsin served 16.4 participants per 1,000 state residents. All 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 2019**

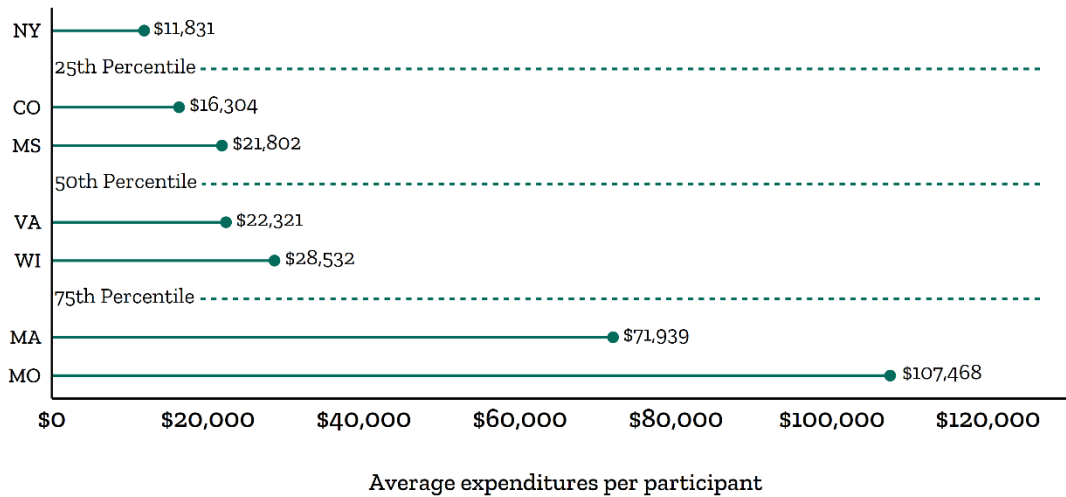


Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, Waiver Target Group, Subgroups, and Age file, and Census Bureau data.

Note: We rounded the quartile ranges and state values to two decimal places in the figure, but states were grouped into quartiles based on unrounded values.

**Waiver expenditures.** For the multiple subgroups LTSS target group, U.S. total average waiver expenditures per section 1915(c) waiver program participant in 2019 was \$25,176, with expenditures ranging from \$11,831 in New York to \$107,468 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 \$35,529 more per participant than Massachusetts, 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 2019**



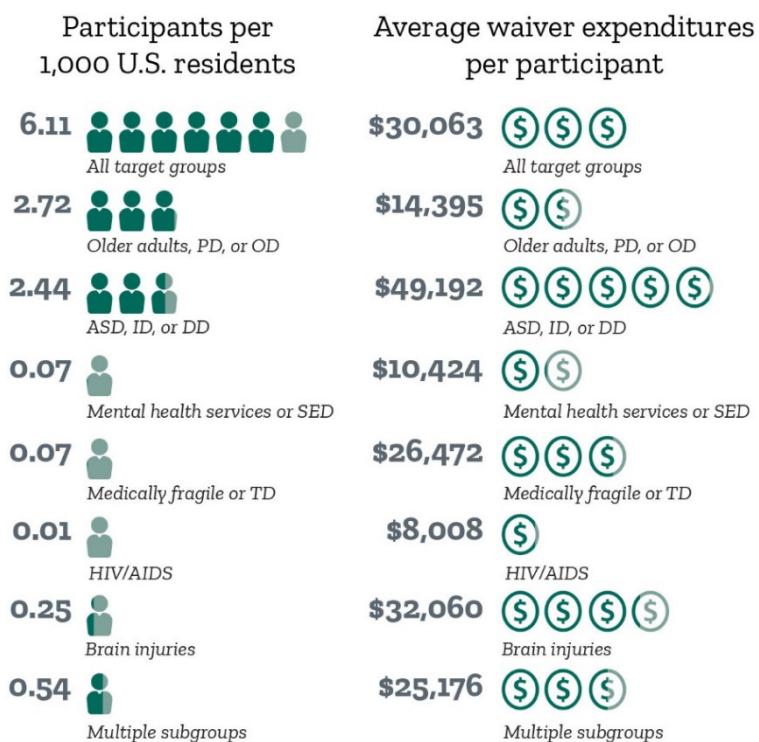
Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports from 2019, Waiver Management System Finder file, and Waiver Target Group, Subgroups, and Age file.

## V. Conclusion

In this report, we provide important insight into section 1915(c) waiver program participants, service use, and expenditures based on annual 372 reports states submitted for 2019. Similar to previous years, national participation in section 1915(c) waiver programs increased in 2019, rising to about 1.9 million participants across 47 states, representing an increase of 5.2 percent relative to 2018. As a proportion of the U.S. population, about 6.11 of every 1,000 residents used section 1915(c) waiver program services in 2019. In contrast, annual average per-participant waiver program expenditures did not grow as much: in 2019, waiver program expenditures averaged \$30,063 per participant compared with \$29,743 in 2018 (Figure V.1). This represents an increase of 1.1 percent in 2019 relative to 2018.

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 2019, waiver programs serving the older adults, people with physical disabilities, or people with other disabilities target group, and those for people with ASD, ID, or DD, had the highest proportion of participants per 1,000 residents and comprised about 85 percent of total waiver program participants. There were 2.72 participants in section 1915(c) waiver programs per 1,000 residents for the older adults, people with physical disabilities, or people with other disabilities population and 2.44 for people with ASD, ID, or DD, respectively, in 2019. Waiver programs focusing on the other five LTSS target groups served less than 1 participant per 1,000 U.S. residents in 2019. 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 with brain

**Figure V.1. Key 2019 statistics for section 1915(c) waiver program participants**



Source: Mathematica’s analysis of Centers for Medicare & Medicaid Services 372 annual reports for 2019, Waiver Management System Waiver Finder System file, Waiver Target Group, Subgroups, and Age file and Census Bureau data. We calculated the number of participants and average waiver expenditures per waiver program year.

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

injuries, people receiving mental health services or with SED, people who are medically fragile or TD, and people with HIV/AIDS.

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, people with physical disabilities, or people with other disabilities target group was \$14,395 in 2019, average waiver expenditures for the ASD, ID, or DD target group were more than three times as much at \$49,192. This finding suggests a topic for additional study. Among the smaller target groups, the lowest observed average section 1915(c) waiver program expenditures were reported for the HIV/AIDS target group (\$8,008), and people with brain injuries had the highest average waiver expenditures in 2019 (\$32,060).

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 262 total waiver programs offered by states in 2019, 46 states offered waiver programs for the ASD, ID, or DD target group, and 40 (85.1 percent) offered waiver programs for the older adult, people with physical disabilities, or people with other disabilities target group. For the remaining five target groups, 17 states (36.2 percent) served the medically fragile or TD population, 15 states (31.9 percent) offered waiver programs for people with brain injuries, 10 (21.3 percent) served people receiving mental health services or with SED, 5 served people with HIV/AIDS (10.6 percent), and 7 served multiple subgroups (14.9 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. The statistics in this report help us understand current program trends and identify topics that might benefit from additional research. 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 2019. We obtained national data from 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 to 2017 data in previous years' 372 annual reports. We recalculated results for 2018 for this report, which will serve as the final analysis of 372 annual report data from 2018. 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 restricted our use of prior year reports to the previous four years. 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 Census Bureau. Nonetheless, these analyses provide helpful insight 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.

**A. 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. We downloaded files for waiver program years 2014 to 2019 on April 20, 2022. We calculated section 1915(c) waiver program participants, service use, and expenditures during 2019 and 2018 to produce most analyses in this report. When no accepted 372 report was available for the year of interest, we used information from the most recent accepted 372 report available during the prior four years. Annual CMS 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 CMS 372 report is June 30, as Table A.1 shows. In this table, we list the number of days between the 2019 and 2018 waiver program year reporting deadlines and data download, which were 294 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 2019 and 2018**

Waiver year	Last possible waiver year date	Latest possible reporting date deadline	Time between reporting deadline and data download
2019	December 31, 2019	June 30, 2021	294 days
2018	December 31, 2018	June 30, 2020	1 year, 294 days

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

**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	Two- to four-digit number 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 <sup>a</sup>
Report Type	Indicating whether it is a “Lag” or “TE” report <sup>a</sup>
Unduplicated Participants	Number of unduplicated people 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 provided to all waiver participants

Table A.2 (continued)

Variable name	Description
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> The meaning of each report type is available in Step 2 of the Methods section.

We obtained the **WMS Finder file (03102022\_Summary Export.xlsx)** from the WMS Help Desk on March 10, 2022. 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 CMS 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 Table A.3 shows.

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 (for example, 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 (for example, “Alaskans Living Independently”)
Original Base Waiver Number	Four- or five-digit number that does not change with subsequent waiver renewals or amendments (for example, 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 (03142022\_FieldValue\_Export\_V2.0.xlsx)** from the WMS Help Desk on March 14, 2022. This file contained all current and historical information about the target groups, subgroups, and ages included in each waiver as of March 2022, allowing us to characterize section 1915(c) waiver program populations through 2019. We used the information in this file to assign target groups, subgroups, and determine whether the waiver served only children during our periods of interest (that is, waiver program years 2018 or 2019), 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
Waiver Number	Finalized, full waiver number, containing two-character state acronym, four- or five-digit base waiver number, renewal number, and amendment indicator (for example, AK.0262.R03.01) <sup>a</sup>
FIELDNAME	Indication of whether a given LTSS population subgroup (for example, autism, aged, brain injury, etc.): Was included in the waiver Had any minimum age criteria Had any maximum age criteria
FIELDVALUE	“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

<sup>a</sup> This is identical to the Waiver Number variable in Table A.3.

As Table A.5 shows, the **WMS Target Group, Subgroups, and Age** file information was used to categorize LTSS populations.

**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)	People with physical disability
Disabled (Other)	People with other disability
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.

This report also used the **Census Bureau State Population Totals and Components of Change (nst-estYYYY-01.xlsx)** file 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 (Census Bureau n.d.). 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>18</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 used the key variables shown in Table A.6.

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

Variable name	Description
State	Numerical value indicating state number
Name	Either United States, region, or state name
Popestimate2018	2018 population, estimated as a projection of 2010 Census
Popestimate2019	2019 population, estimated as a projection of 2010 Census

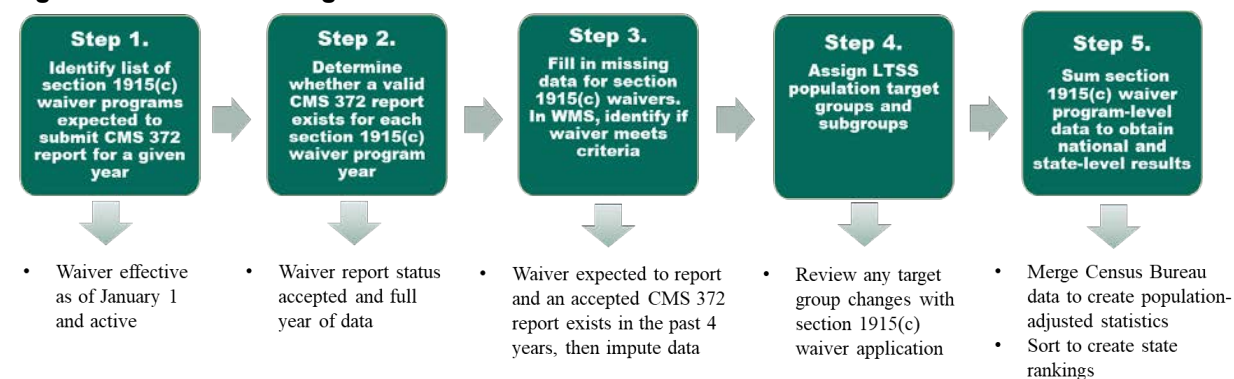
## B. Methods

Overall, our analytic approach comprised five main steps:

1. Identify the section 1915(c) waiver programs active and expected to have annual CMS 372 reports in 2018 and 2019.
2. Determine whether there was a valid CMS 372 annual report for each section 1915(c) waiver program.
3. Fill in missing data for section 1915(c) waiver programs without a CMS 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 Figure A.1 also illustrates.

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



<sup>18</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>.

**Step 1. Identify list of section 1915(c) waiver programs expected to have annual CMS 372 reports in 2018 and 2019.** As we noted, CMS 372 annual reports with financial reporting 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 might 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.<sup>19</sup>

To determine whether a state was expected to submit a CMS 372 report in 2018 and 2019 for a section 1915(c) waiver program, we first compared the historical effective and current effective dates of the section 1915(c) waiver program with the first day of the calendar year (for example, January 1, 2019). If the section 1915(c) waiver program was effective as of January 1 of a given year, then the state was expected to submit a CMS 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 program’s effective date is January 1, 2019), then the state is not expected to submit a report until the anniversary of the waiver program’s 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 CMS 372 submission represents a full year of data (for example, a waiver with an effective date of March 26 reporting for waiver program year ending in 2019 should reflect the period of March 26, 2018, to March 25, 2019). But if the waiver had a termination date before the end of the calendar year (for example, December 31, 2018), CMS guidance requires that states submit a CMS 372 in the months leading up to the termination for that year. For example, if a waiver with an effective date of December 26, 2018, was terminated on November 20, 2019, the state would submit data for report year 2019 for the period between the anniversary of the waiver’s effective date and its termination date (that is, from December 26, 2018, to November 20, 2019).

**Step 2. Determine whether there was a valid CMS 372 annual report for each section 1915(c) waiver program.** We analyzed the CMS 372 Reports by Year file to determine whether there was a valid submitted report for the relevant year for each section 1915(c) waiver program we identified in Step 1. A CMS 372 report was considered valid if had a report status of “Accepted,” indicating CMS’s review of the CMS 372 report is complete and reporting requirements were met (Personal communications between S. Cummins and K. Liao, January 21, 2020).<sup>20</sup>

We then reviewed all accepted CMS 372 reports for section 1915(c) waiver programs expected to report and identified those with (1) 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. After this review, we excluded 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 (that is, 2018 or 2019).

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 CMS 372 annual report file, we corrected and included the record.

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<sup>19</sup> States have six months after the end of each waiver program year to report on quality assurance requirements.

<sup>20</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’s 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.

Anomalous 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 that were expected to have a CMS 372 report in a given year but did not.** 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. Some states have delayed submission of 372 reports for this time period due to flexibilities granted for the COVID-19 public health emergency. To provide a reasonable approximation of participation, service use, and expenditures for these section 1915(c) waiver programs, we used the most recent accepted report available 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.

The proportion of active waiver programs in 2018 and 2019 for which data are estimated from the prior year’s 372 reports is available in Table A.7. For these waiver programs, all of the key variables in Table A.2 are estimated using the most recent accepted prior 372 report available within the past four years. We note individual waiver programs for which we estimated data from prior years with a footnote in Appendix B tables.

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

Waiver program year	Waiver programs expected to report	Waivers with no accepted, valid CMS 372 report for current year, for which prior year data were used	Waivers with no accepted, valid CMS 372 report for current year or prior four years
2018	267	22	3
2019	262	39	4

**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 used 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 in this report align with those used in past years. But 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 called Multiple Subgroups. The use of a Multiple Subgroups group was first employed in Ross et al. (2021b) 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, people with physical disabilities, have brain injuries, or have HIV/AIDS, for example. Additional details are available in 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 to 4, we established the final data set of section 1915(c) waiver programs for each year, including their actual or imputed CMS 372 data and target group assignment. We used this data set 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 groups. 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 2018 and 2019. We ranked states from highest to lowest for all key results. These results are available in Appendix B.

### C. 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, but the information is subject to important limitations. First, the accuracy of these analyses reflects the validity of the underlying data, which are the responsibility of states, CMS, and the Census Bureau. Second, Chapter II of this report uses national data from 2014 to 2016, which we obtained from prior reports analyzing CMS 372 report data, and we did not attempt to update or validate those results. Consequently, differences between results for these earlier years and the current years of analysis (2019 and 2018) might be attributable in part to updates to data sources and analytic approach. Third, to provide a complete picture of trends in section 1915(c) waiver programs, we estimate missing data using the most recently accepted CMS 372 report in the four years before the waiver program report year of interest. However, these data might not be reasonable proxies for the actual waiver program report year in which there were missing data. We imposed a restriction of four years on any estimation of current year data to mitigate this potential risk. Fourth, to avoid overcounting or undercounting, we compared CMS 372 report submissions with partial year data or more than 12 months of data with the waiver program effective period to ensure they aligned. It is important to note that in some cases, a CMS 372 report representing more or less than 12 months of data might represent a legitimate early expiration or extension of a waiver program year because of a revision that resets the effective date.



## Appendix B: Data Tables Excel Workbook Attachment