

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

**ANALYSIS OF CMS 372 ANNUAL REPORTS, 2015 – 2017**

**January 7, 2021**



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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

MFP = Money Follows the Person

MLTC = Managed Long Term Care

MMC = Mainstream Managed Care

OD = other disabilities

PD = physical disabilities

SED = serious emotional disturbances

TD = technologically dependent

TE = temporary extension

WMS = Waiver Management System

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## Executive Summary

**Purpose of this report.** Section 1915(c) of the Social Security Act enlarged the scope of the Medicaid program to allow for the provision of comprehensive long-term care services in home- and community-based settings as an alternative to institutional care. Introduced as part of the Omnibus Budget Reconciliation Act of 1981, state use of section 1915(c) waiver programs grew slowly but steadily. Over the past several decades, states have used section 1915(c) waiver programs, several other federal authorities, and federally funded 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 meet assurances on cost-neutrality; (2) details the type, amount, and cost of services provided; and (3) assesses other aspects of the waiver programs (CMS 2018). CMS and its contractors have produced summary reports of these data in most years. This is the seventh CMS report analyzing information from annual 372 report submissions and focuses on trends in section 1915(c) waiver program participants, service use, and expenditures for 2016 and 2017. To establish changes in section 1915(c) waiver program participants, service use, and expenditures for 2016, we also calculate results for 2015; results from prior years were obtained from previous reports and not re-calculated.

States vary markedly in the types of section 1915(c) waiver programs offered. As in past years, Arizona, Rhode Island, and Vermont had no waiver programs because they provide similar services via demonstrations authorized under section 1115(a) of the Social Security Act. In addition, New Jersey only had one active section 1915(c) waiver program during this period, but because there was no 372 report with an accepted status within the past four years for this waiver program, this state is excluded from our analyses for 2016 and 2017.<sup>1</sup> Thus, 46 states and the District of Columbia (D.C.) are included in this report, and often referenced as 47 states.

**Findings.** Nationally, approximately 1.68 million individuals participated in section 1915(c) waiver programs in 2016, representing a 3.0 percent increase from the prior year. In 2017, the number of national participants dipped slightly to 1.66 million, a 1.4 percent decline. When normalized for overall U.S. population growth, there were approximately 5.36 and 5.25 section 1915(c) waiver program participants per 1,000 total U.S. residents in 2016 and 2017, respectively (Figures ES.1 and ES.2).<sup>2</sup> While participation decreased in 2017 relative to 2016, average waiver program and total Medicaid (waiver and non-waiver program) expenditures per participant increased during this time period. In 2016, average section 1915(c) waiver program expenditures per participant per year were \$27,380, while in 2017 they were \$29,279. In both years, waiver program expenditures constituted around 72 percent of total Medicaid expenditures for section 1915(c) waiver program participants; the remainder were for non-waiver services.

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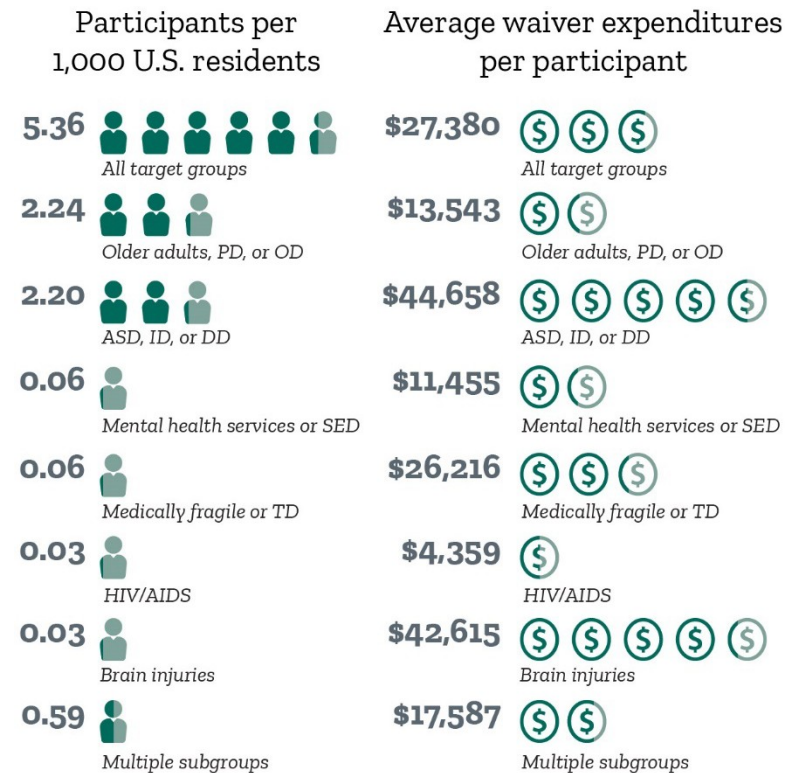
<sup>1</sup> The 372 reports may have a status of accepted, submitted, unlocked, unsubmitted, or unaccepted. The analyses in this report are limited to 372 reports which were accepted, indicating CMS review of the CMS 372 report is complete and reporting requirements were met.

<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, Rhode Island, Vermont, and New Jersey.

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

In both 2016 and 2017, the target groups with the highest participation were those serving (1) older adults or individuals with PD or OD; and (2) individuals with ASD, ID, or DD. There were 2.24 and 2.23 participants in section 1915(c) waiver programs per 1,000 residents for older adults, PD, or OD populations, and 2.20 and 2.28 for individuals with ASD, ID, or DD, respectively in 2016 and 2017. Waiver programs focusing on the other five LTSS target groups served fewer than one participant per 1,000 U.S. residents in these years. Among these five target groups, the waiver programs serving multiple subgroups had the highest proportion of participants per 1,000 residents, followed by individuals receiving mental health services or with SED; people who are medically fragile or TD; individuals with brain injuries; and those with HIV/AIDS.

**Figure ES.1. Key 2016 statistics for section 1915(c) waiver program participants**



Source: Mathematica analysis of 372 annual reports for 2016, Waiver Management System (WMS) characteristics and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

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

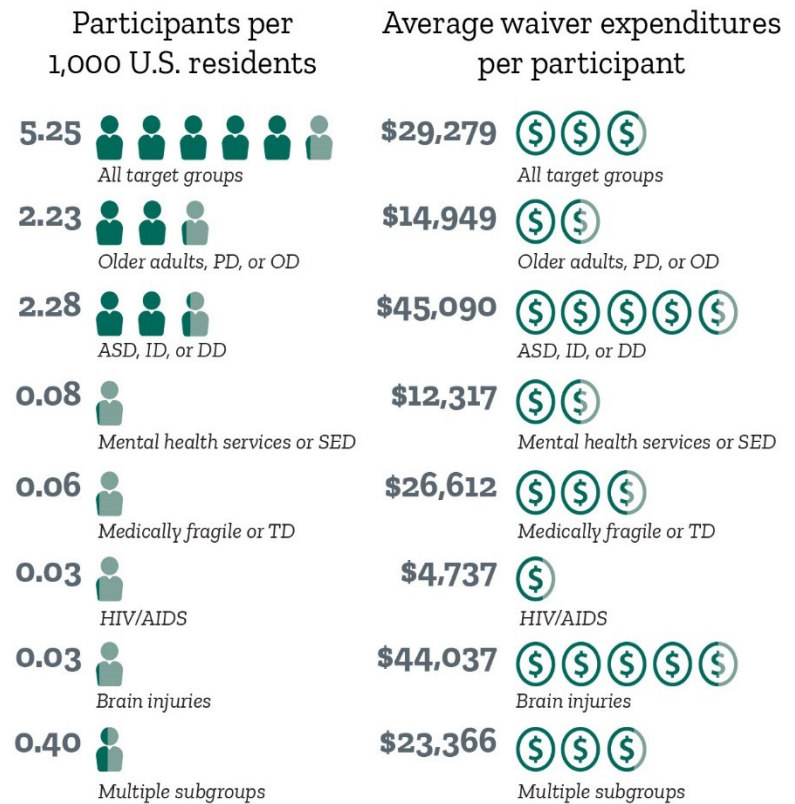
<sup>3</sup> These populations correspond to the target group and subgroup categories selected in the section 1915(c) waiver program application. The multiple subgroups category includes waivers with unique/rare combinations of subgroups that are not necessarily comparable to other waivers. For example, Colorado’s *Elderly, Blind and Disabled Waiver* (#0006) includes older adults, and people with PD or HIV, which effectively combines the older adults, PD or OD target group with the HIV/AIDS target group. Likewise, Wisconsin’s *Family Care Waiver* (#0367) includes older adults, and people with PD, OD, DD or ID, incorporating both the older adults, PD, or OD target group and the ASD, ID, or DD target group.

Average section 1915(c) waiver program expenditures also ranged markedly across the seven target groups. Waiver programs serving people with HIV/AIDS had much lower average expenditures per person compared to other groups: \$4,359 in 2016 and \$4,737 in 2017. In contrast, section 1915(c) waiver programs serving individuals with ASD, ID, or DD and serving people with brain injuries had the highest average expenditures per person, and were approximately 10 times those for HIV/AIDS. In 2016, average expenditures per person for the ASD, ID, or DD and brain injuries groups were \$44,658 and \$42,615 in 2016, and \$45,090 and \$44,037 in 2017, respectively. Average per person expenditures for the remaining four target groups ranged from \$11,455 (mental health services or SED) to \$26,216 (medically fragile or TD) in 2016, and from \$12,317 (mental health services or SED) to \$26,612 (medically fragile or TD) in 2017.

Among the 46 states and the District of Columbia, participation per 1,000 residents and average section 1915(c) waiver program expenditures varied overall, and across the LTSS target groups. In both 2016 and 2017, Wisconsin, Minnesota, Oregon, Illinois, and Idaho all had greater than 10 total section 1915(c) waiver program participants per 1,000 residents, listed from highest (Wisconsin) to lowest (Idaho). Among the remaining states, Kansas, Colorado, Wyoming, Ohio, Iowa, Mississippi and Pennsylvania had between eight and 10 total section 1915(c) waiver participants per 1,000 residents, while in Delaware and Tennessee there was approximately one participant per 1,000 residents.

For section 1915(c) waiver programs serving older adults, or individuals with PD or OD, Minnesota, Illinois, Oregon, Mississippi, and Idaho served the greatest number of participants as a proportion of their populations, exceeding six per 1,000 residents in both years (10.6 in Minnesota and 6.4 in Idaho in 2017). In contrast, North Dakota, Oregon, Idaho, South Dakota, New York, and Wyoming had the highest participation per 1,000 residents in section 1915(c) waiver programs serving individuals with ASD, ID, or DD, exceeding four in both years. However, in these two LTSS population groups (older adults, PD or OD; and ASD, ID, or DD), states with the highest participation did not necessarily have the highest

**Figure ES.2. Key 2017 statistics for section 1915(c) waiver program participants**



Source: Mathematica analysis of 372 annual reports for 2017, WMS characteristics and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

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

average waiver program expenditures. Of the states listed for these target populations, only Minnesota appeared among the five states with the highest average section 1915(c) waiver program expenditures for the older adult, PD, or OD LTSS population in 2016.

For the next two largest target groups—individuals who are medically fragile or TD and individuals who use mental health services or have SED—different states had the greatest participation per 1,000 residents. In both 2016 and 2017, Kansas, Louisiana, and Colorado all served the most individuals using mental health services or with SED (0.5 participants per 1,000 residents or above), while Alaska, Colorado, North Carolina, and South Carolina had the highest proportion of individuals who were medically fragile or TD per 1,000 residents (0.24 participants per 1,000 residents or above). Florida served the highest proportion of individuals with HIV/AIDS in both years (0.36 and 0.34 per 1,000 residents), which was more than double that of the next highest state (South Carolina). Iowa, Illinois, Wyoming, and Minnesota also each served 0.25 or more participants with brain injuries per 1,000 residents in both years, while Wisconsin also consistently served the most participants in waiver programs for multiple subgroups (10 or more per 1,000 residents each year). Similar to the patterns overall and for the two largest population groups (older adults, PD or OD; and ASD, ID, or DD), states with higher proportions of participants in the remaining five groups did not tend to have higher average waiver program expenditures per participant.

**Conclusion.** Section 1915(c) waiver programs comprise an important component of LTSS delivery systems for most states. The results in this report underscore the utility of 372 annual reports for understanding trends in section 1915(c) waiver program participation, service use, and expenditures, for all participants as well as by specific LTSS population target groups.



## I. Introduction

Section 1915(c) of the Social Security Act enlarged the scope of the Medicaid program to allow for the provision of comprehensive long-term care services in home- and community-based settings as an alternative to institutional care. Introduced as part of the Omnibus Budget Reconciliation Act of 1981, state use of section 1915(c) waiver programs grew slowly but steadily. Over the past several decades, states have used section 1915(c) waiver programs, several other federal authorities, and federally funded grant programs to develop a broad range of home and community-based services (HCBS) to provide alternatives to institutionalization for eligible Medicaid beneficiaries. Consistent with many beneficiaries' preferences of where they would like to receive their care, section 1915(c) waiver programs have become a critical component of the Medicaid program and are part of a larger framework of progress toward community integration of older adults and individuals with disabilities that spans 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 state assurances on cost-neutrality are met; (2) details the type, amount, and cost of services provided; and (3) assesses other aspects of the waiver programs (CMS 2018). This information is submitted in CMS Form 372(S), hereafter referred to as the annual 372 reports, via the Waiver Management System (WMS). The WMS is a web-based system that includes the annual 372 reports, as well as other information about section 1915(c) waiver programs, such as their eligible target groups and subgroups, and associated minimum and maximum ages. As such, the annual submission of the 372 reports along with other information available in the WMS provides an important means of monitoring states' provision of HCBS via section 1915(c) waiver programs.

The annual 372 reports reflect information from “waiver program years.” A waiver program year can begin on any day of the year, and generally corresponds to the approval date of the initial waiver program application, renewal, or modification. States have 18 months following the end of the waiver program year to submit the 372 report. For example, a waiver program year that began on March 26, 2015, and ended on March 25, 2016, would be considered a report for waiver program year 2016, and the corresponding annual 372 report would be due by September 25, 2018. A more detailed account of all the data sources, key variables, and methods used in this report is included 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 2016, and 2017.<sup>4</sup> CMS has published six reports to date using annual 372 data to analyze section 1915(c) waiver program trends, which cover 2009 through 2015 (Amos et al. 2018; Eiken 2017; Eiken 2016; Eiken 2015; Eiken 2014; Eiken and Lelchhook 2013).<sup>5</sup> The current report differs from prior reports in several respects by: (1) focusing on annual 372 data from two years, 2016, and 2017, rather than one year; (2) displaying state-level results in an accompanying Excel attachment for ease of stakeholder use; (3) omitting a comparison with Form CMS-64 expenditure data;<sup>6</sup> and (4) updating the waiver program-level labels describing the populations of

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<sup>4</sup> To establish changes in section 1915(c) waiver program participants, service use, and expenditures for 2016, we also calculate results for 2015.

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

<sup>6</sup> This comparison was omitted due to significant differences in reporting periods between the 372 and Form CMS-64 data sources. The 372 report data correspond to the “waiver program year,” which can begin on any day of the

Medicaid beneficiaries and recategorizing some waivers to reflect the selected target groups and subgroups in the section 1915(c) waiver program applications. The seven target groups are presented in Table I.1. In Appendix B, the waiver program-level tables for 2015, 2016, and 2017 include each waiver program’s target group and subgroups. A section 1915(c) waiver program “target group” includes a specific group or groups of individuals who meet the requirements for institutional level of care as defined in 42 CFR §441.301(b)(6), while a “target subgroup” is a smaller subset of individuals within a target group. For example, in the section 1915(c) waiver program application, “Aged” is a subgroup within the target group of “Aged or Disabled, or Both – General” (CMS, 2019).

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

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

Source: Mathematica analysis of WMS characteristics data and section 1915(c) waiver program applications. Additional details regarding LTSS target group assignments are provided in Appendix A.

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

The accuracy of this report reflects the completeness and quality of annual 372 reports for 2015, 2016, and 2017. During these years, three states (Arizona, Rhode Island, and Vermont) did not have section 1915(c) waiver programs. Instead, these states provided similar services to HCBS-eligible populations in demonstrations authorized under section 1115 of the Social Security Act.<sup>7</sup> The remaining 47 states and the District of Columbia (DC) had one or more section 1915(c) waiver programs for which they were required to submit a 372 report during these three years. However, not all section 1915(c) waiver programs expected to report each year had an accepted report at the time of this analysis. In these cases, this report uses data from the most recent accepted 372 report within the prior four years to estimate current year trends. Waiver programs with no accepted report within the past four years do not contribute to the analyses, but are listed as “Not Reported” in the waiver program-level tables in Appendix B. For example, New Jersey operated one section 1915(c) waiver program during this time period, but its last

year, and is not tied to a calendar or fiscal year. For example, at the time of this report, 2017 was the most recent year for which all section 1915(c) waiver programs were required to have 372 reports. However, the 2017 waiver program year covers a wide range of possible reporting periods between January 2, 2016 and December 31, 2017, and does not necessarily align with the calendar, state, or federal fiscal year. In contrast, CMS-64 data are analyzed by federal fiscal year (FFY). Analyses of FFY 2017 and 2018 section 1915(c) waiver program expenditures submitted via Form CMS-64 are available in the Medicaid Long Term Services and Supports Annual Expenditures Report.

<sup>7</sup> While other states also use section 1115 authority to provide HCBS, all other states had at least one active section 1915(c) waiver program through 2017.

accepted 372 report was submitted in 2011. Because those data are more than four years old for the 2016 and 2017 waiver program years, this report was not used to estimate participants, service use, or expenditures. Consequently, data for New Jersey is presented as “Not Reported” in these years. The process for using prior year data to estimate missing current year 372 report information is discussed in more detail in Appendix A, and waiver programs with either estimated or absent current year data are noted in Appendix B.

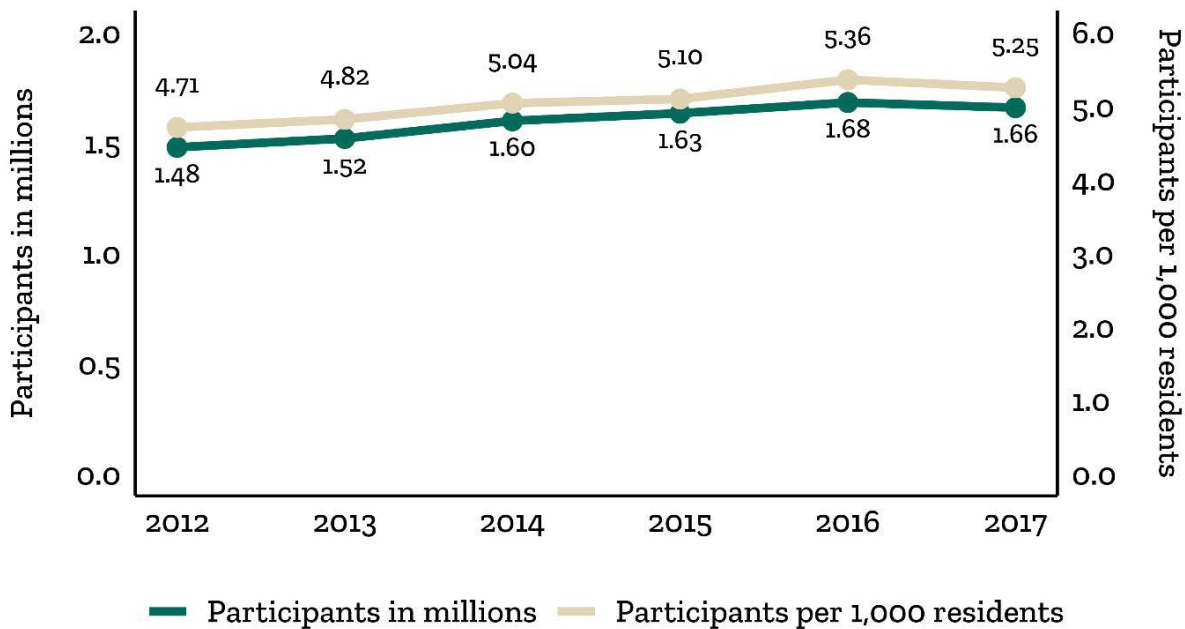
In the remaining sections of this report, we summarize information about section 1915(c) waiver program participants, service use, and expenditures for the 2016 and 2017 waiver program years. In Section II, we examine national-level trends during the most recent five years (2012–2017). We present more detailed national information for 2016 and 2017 in Section III regarding the seven section 1915(c) waiver program target groups, and Section IV includes an analysis of section 1915(c) waiver program participation and expenditures by state. In Section V, we present our conclusions.

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## II. National trends in section 1915(c) waiver program participation and expenditures (2012–2017)

**Participants.** National participation in section 1915(c) waiver programs increased during 2016 relative to 2015, similar to annual increases observed in the previous five years, but then declined slightly in 2017 (Figure II.1).<sup>8</sup> In 2016, the total number of waiver program participants was 1.68 million, while in 2017, it was 1.66 million, representing changes from the previous year of 3.0 and -1.4 percent, respectively (Figure II.2).

**Figure II.1. Section 1915(c) waiver program participants, waiver program years ending in 2012–2017**



Source: Mathematica analysis of CMS 372 annual reports and Census Bureau data from 2015–2017. Data for 2012 – 2014 obtained from Amos et al. (2018).

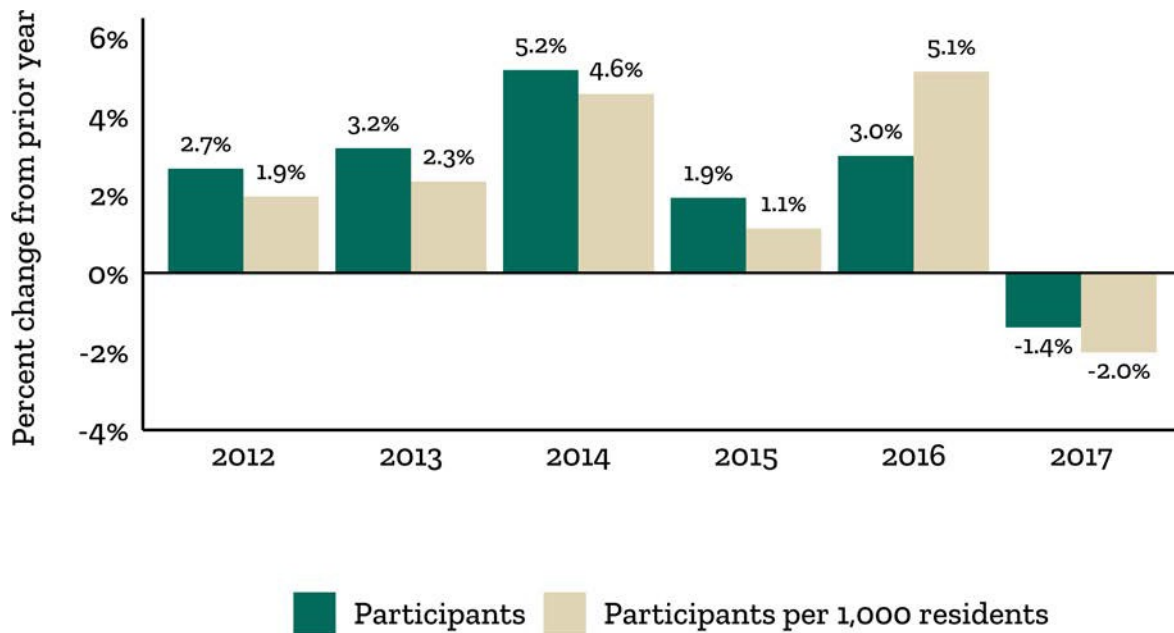
The number of section 1915(c) waiver program participants per 1,000 U.S. residents followed a similar pattern during this same five-year period. For every 1,000 U.S. residents, 5.36 were section 1915(c) waiver program participants in 2016, and 5.25 were participants in 2017 (Figure II.1).<sup>9</sup> These numbers represent annual changes from the prior year in the proportion of residents using section 1915(c) waiver program services of 5.1 percent for 2016 and -2.0 percent for 2017 (Figure II.2).

Through 2015, year-to-year percentage increases in total participants are greater than those for rates per 1,000 residents.

<sup>8</sup> All information in this report is based on 372 reports submitted by May 21, 2020. Reporting for 2017 is more likely to be impacted by data completeness issues relative to earlier years, as described in Appendix A.

<sup>9</sup> To determine the national number of 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, Rhode Island, Vermont, and New Jersey.

**Figure II.2. Change in section 1915(c) waiver program participants, waiver program years ending in 2012–2017**



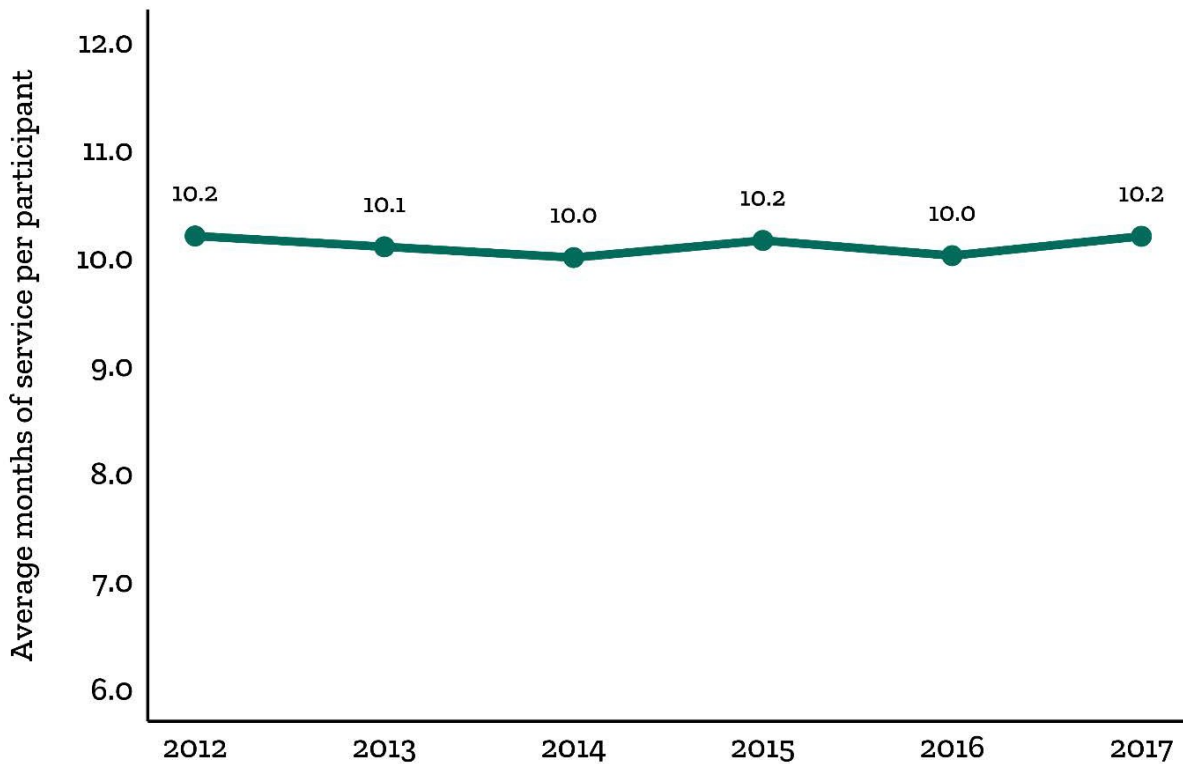
Source: Mathematica analysis of CMS 372 annual reports and Census Bureau data from 2015–2017. Data for 2012 – 2014 obtained from Amos et al. (2018).

For 2012 through 2016, there were increases in total section 1915(c) waiver program participation in each year relative to the prior year. However, the annual growth rate in these years was lower than in 2014. In 2014, we observed a 5.2 percent increase over the prior year in the number of total waiver program participants (Figure II.2). This is more than 2.0 percentage points higher than the growth in the adjacent years (2013 and 2015), and such a high rate of growth has not been observed in any other year since CMS began requiring 372 reporting via the WMS in 2009.<sup>10</sup> The states with the greatest increases during this year were Florida, at 33.5 percent, and Indiana at 18.7 percent.

**Service Use.** Despite overall national growth in section 1915(c) waiver program participation from 2012 to 2017, average months of service use was essentially unchanged during the past five years (Figure II.3). In 2016, the average participant used section 1915(c) waiver program services for 10.0 months of the year; in 2017 the average was 10.2 months. From 2012 through 2017, average section 1915(c) waiver program service use remained between 10.0 months and 10.2 months; the same is true of the period from 2009 through 2011 (Eiken 2013). We explore how this trend differs by section 1915(c) waiver program target groups in Section III.

<sup>10</sup> Reports for 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 2012-2017**



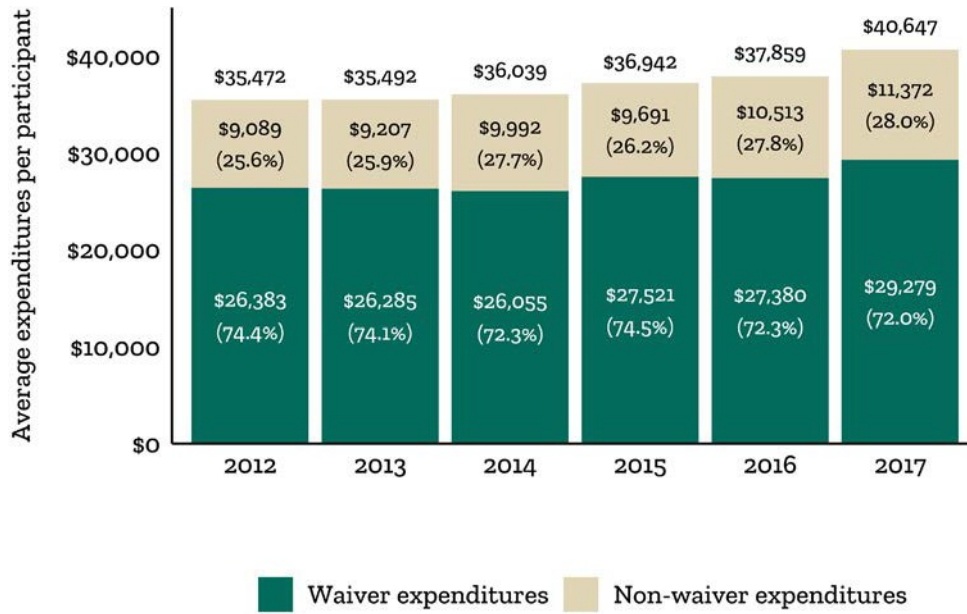
Source: Mathematica analysis of CMS 372 annual reports from 2015–2017. Data for 2012 – 2014 obtained from Amos. et al. (2018).

**Expenditures.** Nationally, annual total waiver program expenditures per section 1915(c) waiver program participant were relatively stable from 2012 through 2014, increased slightly in 2015, and then again in 2017. Annual changes were less than one percent from 2012 through 2014, with average waiver program expenditures remaining steady at approximately \$26,200 (Figure II.4). In 2015, however, expenditures increased relative to 2014 by 5.6 percent, to reach an average of \$27,521 per participant. In 2016, that number decreased marginally by 0.5 percent to \$27,380, and then in 2017 increased markedly by 6.9 percent to reach \$29,279.

Despite these fluctuations, average annual per-person waiver program expenditures remained a relatively stable proportion of total per-person, per-year Medicaid spending during 2012–2017, ranging from 72.0 to 74.5 percent (Figure II.4). We explore these patterns more in depth by key target groups of section 1915(c) waiver program participants, and by state, in the subsequent sections.

This pattern is similar, but not identical, when considering changes in annual average Medicaid non-waiver program expenditures among section 1915(c) waiver program participants during the same period. Average non-waiver program Medicaid expenditures per-person, per-year, were also relatively unchanged during 2012 and 2013, at \$9,089 and \$9,207, respectively. However, in 2014, average non-waiver program expenditures reached \$9,992, dipped slightly in 2015 to \$9,691, and then increased to reach \$10,513 and \$11,372 per participant in 2016 and 2017, respectively (Figure II.4).

**Figure II.4. Average waiver, non-waiver and total Medicaid expenditures per section 1915(c) waiver program participant, waiver program years ending in 2012-2017**



Source: Mathematica analysis of CMS 372 annual reports from 2015–2017. Data for 2012 – 2014 obtained from Amos et al. (2018).



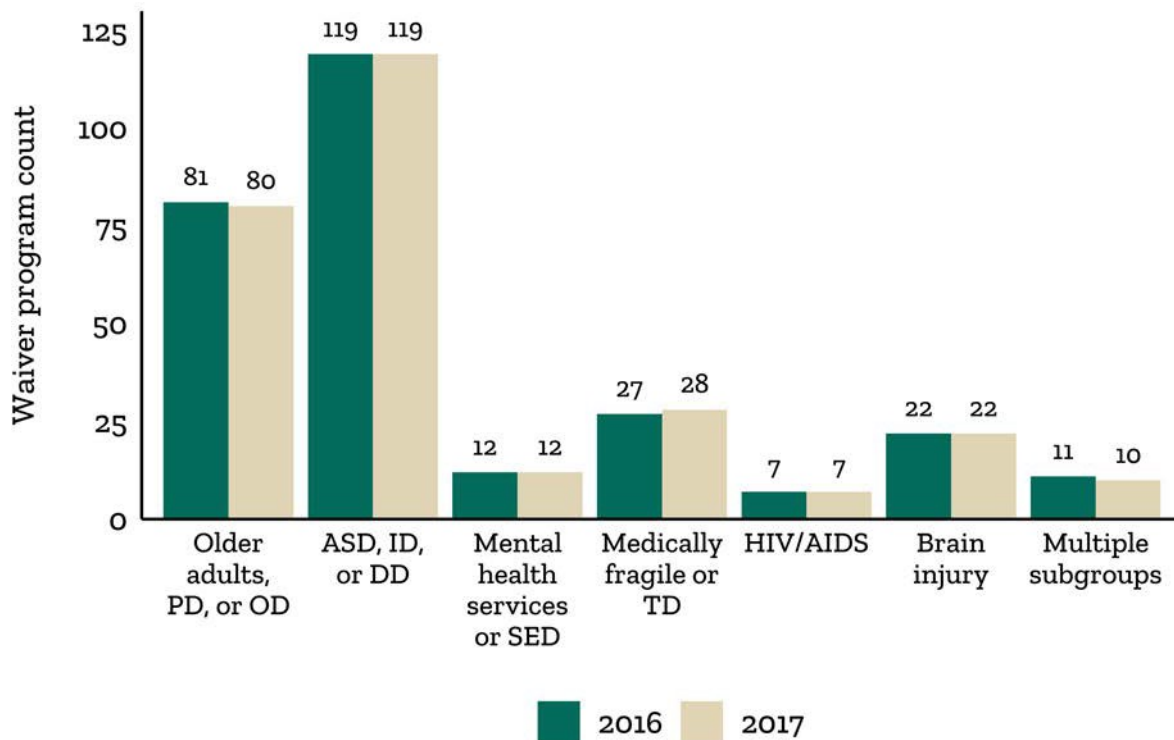
### III. Trends in section 1915(c) waiver program participation and expenditures, by LTSS target group (2016–2017)

**Number and type of section 1915(c) waiver programs.** In 2016, 279 section 1915(c) waiver programs were active across 47 states (Figure III.1), representing a net decline of eight relative to 2015. Ten section 1915(c) waiver programs active in 2015 ended, while two new programs were introduced in 2016.

Arkansas, Ohio, Oklahoma and Wisconsin ended a total of five programs that served the older adult, PD or OD target group (AK 0312, OH 0440, OK 0809, OK 0810, and WI 0368), while Montana, Wisconsin and Wyoming ended three programs serving individuals with ASD, ID, or DD. North Dakota’s *Technology Dependent Medicaid Waiver* (ND 0468) and Pennsylvania’s *HIV/AIDS Home- and Community-Based Waiver* (PA 0192) constituted the remaining programs ended in 2015.

This reduction in the total number of section 1915(c) waiver programs during 2015 was partially offset by the introduction of two new programs in 2016. Utah initiated their *Medically Complex Children’s Waiver* (UT 1246), serving the medically fragile or TD target group, while Washington introduced the *Individual and Family Services Waiver* (WA 1186) for individuals with ASD, ID, or DD.

**Figure III.1. Total active section 1915(c) waiver programs in 2016 and 2017, by LTSS target group**



Source: Mathematica analysis of CMS 372 annual reports from 2016–2017, and WMS characteristics data.

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

In 2017, there was a smaller net decline in active section 1915(c) waiver programs, by just one, for a total of 278 programs. All but two of the waiver programs active in 2016 remained so in 2017. In 2017, New York ended its *Long-Term Care Health Program* waiver program (NY 0034) that served the older adults,

PD, or OD target group. Florida's *Long-Term Care Managed Care* waiver program (FL 0962), which served multiple subgroups, including older adults, individuals with physical disabilities, brain injuries, HIV/AIDS or medically fragile individuals also was not considered active in 2017 for the purposes of this report.<sup>11</sup> The changes in these two waiver programs decreased the number of section 1915(c) waiver programs serving the older adults, PD and OD target group from 81 to 80, and those serving multiple subgroups from 11 to 10.

Despite the ending or inactivity of the waiver programs in New York and Florida, the total number of active section 1915(c) waiver programs only declined by one in 2017, to a total of 278. This is because North Dakota added the *Technology Dependent Medicaid Waiver* (ND 1266), a new section 1915(c) waiver program for ventilator dependent individuals. This new waiver program increased the total number of waiver programs serving the medically fragile or TD target group from 27 to 28 in 2017.

**Participants.** The national total number of section 1915(c) waiver program participants declined slightly from 2016 to 2017, from 1.68 million waiver program participants to 1.66 million (a 1.4 percent decline), as discussed in Section II.

In 2016, two target groups—older adults, PD, or OD and ASD, ID, or DD—together included 1.43 million participants, representing approximately 85 percent of all waiver program participants (43.0 percent and 42.3 percent, respectively in 2016) (Figure III.2.). Waiver programs serving multiple subgroups had the third largest share, comprising 189,289 participants or 11.3 percent of the total. Waiver programs serving the medically fragile or TD, mental health services or SED, HIV/AIDS, and brain injuries were much smaller, ranging from 19,001 to 10,227 participants.

Declines in waiver program participants between 2016 and 2017 were concentrated in three section 1915(c) waiver program target groups: (1) multiple subgroups (declined 31 percent, representing 58,530 participants), (2) HIV/AIDS (declined 4.1 percent, accounting for 386 participants) and (3) older adults, PD, or OD (declined 0.1 percent, corresponding to 567 participants). In particular, the notable drop for the population enrolled in waivers serving multiple subgroups is attributed primarily to the inactivity of the *Long-Term Care Managed Care* waiver in Florida (FL 0962) in 2017 (which served 66,130 participants in 2016). After 2016, individuals eligible for Florida's section 1115 Medically Needy program for Aged and Disabled (MEDS-AD) waiver demonstration were no longer eligible for the *Long-Term Care Managed Care* waiver. In turn, the decline in the older adults, PD, or OD target group is in part due to the termination of New York's *Long-Term Care Health Program* (NY 0034) in 2016 (which served 22,174 participants in 2016). The participants in this New York waiver program were ultimately transitioned into New York's section 1115(a) demonstration waiver, and were eligible to continue to receive LTSS as part of the state's Mainstream Managed Care (MMC) or Managed Long Term Care (MLTC) plans. These declines in waiver program participants offset growth in waiver program participants across the remaining target groups.

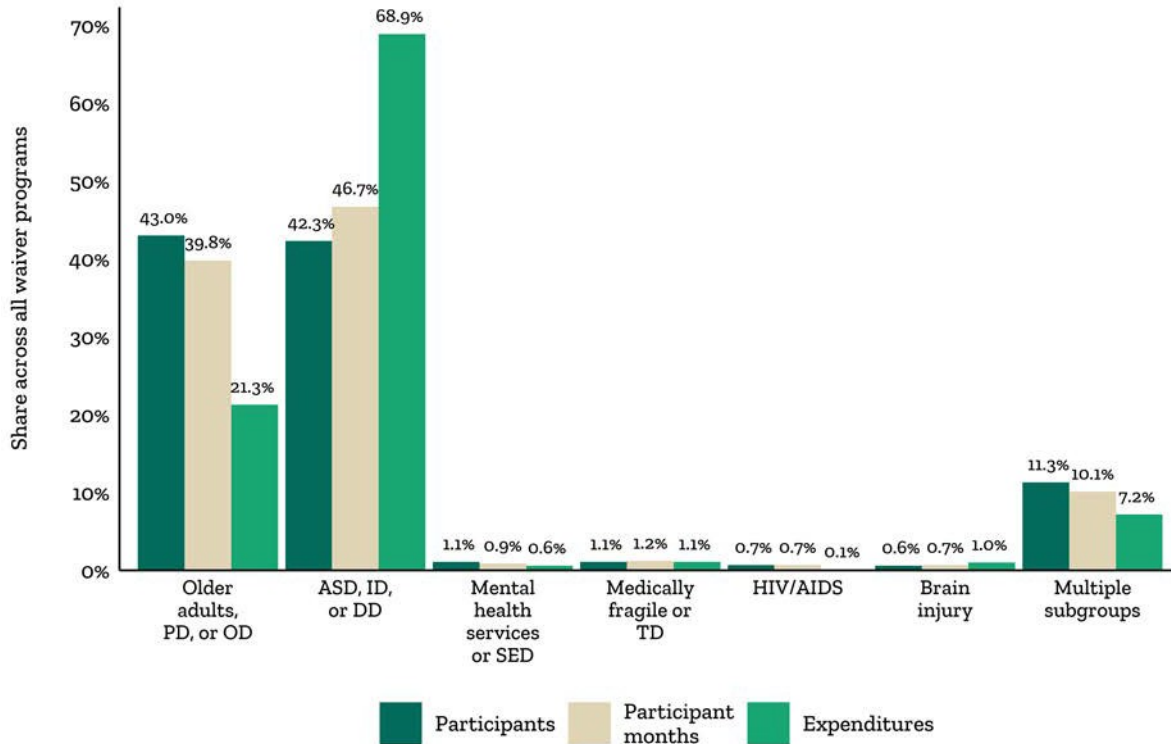
Despite declines in specific target groups, the proportion of participants in each waiver program type remained relatively unchanged from 2016 to 2017 (Figure III.3.). Again, two groups—older adults, PD, or PD and ASD, ID, or DD waiver programs—accounted for about 88.2 percent of overall waiver program participants (43.6 percent and 44.6 percent, respectively). Multiple subgroups remained the third largest group enrolled in waiver programs, while enrollment in waiver programs serving people receiving

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<sup>11</sup> This waiver was later found to be extended but appeared expired and had no CMS 372 report submitted as of the time of these analyses. For these reasons, it was considered inactive for 2017 in this report. Further details regarding CMS 372 data cut-offs and report methodology are described in Appendix A.

mental health services or with SED grew by 31.8 percent, becoming the fourth largest waiver program type in size. The waiver programs serving individuals who were (1) medically fragile or TD, had (2) HIV/AIDS, or (3) brain injuries, comprised the three smallest waiver program types in 2017 (Figure III.3).

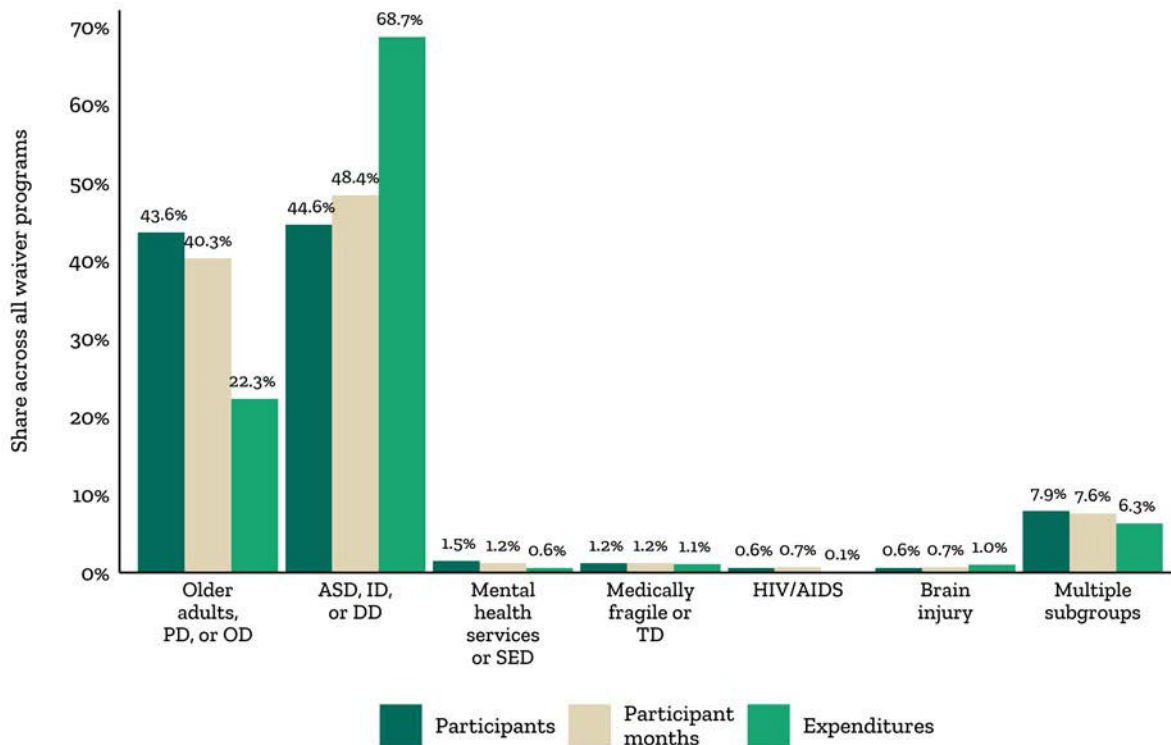
**Figure III.2. Distribution of section 1915(c) waiver program participants, participant months, and waiver program expenditures by LTSS target group, for waiver program year ending in 2016**



Source: Mathematica analysis of CMS 372 annual reports from 2016, and WMS characteristics data.

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

**Figure III.3. Distribution of section 1915(c) waiver participants, participant months, and waiver program expenditures by LTSS target group, for waiver program year ending in 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2017, and WMS characteristics data.

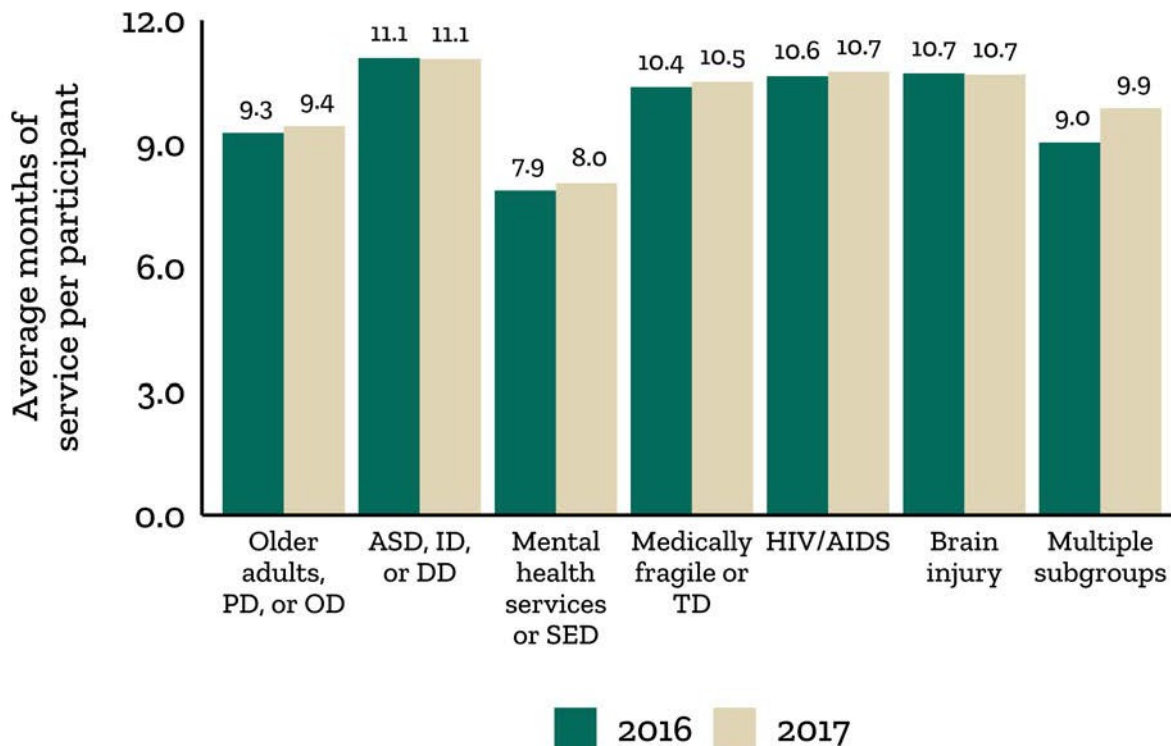
ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technologically dependent.

**Service Use.** Nationwide, the average number of months that participants received section 1915(c) waiver services during the year remained stable at 10.0 months in 2016 and 10.2 months in 2017. In 2016, average months of service use varied by target group. For example, individuals enrolled in section 1915(c) waiver programs for people receiving mental health services or with SED received waiver program services for an average of 7.9 months in 2016, compared to 11.1 months for ASD, ID, or DD populations (Figure III.4). Similar trends were also observed in 2017, with these two groups experiencing the lowest and highest average months of service use, respectively.

Among the other target groups, waiver programs serving people with brain injuries, HIV/AIDS, and who were medically fragile or TD had relatively similar average months of service at 10.7, 10.6, and 10.4 months, respectively, in 2016. Waiver programs serving the older adult, PD, or OD target group had slightly fewer months of service, at an average of 9.3 months. In 2017, average months were essentially unchanged for these four target groups.

In contrast, the waiver programs serving multiple subgroups provided an average of 9.0 months of services in 2016, which increased markedly to 9.9 months in 2017, an increase of 10 percent. However, it is important to place changes among the smaller target groups in context. Because the multiple subgroups target group includes 130,759 participants, even after an increase of 10 percent their total service use comprises only 7.6 percent of all months in 2017 (Figure III.3).

**Figure III.4. Average number of participant months among people receiving section 1915(c) waiver program services by target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017, and WMS characteristics data.

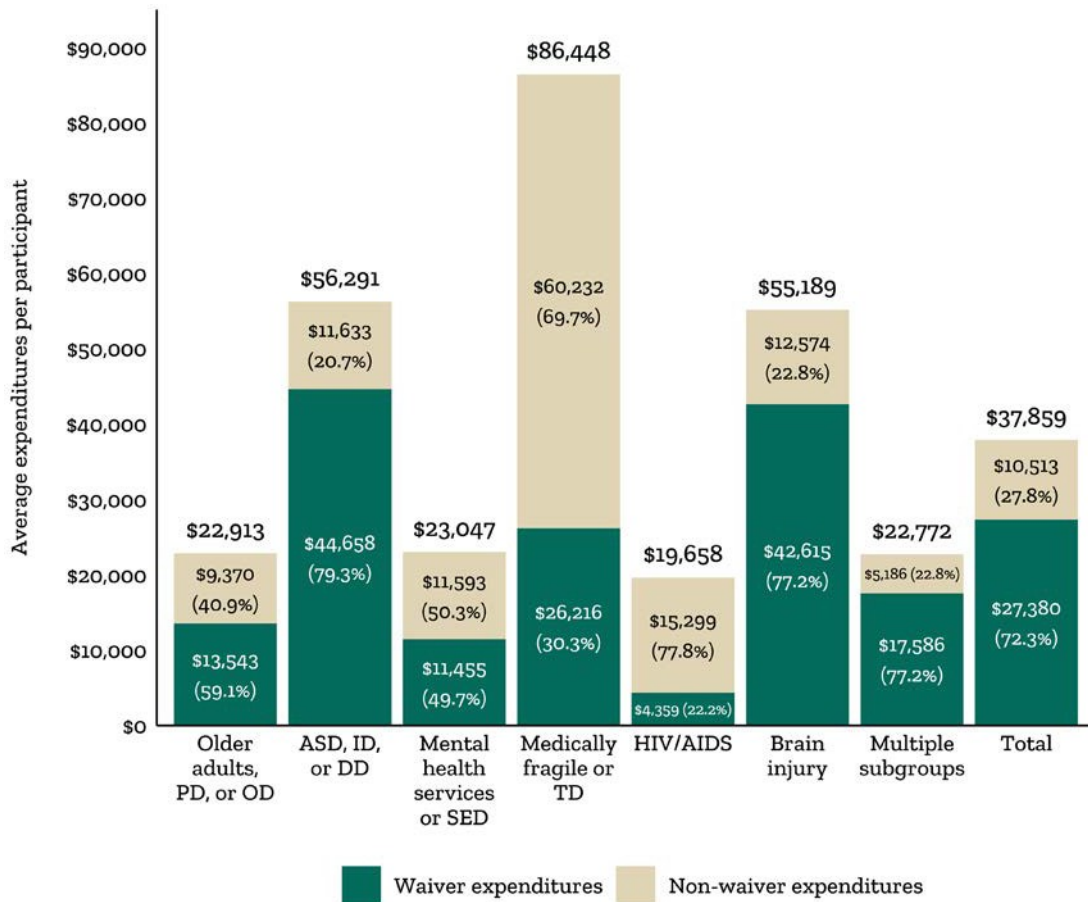
ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technologically dependent.

**Expenditures.** Overall, annual average waiver program expenditures per participant grew by 6.9 percent between 2016 and 2017, from \$27,380 per participant to \$29,279 (Figures III.5. and III.6.). Across target groups, average waiver program expenditures varied markedly. In 2016, section 1915(c) waiver program expenditures per participant were highest for the ASD, ID, or DD target group, at approximately \$44,658 in 2016, followed by brain injuries (\$42,615), medically fragile or TD (\$26,216), multiple subgroups (\$17,586), older adults, PD, or OD (\$13,543), mental health services or SED (\$11,455), and HIV/AIDS (\$4,359) (Figure III.5). Both the average waiver program expenditures and relative spending by target groups did not change noticeably in 2017.

When we assess this distribution of expenditures across the target groups, the ranking of the groups changes. While the ASD, ID, or DD target group had the highest share of total waiver program expenditures at 68.9 percent in 2016, the older adults, PD, or OD target group was the next highest (21.3 percent), followed by multiple subgroups (7.2 percent) (Figure III.2). These percentages reflect how the older adults, PD, or OD and multiple subgroups target groups include greater numbers of participants relative to the smaller target groups. Even though the older adult, PD or OD target group have average expenditures lower than most other groups, they still make up a larger proportion of overall expenditures because of the number of people in this group. The same pattern is observed in 2017, with the ASD, ID, or DD target group reflecting 68.7 percent of all expenditures, followed by older adults, PD, or OD (22.3

percent), and multiple subgroups (6.3 percent). In both years, the remaining target groups (medically fragile or TD, mental health services or SED, brain injuries, and HIV/AIDS) each had 1.1 percent or less share of total expenditures (Figures III.2 and III.3).

**Figure III.5. Average waiver, non-waiver, and total Medicaid expenditures per section 1915(c) waiver program participant by LTSS target group, for waiver program year ending in 2016**

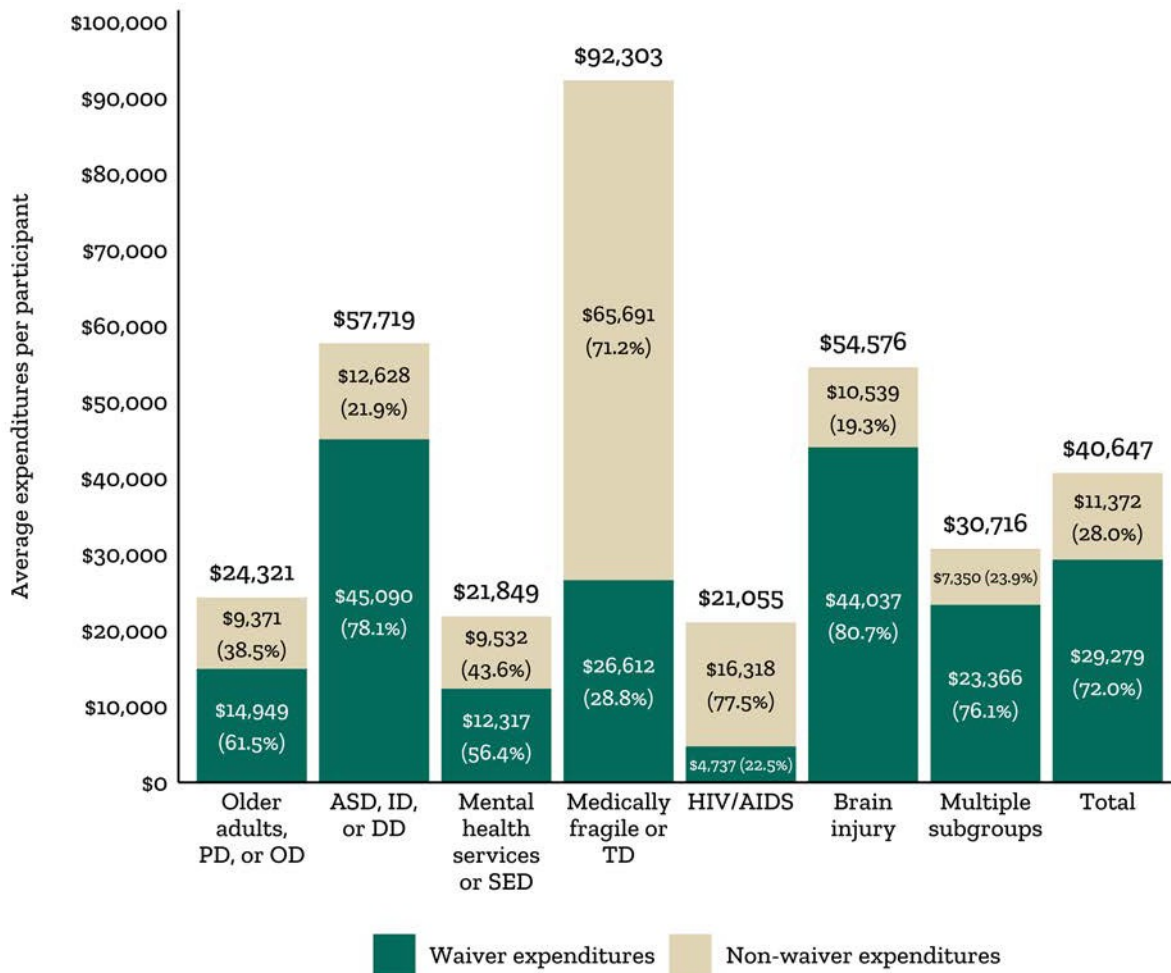


Source: Mathematica analysis of CMS 372 annual reports from 2016, and WMS characteristics data.

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

In terms of average non-waiver program expenditures per participant, there was an overall increase for all participants, from \$10,513 in 2016 to \$11,372 in 2017, an increase of 8.2 percent. With regard to trends across target groups, however, the pattern is quite different relative to average waiver program expenditures. Instead of the ASD, ID, or DD group, it is waiver programs serving people who are medically fragile or TD with the highest average non-waiver program expenditures, at approximately \$60,232 in 2016, followed by the HIV/AIDS target group (\$15,299). The average non-waiver program expenditures among the brain injury, ASD, ID, or OD, and mental health services or SED target groups are quite similar, at \$12,574, \$11,633, and \$11,593 respectively, in 2016. The older adults, PD, or OD and multiple subgroups target groups had the lowest average non-waiver program expenditures, at \$9,370 and \$5,186. Although average non-waiver program expenditure amounts increased in 2017, the trends among target groups did not change (Figure III.6).

**Figure III.6. Average waiver, non-waiver, and total Medicaid expenditures per section 1915(c) waiver program participant by LTSS target group, for waiver program year ending in 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2017, and WMS characteristics data.

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

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## IV. State variation in section 1915(c) waiver program participation and expenditures (2016–2017)

Section 1915(c) waiver programs vary across states because they use these programs to serve different LTSS target groups with diverse levels of need, and provide different services that vary considerably. In this section, we describe state-level trends in section 1915(c) waiver program participation and expenditures for 2016 and 2017, as well as state-level trends for each of the seven LTSS target groups during this same time period.

To understand trends 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 participants per 1,000 total residents per state. We obtained information on total residents per state from the U.S. Census Bureau (Appendix A). Similar to Sections II and III for expenditures, we calculated average expenditures per section 1915(c) waiver program participant for each state in each year.

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

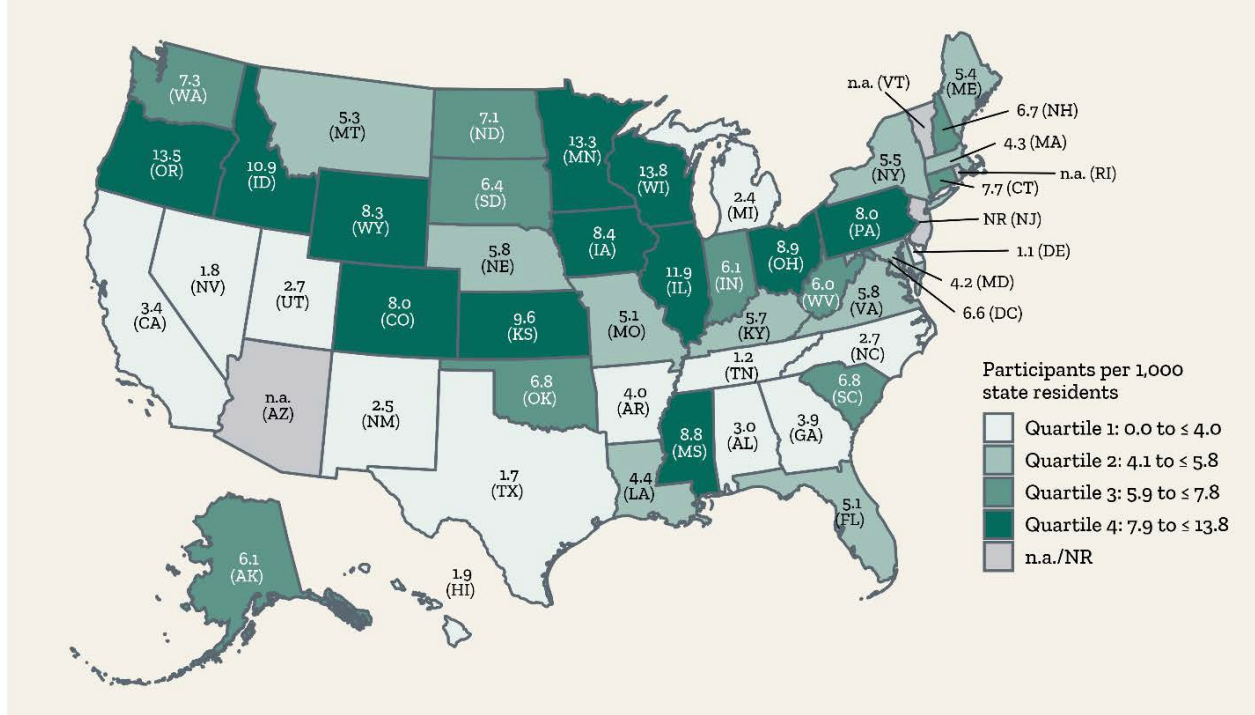
**Participants.** In 2016, the total number of section 1915(c) waiver program participants ranged from approximately one per 1,000 state residents (Delaware and Tennessee) to almost 14 (Wisconsin), and the U.S. total across all 47 states<sup>12</sup> was 5.4 participants per 1,000 state residents (Figure IV.1; Appendix Table B.2). Twenty-eight of the 47 states (60 percent) with section 1915(c) waiver programs had higher rates than the rate for all states. Those in the lowest quartile of section 1915(c) waiver program participants per 1,000 state residents (with fewer than 4.0 participants per 1,000 residents) were Delaware, Tennessee, Texas, Nevada, Hawaii, Michigan, New Mexico, Utah, North Carolina, Alabama, California, and Georgia.<sup>13</sup> Among those in the highest quartile of section 1915(c) waiver program participants per 1,000 state residents (where participants per 1,000 state residents fell between 7.9 and 13.8) were Colorado, Pennsylvania, Wyoming, Iowa, Mississippi, Ohio, Kansas, Idaho, Illinois, Minnesota, Oregon, and Wisconsin. While these trends do provide insight into how states use section 1915(c) waiver programs to provide LTSS, it is important to keep in mind the larger policy context and other authorities states may be using to provide similar services that are reflected in these trends. For example, although Tennessee has the second-lowest number of section 1915(c) participants per 1,000 residents, managed LTSS are provided to additional Medicaid beneficiaries via TennCare, the state's section 1115(a) demonstration.

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<sup>12</sup> As described in Section I, Arizona, Rhode Island, and Vermont did not operate any section 1915(c) waiver programs in 2016 or 2017, and New Jersey did not have an accepted report for the one active waiver the state operated in 2016 and 2017, so these states are not included in totals in this section.

<sup>13</sup> Values were rounded to one decimal place to determine quartiles, and states were categorized into quartiles based on rounded participant counts.

**Figure IV.1. Section 1915(c) waiver program participants per 1,000 state residents, for waiver program year ending in 2016**

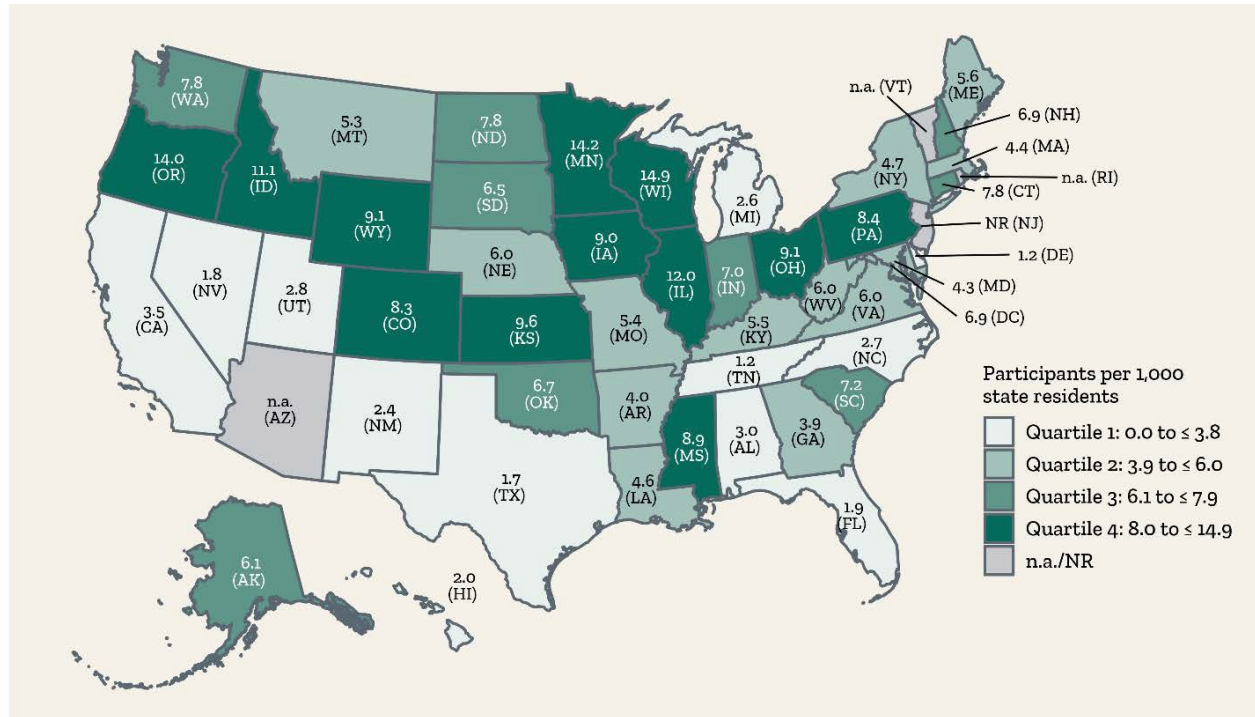


Source: Mathematica analysis of CMS 372 annual reports from 2016 and Census Bureau data.

n.a. = not applicable; NR = not reported.

The number of section 1915(c) waiver program participants per 1,000 state residents in 2017 was similar to that in 2016. The U.S. total was 5.3 participants per 1,000 residents, down from 5.4 in 2016, and ranged from around one (Tennessee and Delaware) to about 15 (Wisconsin) (Figure IV.2; Appendix Table B.1). Twenty-nine of the 47 states (62 percent) with section 1915(c) waiver programs had higher rates than the rate across all states, compared to 28 states (60 percent) in 2016. The states that fell into the lowest quartile of waiver program participants per 1,000 state residents in 2017 included the same states as 2016, except for the addition of Florida (replacing Georgia). The number of waiver program participants per 1,000 state residents in Florida changed from approximately 5 in 2016 to 2 in 2017, which dropped it to the lowest quartile of states in 2017. This change is due to the inactivity of Florida’s *Long-Term Care Managed Care* 1915(c) waiver program (FL 0962), which served around 66,000 participants, as noted in Section III. The rank order of states in the highest quartile of section 1915(c) waiver program participants per 1,000 state residents changed slightly in 2017 compared to 2016 but the list of states remained the same in both years.

**Figure IV.2. Section 1915(c) waiver program participants per 1,000 state residents, for waiver program year ending in 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2017 and Census Bureau data.

n.a. = not applicable; NR = not reported.

**Waiver expenditures.** As noted previously, in 2016, the U.S. total average waiver expenditures per waiver program participant was \$27,380, but this average masks considerable state variation (Figure IV.3; Appendix Table B.2). The average in each state ranged from \$1,778 in Oregon to \$117,972 in Delaware. These two states were extremes at the low and high range of average expenditures. Specifically, Illinois, which had the second lowest average expenditures, spent \$11,864 more per participant on average than Oregon in 2016 (or a total of \$13,642 per waiver program participant). Tennessee, which had the second highest average expenditures, spent \$35,860 less per participant on average than Delaware in 2016 (or a total of \$82,112 per participant). Oregon had particularly low expenditures because they provide a substantial proportion of HCBS to eligible Medicaid beneficiaries through the Community First Choice section 1915(k) State Plan option.<sup>14</sup> In contrast, Delaware has particularly high expenditures because there was only one waiver program in 2016 (DE 0009 – *DDDS Lifespan Waiver*), serving a small number (1,085) of individuals with ASD, ID, or DD who had relatively high average waiver program expenditures.

Twenty-seven of the 47 states (57 percent) with section 1915(c) waiver programs had higher average expenditures than the U.S. total average (\$27,380) in 2016. States in the lowest quartile of average expenditures per participant in 2016 were Oregon, Illinois, Washington, Florida, Mississippi, South Carolina, Idaho, Iowa, Colorado, Oklahoma, Wyoming, and Indiana. Among those in the highest quartile

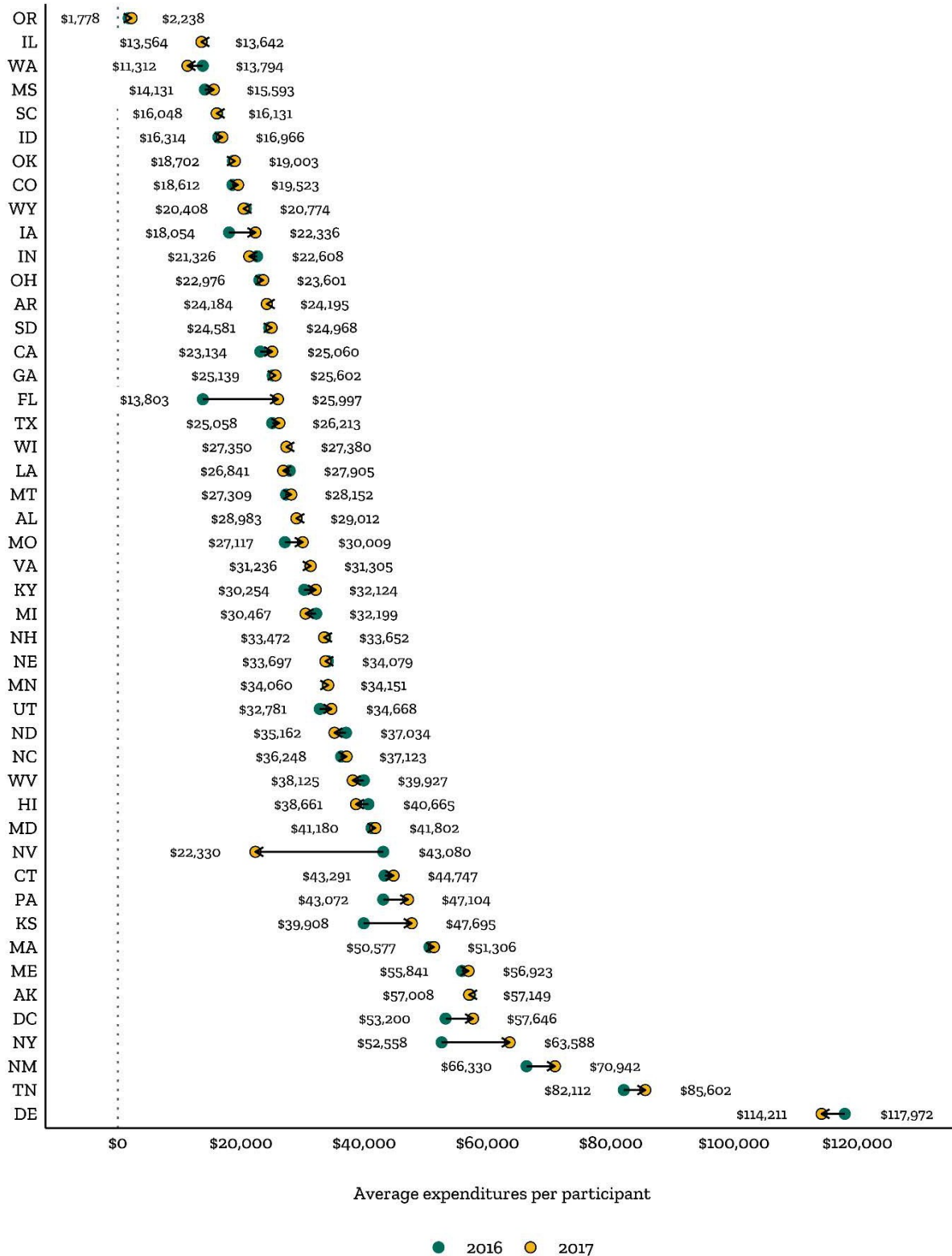
<sup>14</sup> <https://www.medicaid.gov/sites/default/files/2019-12/or-cfc-spa-matrix.pdf>

of average expenditures were Maryland, Pennsylvania, Nevada, Connecticut, Massachusetts, New York, District of Columbia, Maine, Alaska, New Mexico, Tennessee, and Delaware.

In 2017, U.S. total average waiver expenditures per participant was \$29,279 (Figure IV.3; Appendix Table B.1), up \$1,899 from 2016. Oregon and Delaware once again had the lowest and highest average expenditures (\$2,238 and \$114,211, respectively), although the difference between them narrowed in 2017 (\$111,973 compared to \$116,194 in 2016). Twenty-four of the 47 states (51 percent) with waiver programs in 2017 had higher average waiver expenditures than the U.S. total (\$29,279), which is a slight decline compared to the number of states (27) above the U.S. total in 2016.

The states in the lowest quartile of average waiver expenditures per participant in 2017 included the same states as 2016, except Nevada replaced Florida. Similarly, the states in the highest quartile of average expenditures per participant included the same states in 2017 as 2016, except for the addition of Kansas (replacing Nevada). The states with the largest declines in average waiver expenditures per section 1915(c) waiver program participant between 2016 and 2017 were Nevada (48 percent) and Washington (18 percent). In Nevada, the change was driven by a large decline in expenditures for the *HCBS Waiver for Individuals with Intellectual and Developmental Disabilities* (NV 0125) between 2016 and 2017, and in Washington, it was driven by a large decline in expenditures for the *COPEs Waiver* program (WA 0049). The decrease in Washington may be due to the state's use of a Community First Choice section 1915(k) State Plan option to deliver some HCBS. States with the largest increases in average waiver expenditures per participant between 2016 and 2017 were Missouri (11 percent), Kansas (20 percent), New York (21 percent), Iowa (24 percent), Oregon (26 percent), and Florida (88 percent). In Florida, the marked increase is due to the temporary inactivity of FL 0962 in 2017; during 2016 this waiver served the highest proportion of section 1915(c) waiver participants in the state (66,000) and included individuals with brain injuries and the medically fragile. Despite serving populations with complex care needs, average waiver expenditures for FL 0962 in 2016 were relatively low, at \$7,712, compared to those for Florida's *Developmental Disabilities Individual Budgeting Waiver* (FL 0867), which served the next highest proportion of 1915(c) participants (30,120) and had much higher average waiver expenditures of \$29,847. Florida's statewide average waiver expenditures in 2017 are thus a reflection of the higher expenditures per participant for FL 0867.

**Figure IV.3. Average waiver expenditures per section 1915(c) waiver program participant, for waiver program years ending in 2016 and 2017**



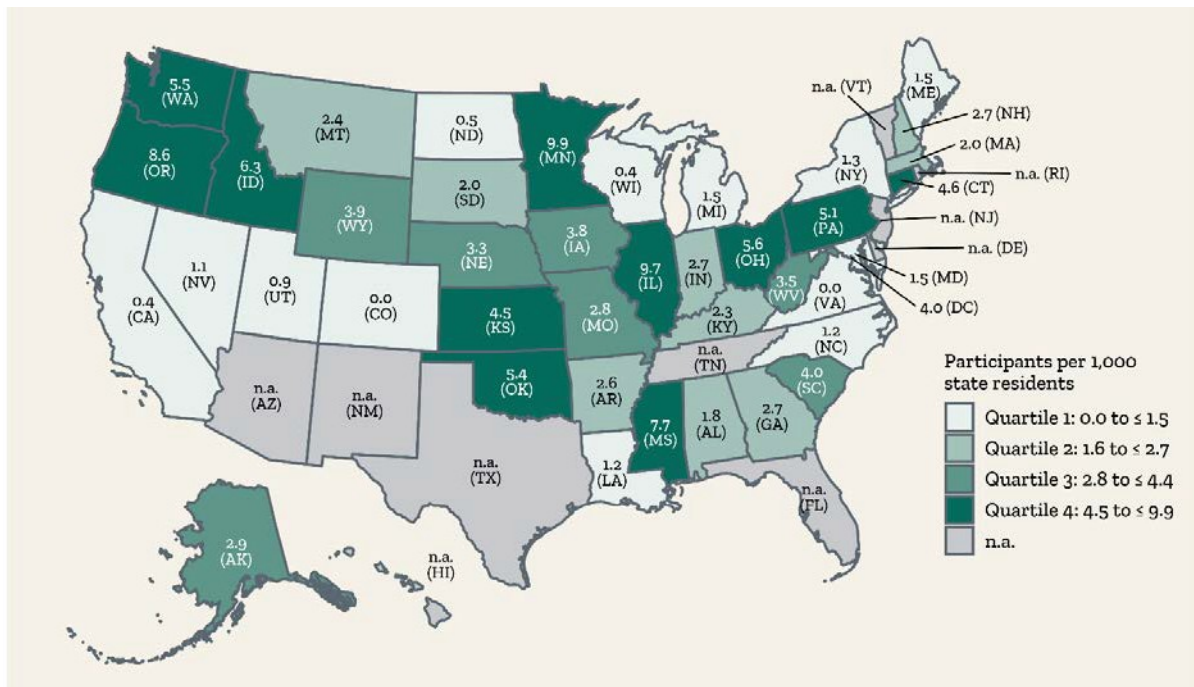
Source: Mathematica analysis of CMS 372 annual reports from 2016-2017.

Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Those with small decreases in average expenditures included: South Carolina (from \$16,131 to \$16,048), Arkansas (from \$24,195 to \$24,184), Wisconsin (from \$27,380 to \$27,350), Alabama (from \$29,012 to \$28,983), New Hampshire (from \$33,652 to \$33,472), Nebraska (from \$34,079 to \$33,697), and Alaska (from \$57,149 to \$57,008). Those with small increases in average expenditures included: Oregon (from \$1,778 to \$2,238), Oklahoma (from \$18,702 to \$19,003), South Dakota (from \$24,581 to \$24,968), Georgia (from \$25,139 to \$25,602), Virginia (from \$31,236 to \$31,305), and Minnesota (from \$34,060 to \$34,151).

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

**Participants.** Forty-one of the 47 states (87 percent) with section 1915(c) waiver programs in 2016 provided services for the older adult, PD, or OD target group. Delaware, Florida, Hawaii, New Mexico, Tennessee, and Texas did not operate any waiver programs for this LTSS target group in 2016. The number of older adult, PD, or OD waiver program participants per 1,000 state residents ranged from less than one (Virginia and Colorado tied for lowest) to almost 10 (Minnesota), and the U.S. rate across all 41 states was 2.2 per 1,000 state residents (Figure IV.4; Appendix Table B.5). A total of six states served fewer than one older adult, PD, or OD section 1915(c) waiver program participant per 1,000 state residents (Virginia, Colorado, California, Wisconsin, North Dakota and Utah). Twenty-five of the 41 states (61 percent) had higher rates than the U.S. rate (2.2) in 2016. States in the lowest quartile with fewer than 1.5 participants per 1,000 residents were Virginia, Colorado, California, Wisconsin, North Dakota, Utah, Nevada, Louisiana, North Carolina, New York, Maine, and Michigan. Those in the highest quartile (where participants were greater than or equal to 4.5 per 1,000 residents) were Kansas, Connecticut, Pennsylvania, Oklahoma, Washington, Ohio, Idaho, Mississippi, Oregon, Illinois, and Minnesota.

**Figure IV.4. Section 1915(c) waiver program participants per 1,000 state residents for the older adults, PD, or OD target group, for waiver program year ending in 2016**

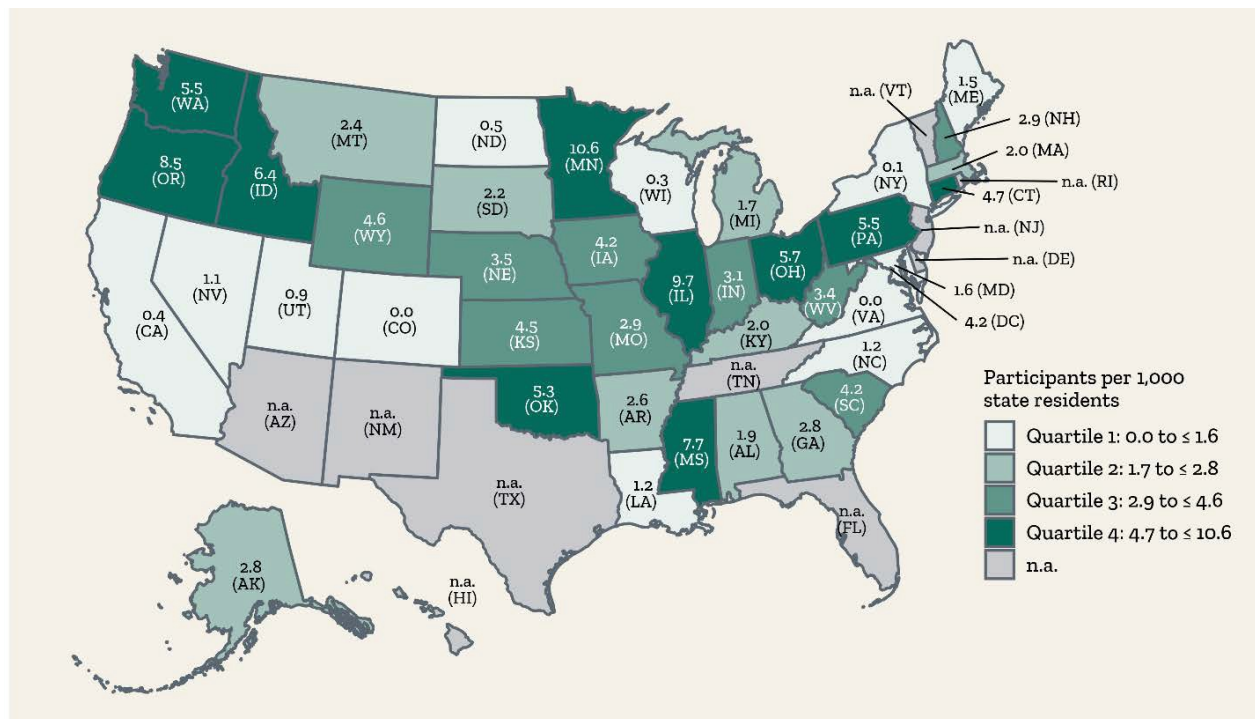


Source: Mathematica analysis of CMS 372 annual reports from 2016, WMS characteristics, and Census Bureau data.

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

The 2017 data show the same patterns for section 1915(c) waiver programs for older adults, PD, or OD. The same number of states operated waiver programs for this LTSS target group in 2017 as in 2016. The U.S. total number of waiver program participants per 1,000 state residents was again 2.2, ranging from 0.0 in Virginia and Colorado to approximately 11 in Minnesota (Figure IV.5; Appendix Table B.4). Seven states served fewer than one older adult, PD, or OD waiver program participant per 1,000 state residents (Virginia, Colorado, New York, Wisconsin, California, North Dakota and Utah). The only difference in these states in 2017 compared to 2016 was the addition of New York to the group of states serving fewer than one participant per 1,000 state residents. As noted in Section III, NY 0034 ended in 2016, and participants were transitioned into the state’s section 1115(a) demonstration and were eligible to receive LTSS through New York’s MMC and MLTC plans. This waiver program previously served approximately 22,000 older adults, PD, or OD, resulting in fewer people in this LTSS target group in 2017. Similar to 2016, 25 of the 41 states (61 percent) had higher rates the U.S. rate in 2017 (2.2). Most of the same states were in the lowest and highest quartiles of section 1915(c) waiver program participants per 1,000 state residents for this target group in 2017, so the trends were relatively stable across all states between the two years.

**Figure IV.5. Section 1915(c) waiver program participants per 1,000 state residents for the older adults, PD, or OD target group, for waiver program year ending in 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2017, WMS characteristics, and Census Bureau data.

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

**Waiver expenditures.** In 2016, the U.S. total average waiver expenditures per older adult, PD or OD waiver program participant was \$13,543. Average waiver expenditures per section 1915(c) waiver program participant for this LTSS target population ranged from \$913 in Oregon to \$37,321 in Kansas (Figure IV.6; Appendix Table B.4). Like the findings for all section 1915(c) waiver programs, Oregon had particularly low waiver expenditures in 2016; Washington, which had the second lowest average expenditures, spent \$3,857 more per participant on average than Oregon in 2016 (or a total of \$4,770 per older adult, PD, or OD waiver program participant). States in the lowest quartile of average waiver

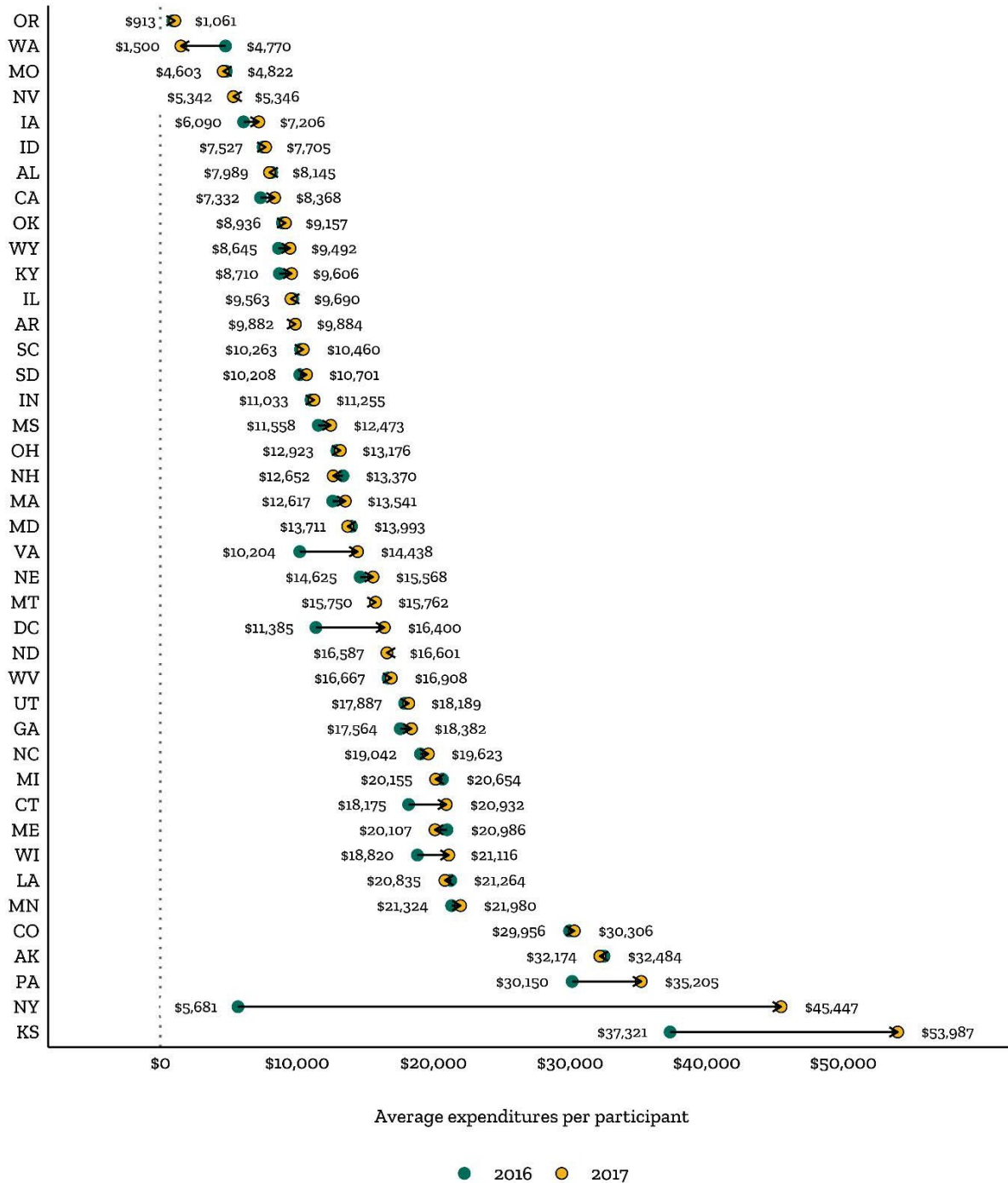
expenditures per waiver program participant were Oregon, Washington, Missouri, Nevada, New York, Iowa, California, Idaho, Alabama, Wyoming, and Kentucky. Eighteen of 41 states (44 percent) had average waiver expenditures greater than the U.S. total average. Among those in the highest quartile of average waiver expenditures were Connecticut, Wisconsin, North Carolina, Michigan, Maine, Louisiana, Minnesota, Colorado, Pennsylvania, Alaska, and Kansas.

U.S. annual total average waiver expenditures per older adult, PD, or OD waiver program participant in 2017 was \$14,949. This was an increase of \$1,406 (10 percent) over the amount in 2016 for this target group. Average waiver expenditures ranged from a low of \$1,061 in Oregon to a high of \$53,987 in Kansas in 2017, and 19 of 41 states (46 percent) had average waiver expenditures greater than the U.S. total average. The states in the lowest quartile of average waiver expenditures per older adult, PD, or OD remained the same in 2017 as in 2016, except for the addition of Illinois and Oklahoma to the lowest quartile in 2017 (replacing Kentucky and New York).

The major difference in states in the highest quartile for this LTSS target group was that North Carolina dropped out of this quartile in 2017 and New York moved into this quartile in 2017, having not been within it in 2016. The state with the largest decline in average waiver expenditures per older adult, PD, or OD section 1915(c) waiver program participant between 2016 and 2017 was Washington (69 percent decline). The decline in Washington is associated with a marked decrease in average waiver expenditures for the *COPES Waiver* program (WA 0049), which is the largest waiver serving the older adult, PD, or OD population in the state. Average waiver expenditures among *COPES Waiver* program participants declined from around \$4,700 in 2016 to \$460 in 2017; however, average non-waiver expenditures increased from \$14,524 to \$23,359 during the same period, suggesting a change in services. These changes may be due to Washington's use of a Community First Choice section 1915(k) State Plan option to deliver some HCBS. Among the states with the largest increases from 2016 to 2017 were Wisconsin (12 percent), California (14 percent), Connecticut (15 percent), Oregon (16 percent), Pennsylvania (17 percent), Iowa (18 percent), Virginia (41 percent), District of Columbia (44 percent), Kansas (45 percent), and New York (700 percent). As discussed previously, during 2016, a section 1915(c) waiver serving this target group in New York ended (NY 0034), and participants transitioned to the state's section 1115(a) demonstration, and were eligible to continue to receive LTSS as part of the state's MMC and MLTC plans. The state's remaining section 1915(c) waiver program serving this target group, New York's *Nursing Home Transition & Diversion Medicaid Waiver* (NY 0444) had far fewer participants with comparatively high average waiver expenditures.



**Figure IV.6. Average waiver expenditures per section 1915(c) waiver program participant for the older adults, PD, or OD target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Those with small decreases in average expenditures included: Missouri (from \$4,822 to \$4,603), Nevada (from \$5,346 to \$5,342), Alabama (from \$8,145 to \$7,989), Illinois (from \$9,690 to \$9,563),

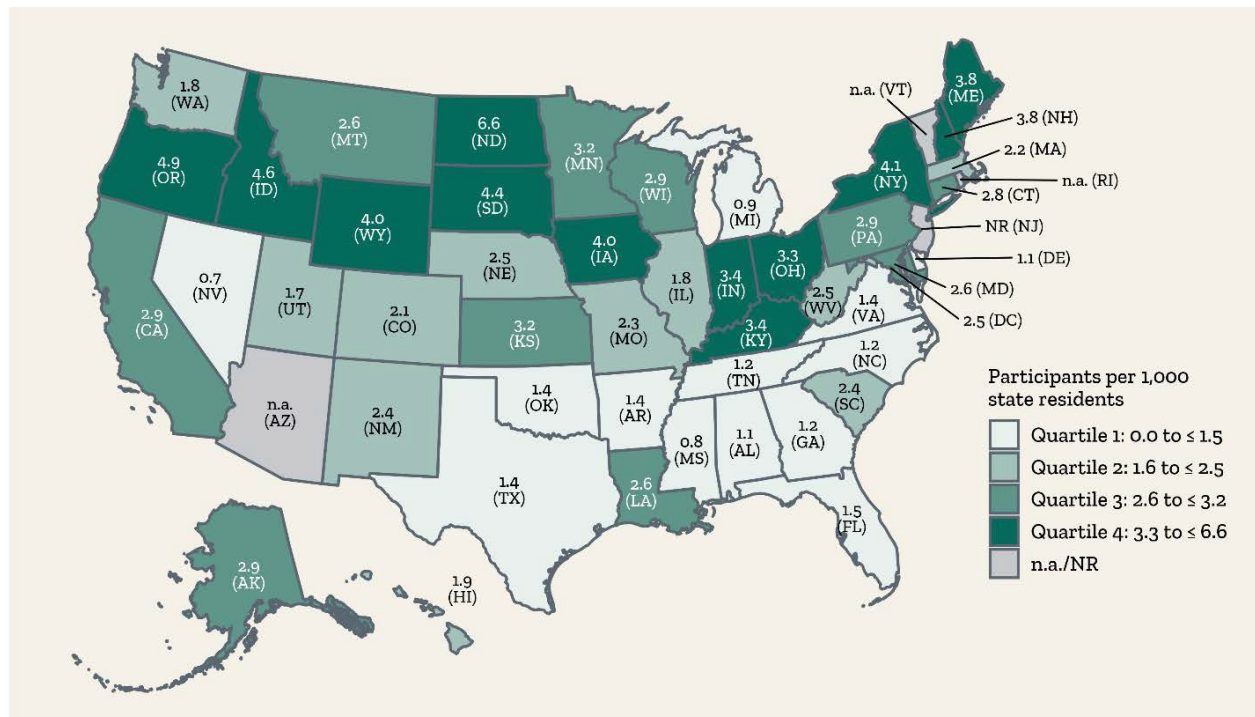
and North Dakota (from \$16,601 to \$16,587). Those with small increases in average expenditures included: Oregon (from \$913 to \$1,061), Idaho (from \$7,527 to \$7,705), Oklahoma (from \$8,936 to \$9,157), Arkansas (from \$9,882 to \$9,884), South Carolina (from \$10,263 to \$10,460), Indiana (from \$11,033 to \$11,255), Ohio (from \$12,923 to \$13,176), Montana (from \$15,750 to \$15,762), West Virginia (from \$16,667 to \$16,908), and Utah (from \$17,887 to \$18,189).

OD = other disabilities; PD = physical disabilities.

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

**Participants.** All 47 states with active section 1915(c) waiver programs in 2016 had waivers for the ASD, ID, or DD target group. The number of participants per 1,000 state residents for this LTSS target group ranged from just under one (Nevada) to almost 7 (North Dakota), and the U.S. rate across all states was 2.2 waiver program participants per 1,000 state residents (Figure IV.7; Appendix Table B.5). States in the lowest quartile of ASD, ID, or DD waiver program participants per 1,000 state residents (fewer than 1.5 participants per 1,000 residents) were Nevada, Mississippi, Michigan, Alabama, Delaware, Georgia, North Carolina, Tennessee, Oklahoma, Virginia, Arkansas, Texas, and Florida. Twenty-eight of the 47 states (60 percent) had higher rates than the U.S. rate in 2016. Those in the highest quartile (greater than or equal to 3.3 participants per 1,000 residents) were Ohio, Kentucky, Indiana, New Hampshire, Maine, Iowa, Wyoming, New York, South Dakota, Idaho, Oregon, and North Dakota.

**Figure IV.7. 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 2016**



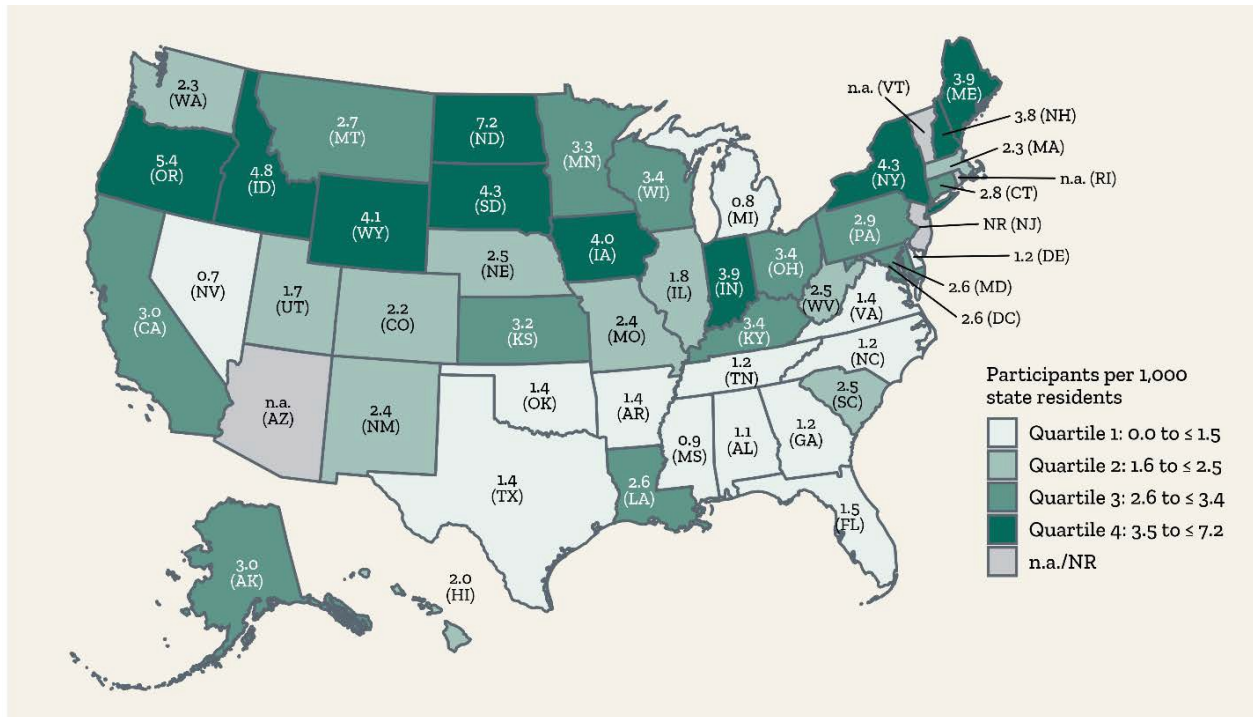
Source: Mathematica analysis of CMS 372 annual reports from 2016 and Census Bureau data.

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

The same number of states operated section 1915(c) waiver programs for ASD, ID, or DD in 2017 as 2016, and there were similar patterns overall in both years. In 2017, the overall U.S. rate increased slightly to 2.3 waiver program participants per 1,000 state residents (up from 2.2 in 2016) and the range

was again just under one (Nevada) to slightly above 7 (North Dakota) (Figure IV.8; Appendix Table B.4). The same states were in the lowest quartile of ASD, ID, or DD participants per 1,000 state residents in 2016 and 2017, even though the rank order changed slightly. States in the highest quartile were also similar, with the only difference being Ohio and Kentucky were no longer in the highest quartile in 2017.

**Figure IV.8. 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 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2017 and Census Bureau data.

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

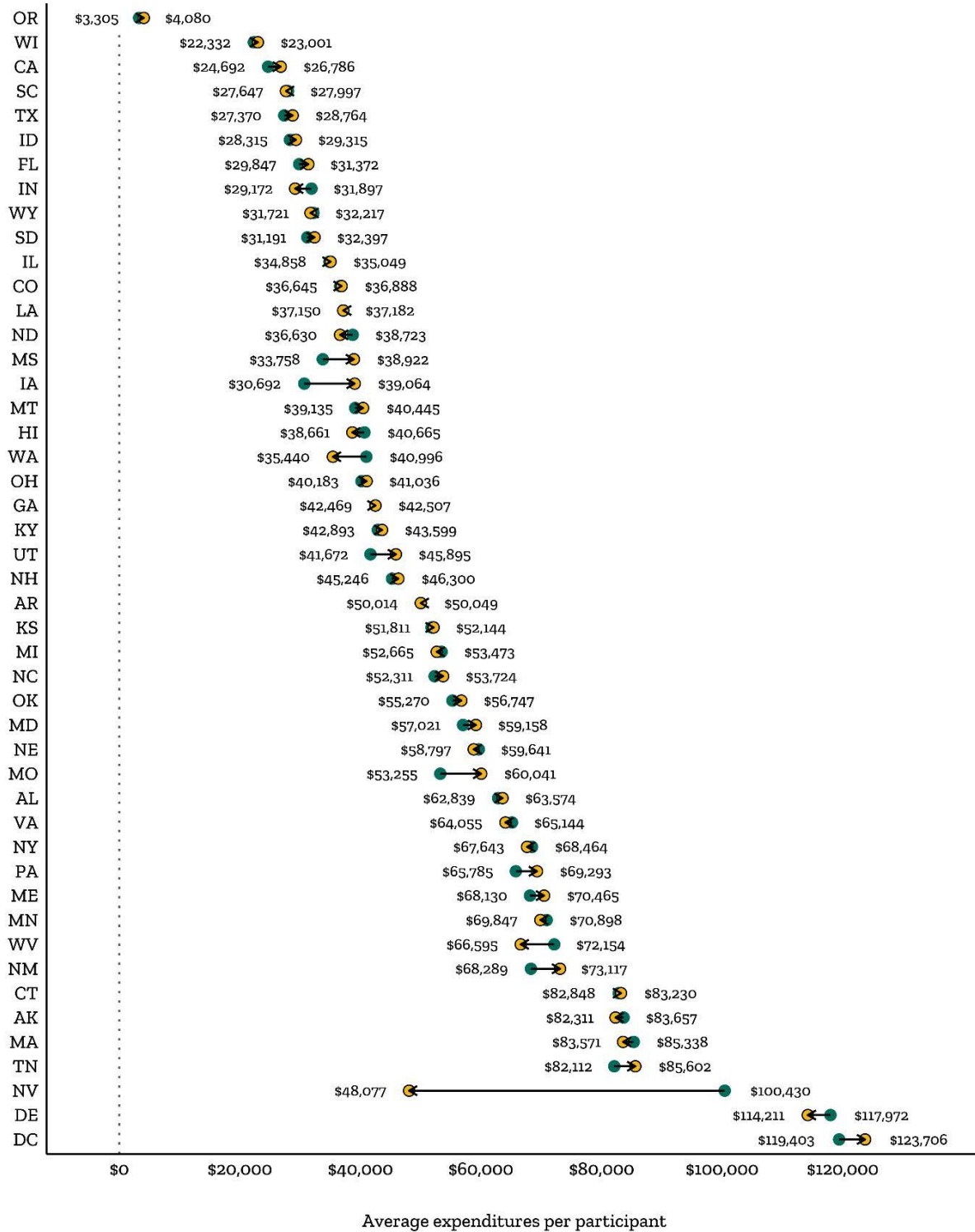
**Waiver expenditures.** In 2016, U.S. total annual average waiver expenditures per ASD, ID, or DD waiver program participant was \$44,658. Twenty-four of 47 states (51 percent) had average waiver expenditures greater than the U.S. total average (Figure IV.9; Appendix Table B.5). Annual average waiver expenditures per section 1915(c) waiver program participant for this LTSS target group ranged from \$3,305 in Oregon to \$119,403 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 Wisconsin at \$22,332. States in the lowest quartile of average waiver expenditures per ASD, ID, or DD waiver program participant were Oregon, Wisconsin, California, Texas, South Carolina, Idaho, Florida, Iowa, South Dakota, Indiana, Wyoming, and Mississippi. Those in the highest quartile of average waiver expenditures included Maine, New Mexico, New York, Minnesota, West Virginia, Tennessee, Connecticut, Alaska, Massachusetts, Nevada, Delaware, and District of Columbia.

The U.S. total average waiver expenditures per section 1915(c) waiver program participant for the ASD, ID, or DD target group remained relatively steady between 2016 and 2017, increasing by \$432 (about one percent) from \$44,658 in 2016 to \$45,090 in 2017. Twenty-five of 47 states (53 percent) had average

waiver expenditures greater than the U.S. total average in 2017. Oregon and the District of Columbia ranked as having the lowest and highest average waiver expenditures, respectively, in both 2016 and 2017, but the range in average waiver expenditures per participant for this LTSS target population across states increased in 2017 compared to the range in 2016 as expenditures changed in Oregon and the District of Columbia (from \$3,305 to \$4,080 and \$119,402 to \$123,706, respectively). As noted in the state-level analysis of all LTSS target groups (Section IV.1), Oregon has relatively low section 1915(c) waiver program expenditures because they provide a substantial proportion of HCBS to eligible Medicaid beneficiaries through the Community First Choice section 1915(k) State Plan option.

Most states in the lowest quartile of average waiver expenditures per ASD, ID, or DD waiver program participant in 2017 were the same as those in 2016, except for the addition of Illinois in 2017 (replacing Iowa in the lowest quartile). Similarly, the states in the highest quartile of average waiver expenditures for this target group were mostly the same in 2017 as in 2016, except for the addition of Pennsylvania to the highest quartile (replacing Nevada). States with the largest declines in average waiver expenditures per ASD, ID, or DD waiver program participant between 2016 and 2017 were Nevada (52 percent) and Washington (14 percent). In Nevada, the change was due to declines in expenditures for NV 0125, as previously noted in Section IV. Among the states with the largest increase between 2016 and 2017 were Missouri (13 percent), Mississippi (15 percent), Oregon (23 percent), and Iowa (27 percent). In Iowa, this is reflective of increases in the *HCBS – Intellectual Disabilities Waiver* (IA 0242), the only waiver program serving this target group, which had an increase in average waiver expenditures from approximately \$30,700 in 2016 to \$39,000 in 2017.

**Figure IV.9. Average waiver expenditures per section 1915(c) waiver program participant for the ASD, ID, or DD target group, waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

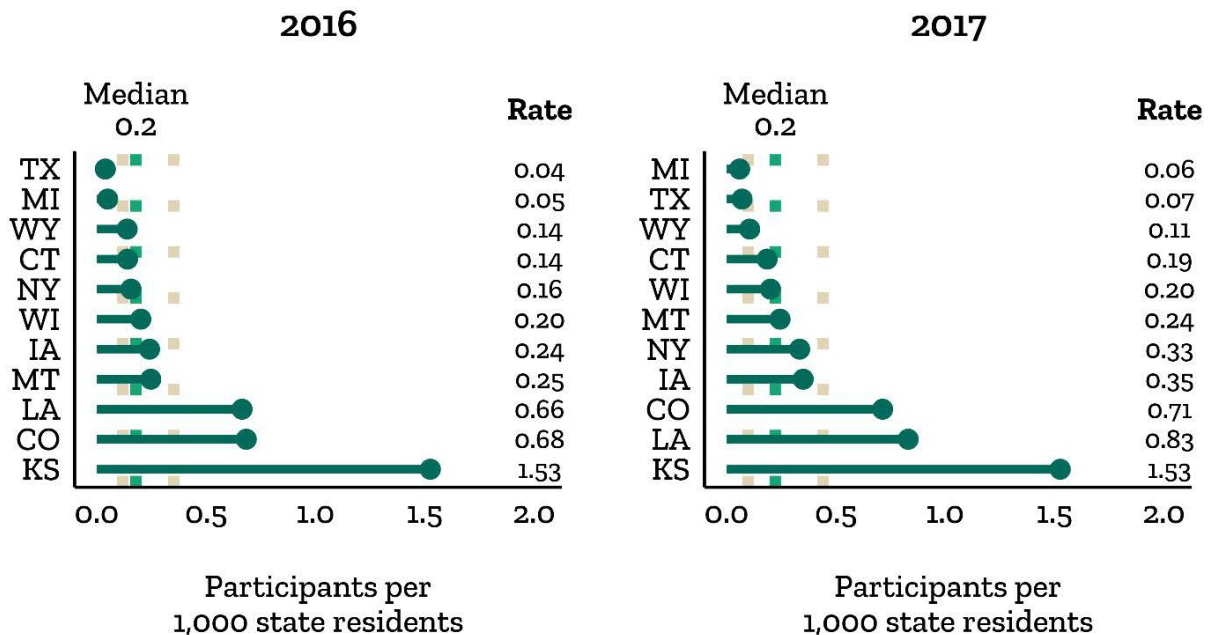
Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Those with small decreases in average expenditures included: South Carolina (from \$27,997 to \$27,647), Louisiana (from \$37,182 to \$37,150), and Arkansas (from \$50,049 to \$50,014). Those with small increases in average expenditures included: Illinois (from \$34,858 to \$35,049), Colorado (from \$36,645 to \$36,888), Georgia (from \$42,469 to \$42,507), Kansas (from \$51,811 to \$52,144), and Connecticut (from \$82,848 to \$83,230).

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

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

**Participants.** In 2016, 11 of the 47 states (23 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. Kansas was the only state that served more than one section 1915(c) waiver program participant per 1,000 state residents for this target population (Figure IV.10; Appendix Table B.5). The number of waiver program participants per 1,000 state residents, and the overall distribution of states serving the mental health services or SED target group in 2017 followed the patterns of 2016. In both years, Texas and Michigan were at the lowest end of the distribution for mental health services or SED waiver program participants per 1,000 state residents, while Kansas, Colorado, and Louisiana were at the highest end.

**Figure IV.10. Section 1915(c) waiver program participants per 1,000 state residents for the mental health services or SED target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017, and Census Bureau data.

Note: Medians across states with these programs are represented by green squares, tan squares reflect the 25th and 75th percentile values.

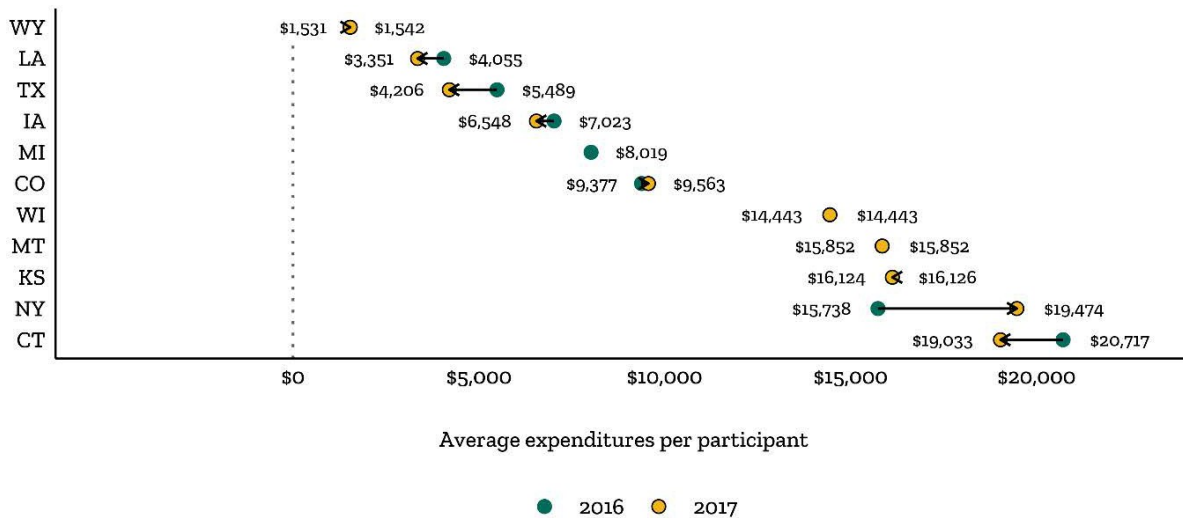
SED = serious emotional disturbances.

**Waiver expenditures.** For the mental health services or SED LTSS target group, U.S. annual total average waiver expenditures per waiver program participant in 2016 was \$11,455 and ranged from \$1,531 in Wyoming to \$20,717 in Connecticut (Figure IV.11, Appendix Table B.5). Five of the 11 states (46 percent) with section 1915(c) waiver programs for this LTSS target group had average waiver

expenditures greater than the U.S. total average in 2016. States at the lowest end of the distribution were Wyoming (\$1,531), Louisiana (\$4,055) and Texas (\$5,489), while states at the highest end of the distribution were Montana (\$15,852), Kansas (\$16,126), and Connecticut (\$20,717).

In 2017, the U.S. total average total waiver expenditures per mental health services or SED waiver program participant increased by \$862 (8 percent) to reach \$12,317. Wyoming remained the state with the lowest average waiver expenditures for this target group (\$1,542), while New York (\$19,474) replaced Connecticut as the state with the highest average waiver expenditures in 2017; Connecticut came in a close second at \$19,033.

**Figure IV.11. Average waiver expenditures per section 1915(c) waiver program participant for the mental health services or SED target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Between 2016 and 2017, average expenditures for Wyoming increased from \$1,531 to \$1,542 and average expenditures for Kansas decreased from \$16,126 to \$16,124. Average expenditures for Wisconsin and Montana did not change (\$14,443 and \$15,852, respectively) between 2016 and 2017.

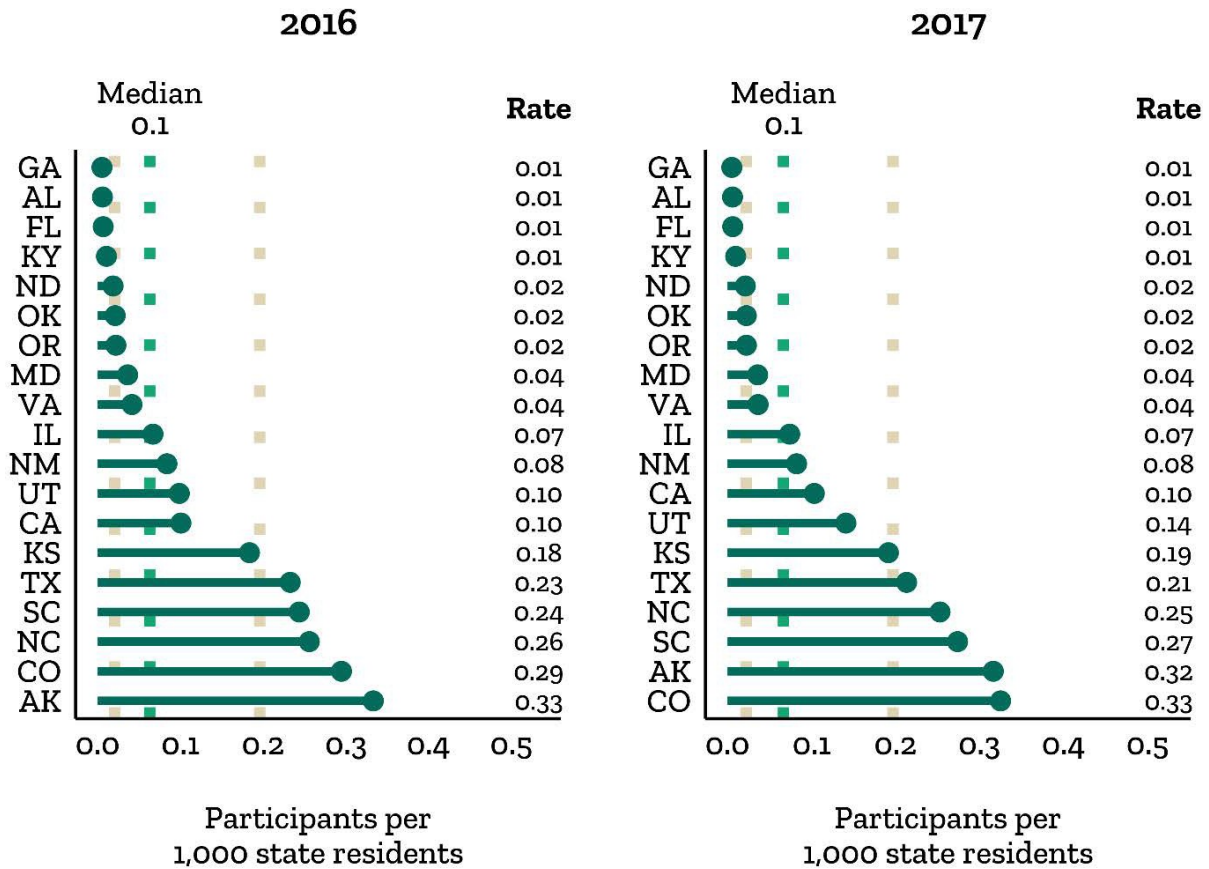
SED = serious emotional disturbances.

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

**Participants.** Nineteen of the 47 states (40 percent) with section 1915(c) waiver programs in 2016 served the medically fragile or TD LTSS target group. All states served fewer than one section 1915(c) program participants per 1,000 state residents, ranging from 0.01 to 0.33 (Figure IV.12; Appendix Table B.5). Ten of the 19 states (53 percent) had higher rates than the U.S. rate in 2016 of 0.06. States in the lowest quartile for medically fragile or TD waiver program participants per 1,000 state residents (fewer than 0.02 participants per 1,000 residents) were Georgia, Alabama, Florida, and Kentucky, and those in the highest quartile (greater than 0.18 participants per 1,000 residents) were Texas, South Carolina, North Carolina, Colorado, and Alaska, but the range across states was small. The same patterns were observed in 2017 for the medically fragile or TD section 1915(c) waiver programs—the overall range of medically fragile or

TD waiver program participants per 1,000 state residents and general ranking of states was largely unchanged between the two years.

**Figure IV.12. Section 1915(c) waiver program participants per 1,000 state residents for the medically fragile or TD target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017, and Census Bureau data.

Note: Medians across states with these programs are represented by green squares, tan squares reflect the 25th and 75th percentile values.

TD = technologically 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 2016 was \$26,216, ranging from \$1,871 in Oregon to \$89,326 in Kansas (Figure IV.13; Appendix Table B.5). Eight of the 19 states (42 percent) with waiver programs for this target group had average waiver expenditures greater than the U.S. average. States in the lowest quartile of average expenditures per medically fragile or TD waiver program participant were Oregon, Illinois, South Carolina, Florida, and Colorado, and states in the highest quartile included Oklahoma, Alabama, Kentucky, Virginia, and Kansas.

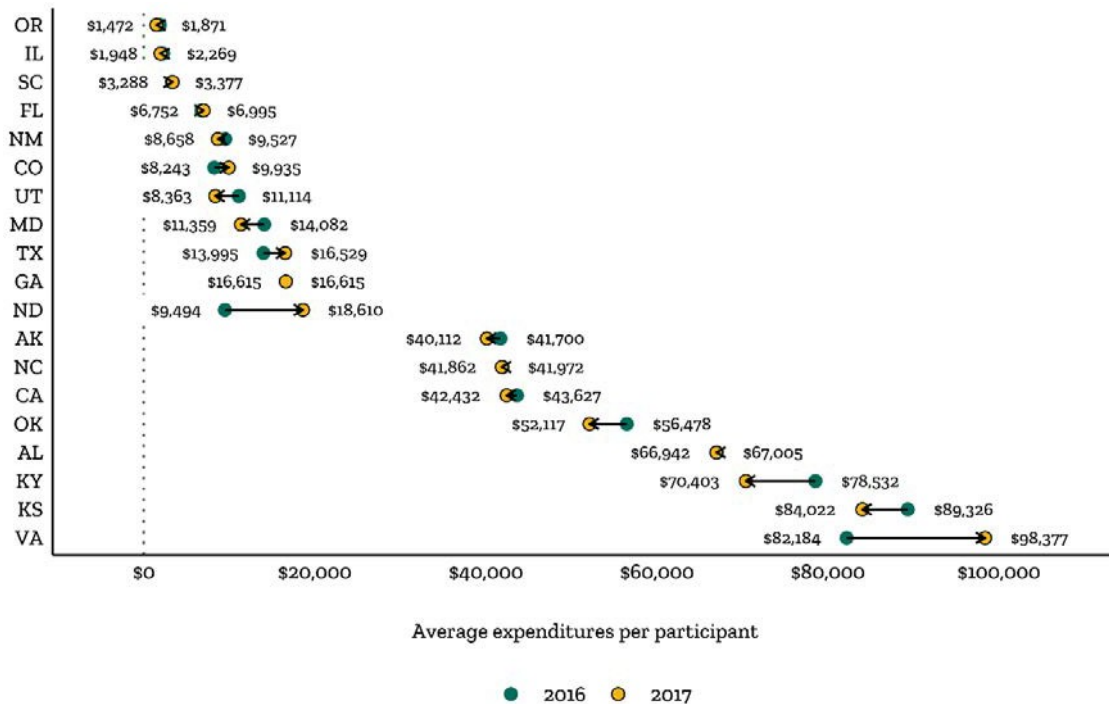
In 2017, the U.S. total annual average waiver expenditures per medically fragile or TD waiver program participant increased slightly, from \$26,216 in 2016 to \$26,612 in 2017, or two percent. The difference between the lowest and highest states for the medically fragile or TD target group increased in 2017 compared to 2016 due to a decrease in expenditures for the lowest state and an increase in expenditures



for the highest state between the two years. Oregon remained the lowest state in 2017 with average waiver expenditures of \$1,472 per section 1915(c) waiver program participant (down from \$1,871 in 2016). Virginia was the highest state in 2017 with average waiver expenditures of \$98,377 per section 1915(c) waiver program participant (up from \$82,184 in 2016); Virginia replaced Kansas as the state with the highest per participant spending in 2017.

Although the rank order differed slightly between 2016 and 2017, the states in the lowest quartile remained the same, except for the addition of Utah in 2017 (replacing Colorado) due to a decline of 25 percent in Utah and an increase of 21 percent in Colorado between the two years. The same states remained in the highest quartile in 2017 as in 2016. Several states had large changes in average waiver expenditures per medically fragile or TD waiver program participant between 2016 and 2017. States with the largest declines from 2016 to 2017 were Utah (25 percent), Oregon (21 percent), Maryland (19 percent), and Illinois (14 percent), and states with the largest increases from 2016 to 2017 were Texas (18 percent), Virginia (20 percent), Colorado (21 percent), and North Dakota (96 percent). In North Dakota, the section 1915(c) waiver programs serving this target group included fewer than 20 participants, so average waiver expenditures were subject to greater variation.

**Figure IV.13. Average waiver expenditures per section 1915(c) waiver program participant for the medically fragile or TD target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

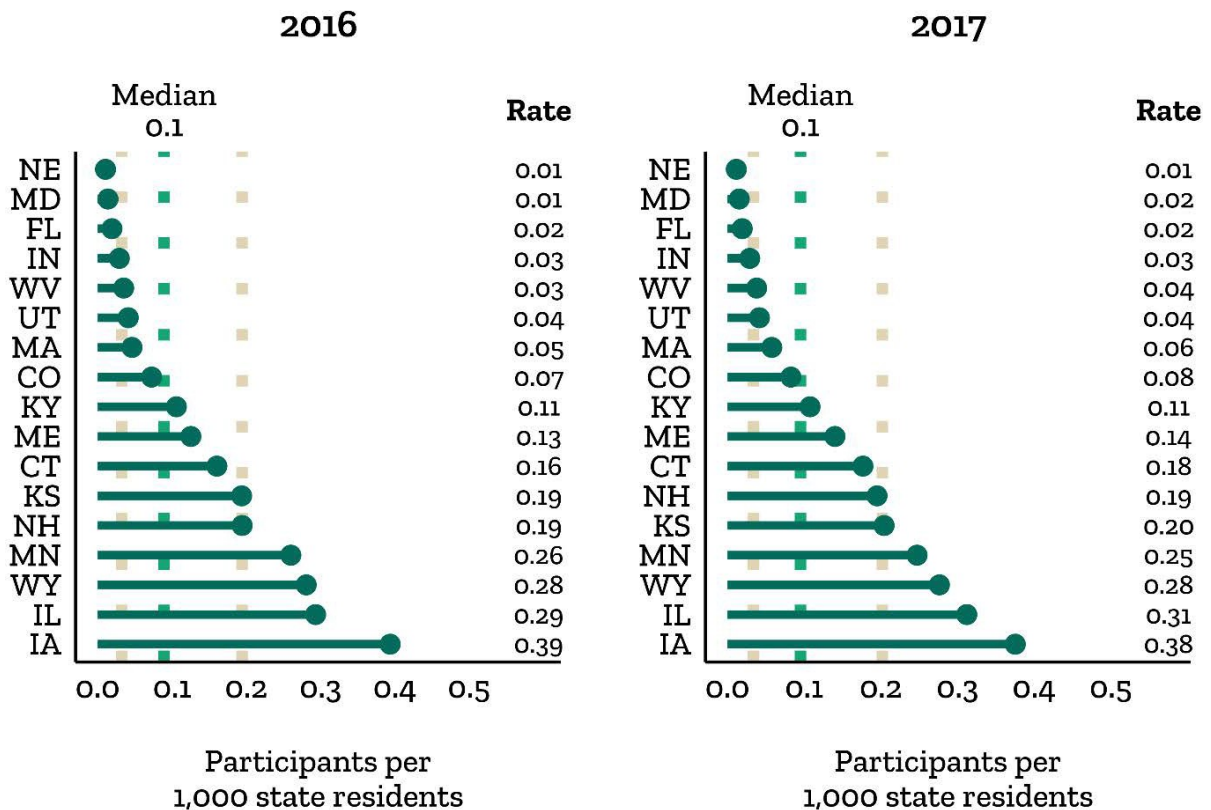
Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Those with small decreases in average expenditures included: Oregon (from \$1,871 to \$1,472), Illinois (from \$2,269 to \$1,948), North Carolina (from \$41,972 to \$41,862), and Alabama (from \$67,005 to \$66,942). Between 2016 and 2017, average expenditures for South Carolina and Florida increased, from \$3,288 to \$3,377 and \$6,752 to \$6,995, respectively. Average expenditures for Georgia did not change between 2016 and 2017, remaining at \$16,615.

TD = technologically dependent.

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

**Participants.** In both 2016 and 2017, 18 of 47 states (38 percent) with section 1915(c) waiver programs served the brain injuries LTSS target group. However, New York’s *TBI Waiver* program (NY 0269) had no 372 reports with an accepted status within the past four years for either 2016 or 2017, and could not be included in these analyses. All of the remaining states served fewer than one section 1915(c) waiver program participant per 1,000 state residents for this LTSS target group (Figure IV.14; Appendix Table B.5), and the range across states was 0.01 to 0.39 participants per 1,000 state residents in 2016 and 0.01 to 0.38 in 2017. Overall patterns were similar in 2016 and 2017, and the U.S. total remained the same at 0.03 in both years.

**Figure IV.14. Section 1915(c) waiver program participants per 1,000 state residents for the brain injuries target group, for waiver program years ending in 2016 and 2017**



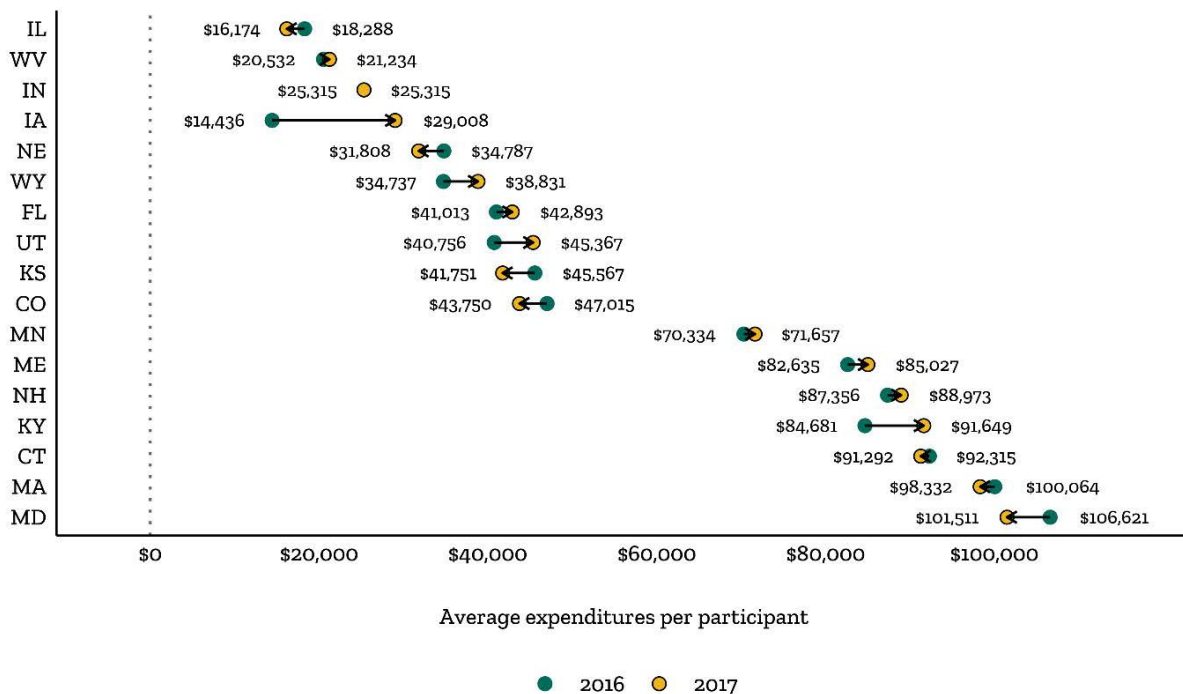
Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and Census Bureau data.

Note: Medians across states with these programs are represented by green squares, tan squares reflect the 25th and 75th percentile values. New York had an active waiver serving the brain injuries target group in both 2016 and 2017, but is not included due to absence of an accepted 372 report within the past four years.

**Waiver expenditures.** For the brain injuries LTSS target group, U.S. annual average total waiver expenditures per section 1915(c) waiver program participant in 2016 was \$42,615 and ranged from \$14,436 in Iowa to \$106,621 in Maryland (Figure IV.15, Appendix Table B.5). Nine of the 17 states (53 percent) with active section 1915(c) waiver programs and available data for this target group had average waiver expenditures greater than the U.S. total average in 2016 (\$42,615). States at the lowest end of the distribution were Iowa, Illinois, and West Virginia, while states at the highest end of the distribution were Connecticut, Massachusetts and Maryland.

In 2017, the U.S. total average waiver expenditures per brain injuries waiver program participant increased by \$1,422 (3 percent) to reach \$44,037. The largest increase at the state-level was observed in Iowa, which increased by 101 percent, the result of increases in average waiver expenditures for its *HCBS Brain Injury Waiver* program (IA 0299). Illinois and West Virginia remained at the lowest end of the distribution in 2017, with Illinois replacing Iowa as the state with the lowest average waiver expenditures for brain injuries waiver programs. Maryland and Massachusetts remained the states with the highest average section 1915(c) waiver program expenditures for this target group (\$101,511 and \$98,332, respectively), while Kentucky replaced Connecticut in the third position by a very small margin (\$91,649 in Kentucky versus \$91,292 in Connecticut) due to an eight percent increase in average waiver expenditures between 2016 and 2017.

**Figure IV.15. Average waiver expenditures per section 1915(c) waiver program participant for the brain injuries target group, for waiver program years ending in 2016 and 2017**



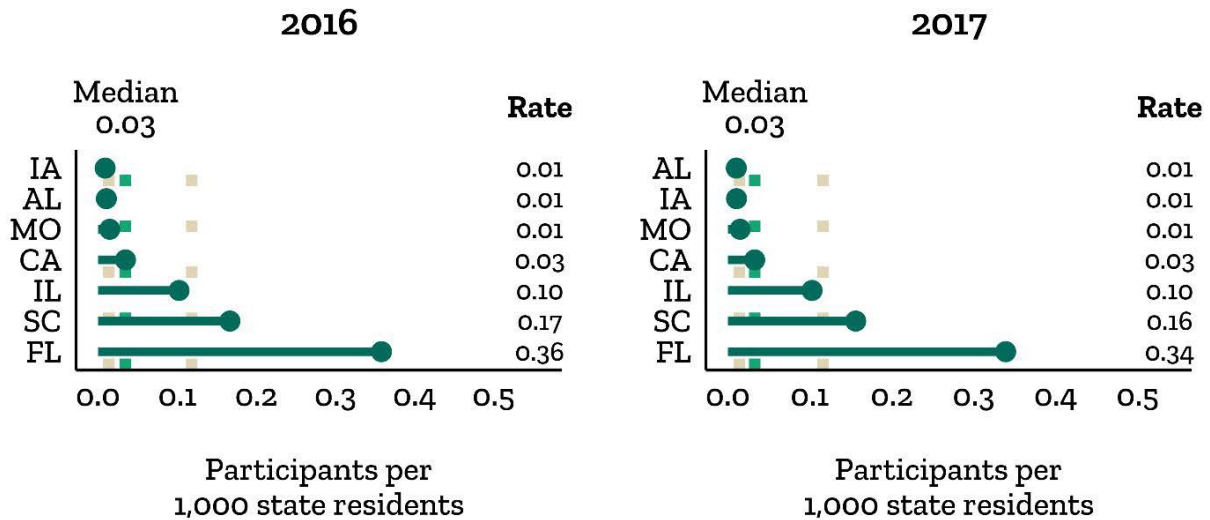
Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Average expenditures for Indiana did not change between 2016 and 2017, remaining at \$25,315. New York had an active waiver serving the brain injuries target group in both 2016 and 2017, but is not included due to absence of an accepted 372 report within the past four years.

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

**Participants.** In 2016 and 2017, seven of 47 states (15 percent) with section 1915(c) waiver programs served the HIV/AIDS LTSS target group. All states served fewer than one section 1915(c) program participant per 1,000 state residents for this LTSS target group (Figure IV.16; Appendix Table B.5). The range across the seven states was 0.01 (in Iowa, Alabama, and Missouri) to 0.36 (in Florida) participants per 1,000 state residents. The overall patterns, including the U.S. average, range across states, and state rankings were similar in 2016 and 2017.

**Figure IV.16. Section 1915(c) waiver program participants per 1,000 state residents for the HIV/AIDS target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and Census Bureau data.

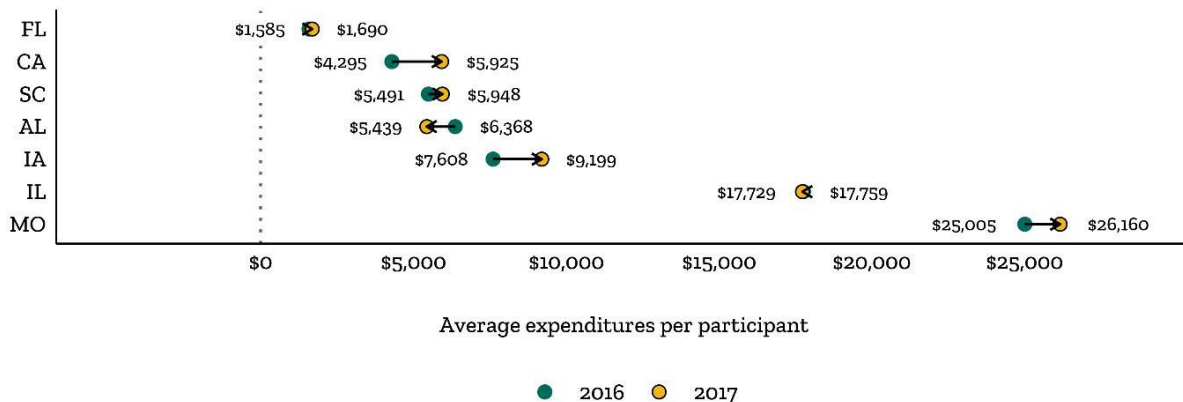
Note: Medians across states with these programs are represented by green squares, tan squares reflect the 25th and 75th percentile values.

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

**Waiver expenditures.** In 2016, the U.S. annual average waiver expenditures per HIV/AIDS waiver program participant was \$4,359 and ranged from \$1,585 in Florida to \$25,005 in Missouri (Figure IV.17, Appendix Table B.5). Five of the seven states (71 percent) with section 1915(c) waiver programs for this LTSS target group had average waiver expenditures greater than the U.S. average in 2016. States at the lowest end of the distribution were Florida and California, while states at the highest end of the distribution were Illinois and Missouri.

In 2017, the U.S. total average waiver expenditures per section 1915(c) waiver program participant for HIV/AIDS increased by \$378 (9 percent) to reach \$4,737. The largest increases at the state-level between 2016 and 2017 were observed in California and Iowa, which increased by 38 and 21 percent, respectively. These changes were the result of increases in average waiver expenditures for California’s *HIV/AIDS Waiver* program (CA 0183) and Iowa’s *HCBS – AIDS/HIV Waiver* program (IA 0213). The increase in average waiver expenditures per HIV/AIDS waiver program participant in California changed the state’s overall ranking from the second to the third lowest. Overall, state rankings at the highest end of the distribution remained the same and Florida remained the lowest state in both years, but there were small changes in state rankings for the states in the middle of the distribution.

**Figure IV.17. Average waiver expenditures per section 1915(c) waiver program participant for the HIV/AIDS target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

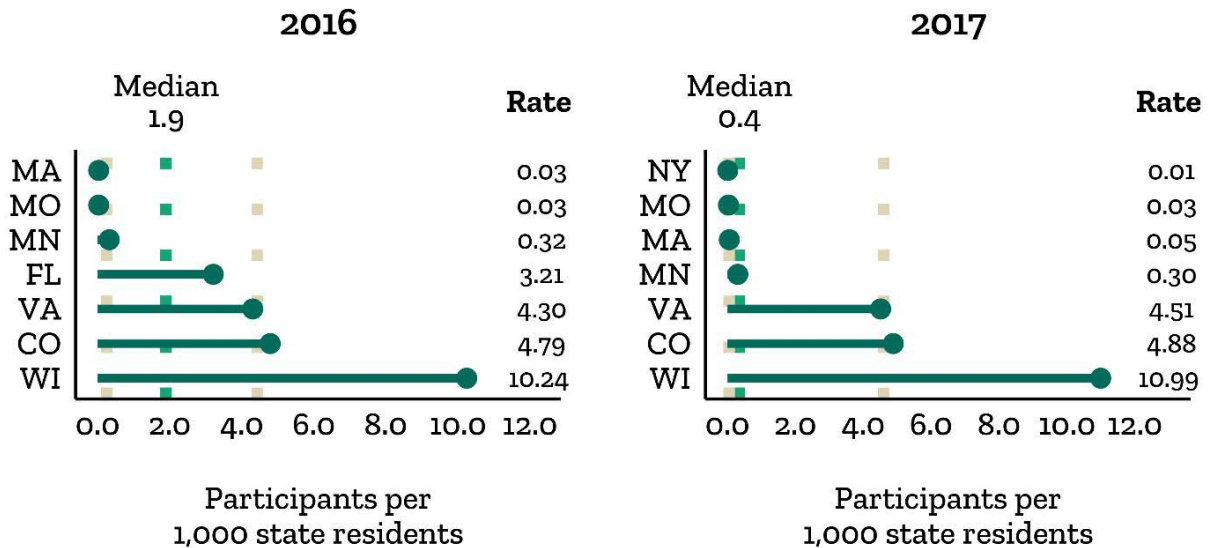
Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Between 2016 and 2017, average expenditures for Florida increased from \$1,585 to \$1,690 and average expenditures for Illinois decreased from \$17,759 to \$17,729.

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

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

**Participants.** In 2016, 8 of 47 states (17 percent) with section 1915(c) waiver programs served the multiple subgroups target group, but due to temporary inactivity in Florida’s *Long-Term Care Managed Care Waiver* (FL 0962), the number of states with multiple subgroups waiver programs dropped to seven (15 percent). When this waiver was renewed later in 2017, it was amended to include only older adults or individuals with physical disabilities; people with greater medical needs such as those with HIV/AIDS or traumatic brain injury were served via Florida’s MEDS-AD section 1115 demonstration. Although there were three states (Massachusetts, Missouri, and Minnesota) serving fewer than one program participant per 1,000 state residents for this LTSS target group in 2016, four states served approximately 3 (Florida), 4 (Virginia), 5 (Colorado), and 10 (Wisconsin) section 1915(c) waiver program participants per 1,000 state residents (Figure IV.18; Appendix Table B.5). Although New York had two section 1915(c) waiver programs serving the multiple subgroups target group in 2016, neither had an accepted 372 report within the past four years, and thus could not be included in this analysis. In 2017, four states (New York, Missouri, Massachusetts, and Minnesota) served fewer than one multiple subgroups waiver program participant per 1,000 state residents, and the remaining three states served slightly more people than in 2016. Specifically, Virginia increased waiver program participants per 1,000 state residents to 5, Colorado remained at 5, and Wisconsin increased to 11.

**Figure IV.18. Section 1915(c) waiver program participants per 1,000 state residents for the multiple subgroups target group, for waiver program years ending in 2016 and 2017**



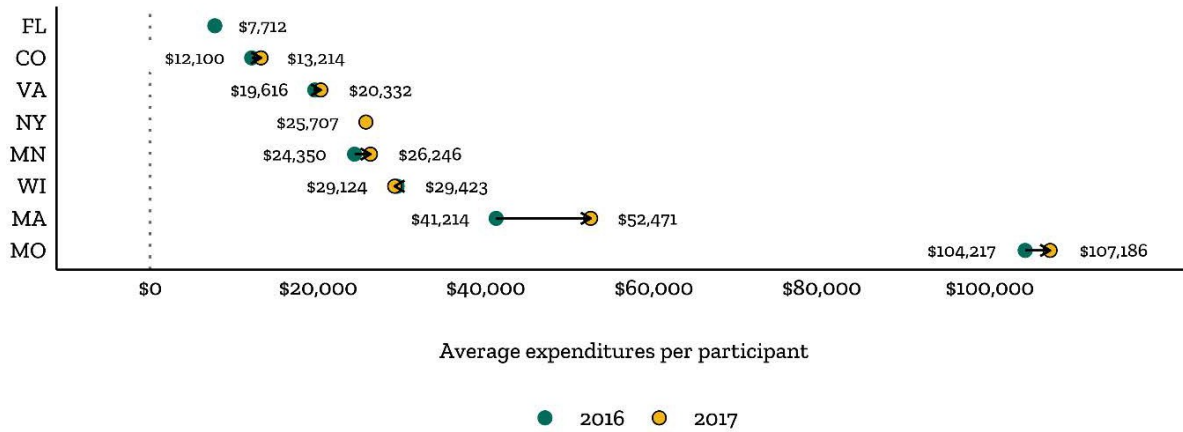
Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and Census Bureau data.

Note: Medians across states with these programs are represented by green squares, tan squares reflect the 25th and 75th percentile values. New York had two active waivers serving the multiple subgroups target group in both 2016 and 2017, but is not included in the 2016 analysis due to absence of an accepted 372 report within the past four years.

**Waiver expenditures.** For the multiple subgroups LTSS target group, U.S. total average waiver expenditures per section 1915(c) waiver program participant in 2016 was \$17,587 and ranged from \$7,712 in Florida to \$104,217 in Missouri (Figure IV.19, Appendix Table B.5). Five of the 7 states (71 percent) with active section 1915(c) waiver programs and available data for this LTSS target group had average waiver expenditures greater than the U.S. total average in 2016. States at the lowest end of the distribution were Florida and Colorado, while states at the highest end of the distribution were Massachusetts and Missouri.

In 2017, the U.S. total average waiver expenditures per section 1915(c) waiver program participant for the multiple subgroups target group increased by \$5,779 (33 percent) to reach \$23,366. With the elimination of Florida’s waiver for this target group, Colorado became the lowest spending state in 2017 at \$13,214. Missouri remained the highest spending state in 2017, with average waiver expenditures per participant of \$107,186 (up from \$104,217 in 2016). The largest increase between 2016 and 2017 at the state-level was observed in Massachusetts, which increased by 27 percent. This change was the result of increases in average waiver expenditures for two waivers in Massachusetts serving Money Follows the Person (MFP) participants (MA 1027 and MA 1028), which both serve a mixture of older adults, people with PD, and mental health services. Despite the increase in 2017, this did not change Massachusetts’s overall rank as the state with the second highest average waiver expenditures in both years.

**Figure IV.19. Average waiver expenditures per section 1915(c) waiver program participant for the multiple subgroups target group, for waiver program years ending in 2016 and 2017**



Source: Mathematica analysis of CMS 372 annual reports from 2016-2017 and WMS characteristics data.

Note: States are ordered from lowest to highest by the calculated average of 2016 and 2017 expenditures for each state. Several states had small changes in average expenditures between 2016 and 2017. Between 2016 and 2017, average expenditures for Wisconsin decreased from \$29,423 to \$29,124. New York had two active waivers serving the multiple subgroups target group in both 2016 and 2017, but is not included in the 2016 analysis due to absence of an accepted 372 report within the past four years. Average expenditures for New York were \$25,707 in 2017.

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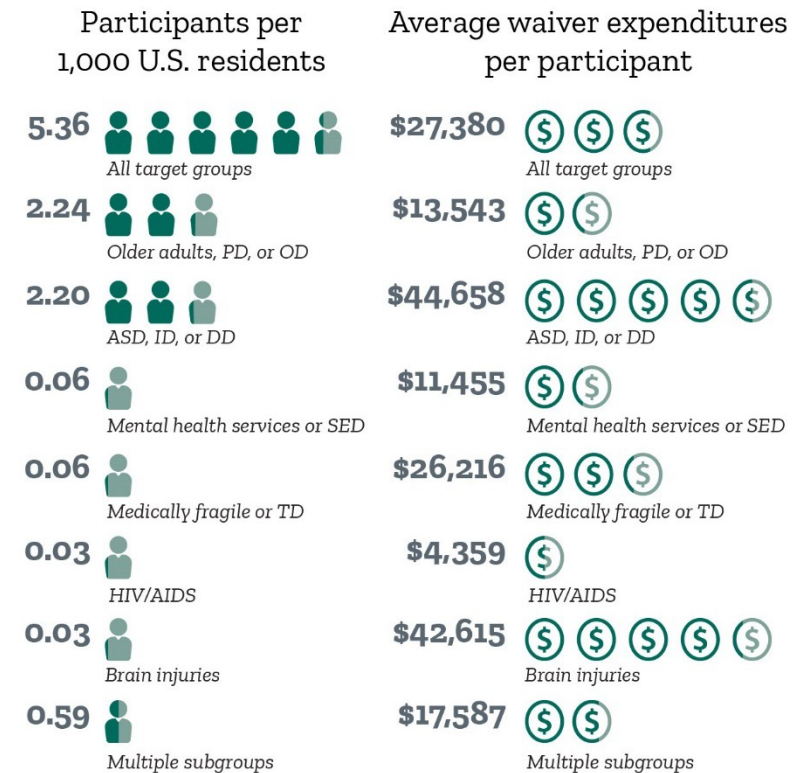


## V. Conclusion

In this report, we provide important insights into section 1915(c) waiver program participants, service use, and expenditures based on annual 372 reports submitted by states for 2016 and 2017. Similar to the previous five years, national participation in section 1915(c) waiver programs increased during 2016, rising to 1.68 million participants, representing an increase of 3.0 percent relative to 2015. However, it declined by 1.4 percent in 2017, to approximately 1.66 million participants. As a proportion of the U.S. population, approximately 5.36 of every 1,000 residents used section 1915(c) waiver program services in 2016, falling to 5.25 residents in 2017. While overall participation declined slightly from 2016 to 2017, the reverse was true for average waiver program expenditures: in 2016, waiver program expenditures averaged \$27,380 per participant, while in 2017, they increased to an average of \$29,279 (Figures V.1 and V.2).

In addition to these national trends, our analyses reveal important variation in section 1915(c) waiver program participation and expenditures by LTSS target group and by state. In both 2016 and 2017, waiver programs serving the older adults, PD, or OD target group, and those for individuals with ASD, ID, or DD, had the highest proportion of participants per 1,000 residents, and comprised approximately 85 percent of total waiver program participants in both years. There were 2.24 and 2.23 participants in section 1915(c) waiver programs per 1,000 residents for older adults, PD, or OD populations, and 2.20 and 2.28 for individuals with ASD, ID, or DD, respectively, in 2016 and 2017. Waiver programs focusing on the other five LTSS target groups served fewer than one participant per 1,000 U.S. residents in these years. Among these five target groups, the waiver programs serving multiple subgroups had the highest proportion of participants per 1,000 residents, followed by individuals receiving mental health services or with SED, people who are medically fragile or TD, individuals with brain injuries, and those with HIV/AIDS.

**Figure V.1. Key 2016 statistics for section 1915(c) waiver program participants**



Source: Mathematica analysis of 372 annual reports for 2016, WMS characteristics and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

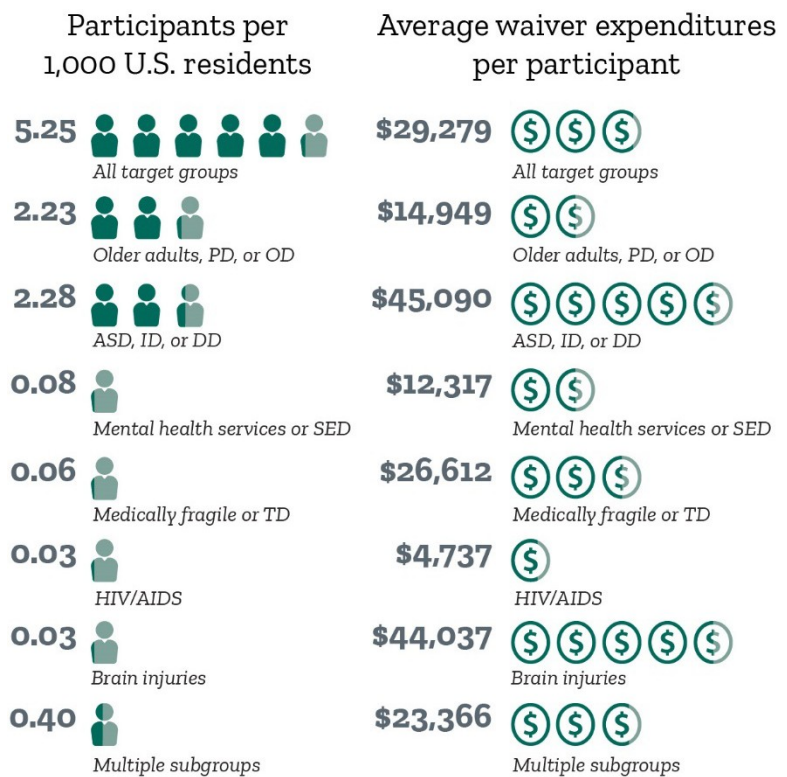
ASD = autism spectrum disorder; DD = developmental disabilities; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome; ID = intellectual disabilities; OD = other disabilities; PD = physical disabilities; SED = serious emotional disturbance; TD = technologically dependent.

For these two largest waiver program types, participation is similar but average expenditures differ markedly. While average waiver program expenditures per participant for the older adults, PD, and OD target group was \$13,543 in 2016 and \$14,949 in 2017, average waiver expenditures for the ASD, ID, or DD group were about three times as much, at over \$44,600 in both years. Among these smaller target groups, the lowest observed average section 1915(c) waiver program expenditures were reported for the HIV/AIDS target group (\$4,359 in 2016; \$4,737 in 2017), while those with brain injuries had the highest average waiver expenditures in both years (\$42,615 in 2016; \$44,037 in 2017).

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 during this time period. While there were 278 total waiver programs offered by states in 2016, all 47 states offered waiver programs for the ASD, ID, or DD target group, and 41 of 47 (87.2 percent) offered waivers for the older adult, PD, or OD target group. For the remaining five target groups, 19 states (40.4 percent) served the medically fragile or TD population, 18 states (38.3 percent) offered waiver programs to people with brain injuries, 11 (23.4 percent) provided mental health services or served people with SED, 8 were for people with HIV/AIDS (17.0 percent), and 8 served multiple subgroups (17.0 percent). In 2017, states served the same number and types of target groups with the exception of waiver programs serving those with HIV/AIDS, which declined to 7.

The results in this report underscore the utility of 372 annual reports for understanding trends in section 1915(c) waiver program participation, service use, and expenditures, for all participants as well as by specific LTSS population target groups. However, they are subject to several important limitations. First, although Section II of this report presents five-year trends, our analyses were limited to waiver program years 2015, 2016, and 2017. National data from 2012, 2013, and 2014 were obtained from prior reports analyzing 372 annual report data and were not verified for accuracy in our analyses. Second, to provide a complete picture of trends in section 1915(c) waiver programs, we estimate missing data using prior

**Figure V.2. Key 2017 statistics for section 1915(c) waiver program participants**



Source: Mathematica analysis of 372 annual reports for 2017, WMS characteristics and Census Bureau data. Number of participants and average waiver expenditures are calculated per waiver program year.

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

accepted 372 annual reports. However, these data may not be reasonable proxies for the year in which there was missing data. To limit the risk of making inaccurate assumptions, we imposed a restriction of four years on any estimation using prior year reports. Finally, the accuracy of these analyses are at least partially a reflection of the validity of the underlying data, which are the responsibility of states, CMS, and the U.S. Census Bureau. Nonetheless, these analyses provide important insights on section 1915(c) waiver programs, which comprise an important component of LTSS delivery systems in most states.

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

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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.

### Data sources and key variables

The **CMS 372 Reports by Year** (rptWvr372Base.csv) files available from the Waiver Management System (WMS) are the foundation for most analyses in this report. Files for waiver program years 2015, 2016, and 2017 were downloaded on May 21, 2020. We utilized 2015 data to calculate changes in section 1915(c) waiver program participants, service use, and expenditures from 2015 to 2016. 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 shown in Table A.1. In this table, we list the number of days between each waiver program year reporting deadline and data download, ranging from 326 days for waiver program year 2017 to almost three years for waiver program year 2015, between when data were due and when data were obtained for this report.

**Table A.1. CMS 372 waiver program reporting deadlines for 2015–2017**

Waiver year	Last possible waiver year date	Latest possible reporting date deadline	Time between reporting deadline and data download
2015	December 31, 2015	June 30, 2017	2 years, 326 days
2016	December 31, 2016	June 30, 2018	1 year, 326 days
2017	December 31, 2017	June 30, 2019	326 days

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

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

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

Variable name	Description
D'	Estimated annual average per capita Medicaid cost for all other services provided to all waiver participants
D + D'	Estimated annual average per capita Medicaid costs for all HCBS and other services for all waiver participants

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

The section **1915(c) Waiver List (1915cTables-New&ExpiredWaivers-1.xlsx)** was provided by IBM Watson Health, the contractor that previously produced the CMS reports analyzing CMS 372 data. 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 section 1915(c) Waiver List provides 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 drew on the following key variables from this file, as shown in Table A.3.

**Table A.3. Key variables in the section 1915(c) Waiver List**

Variable name	Description
State	Section 1915(c) waiver program state
Waiver Number	Finalized waiver number listed in Waiver Detail Finder
Target Population	Label assigned by IBM Watson Health to analyze trends by LTSS populations
Terminated Date	Termination date for most current waiver revision, also reviewed using the <b>Waiver Finder</b> in the WMS

LTSS = long-term services and supports; WMS = Waiver Management System.

The **Waiver Characteristics Data (WvrCharRegionI-X.csv)** files available from the WMS were also utilized for this report. These files, which are produced for each CMS region, reflect information extracted from section 1915(c) Waiver Program Applications for all currently active waivers. We downloaded all available files on February 27, 2020, and utilized the following key variables, as shown in Table A.4.

**Table A.4. Key variables in the Waiver Characteristics Data file**

Variable name	Description
State	Section 1915(c) waiver program state
Current Waiver Number	Reflects two-digit state abbreviation, base waiver number, and revision number (e.g., CT.0140.06.01)
Program Title	Official state section 1915(c) waiver program name
Approved Effective Date	Effective date for most current section 1915(c) waiver program revision
Expiration Date	Expiration date for most current section 1915(c) waiver program revision

Variable name	Description
Target Group	Population target group to which the section 1915(c) waiver program will deliver services, from the section 1915(c) waiver program application Appendix B. If True, then section 1915(c) waiver program will deliver services to this group as reflected in the section 1915(c) waiver program application Appendix B. The target groups include subgroup options for each group that a state may select for that target group.
Target group	Target subgroups
Aged or Disabled, or Both – General	Aged, Disabled (Physical), Disabled (Other)
Aged or Disabled, or Both – Specific Recognized Subgroups	Brain Injury, Medically Fragile, or Technologically Dependent, HIV/AIDS
Intellectual Disability or Developmental Disability, or Both	Autism, Developmental Disability, Intellectual Disability
Mental Illness	Mental Illness, Serious Emotional Disturbance
Multiple Subgroups	Variable

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

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

We downloaded the 2010–2019 file on April 30, 2020, and utilized the following key variables, as shown in Table A.5.

**Table A.5. Key variables in the U.S. Census Bureau state population totals and components of change**

Variable name	Description
State	Numerical value indicating state number
Name	Either United States, region, or state name
Popestimate2015	2015 population, estimated as a projection of 2010 Census
Popestimate2016	2016 population, estimated as a projection of 2010 Census
Popestimate2017	2017 population, estimated as a projection of 2010 Census

The **WMS Waiver Finder** (<https://wms-mmdl.cms.gov/WMS/faces/protected/report/reportsMenu.jsp>). We used this system to obtain section 1915(c) waiver program-level information, such as effective and

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

expiration dates, termination status, and LTSS population target groups and subgroups served by each section 1915(c) waiver program. The WMS Waiver Finder lists each waiver program by state, base waiver number, and application title, and indicates the waiver status (i.e., Active).

The **CMS State Waivers List** (<https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>). For some waiver programs, we used information available from this source to cross-reference section 1915(c) waiver program information, such as effective and expiration dates, termination status, and LTSS population target groups and subgroups served by each section 1915(c) waiver program. This list served as a supplemental source to the **WMS Waiver Finder**.

The **WMS CMS 372 Reports by Base Waiver Number** (<https://wms-mmdl.cms.gov/WMS/faces/protected/report/reportsMenu.jsp>). We used this system on an ad hoc basis as a supplement to the **CMS 372 Reports by Year**. The CMS 372 Reports by Base Waiver Number provides the same demographic information and service data obtained by entering the state and waiver number of interest.

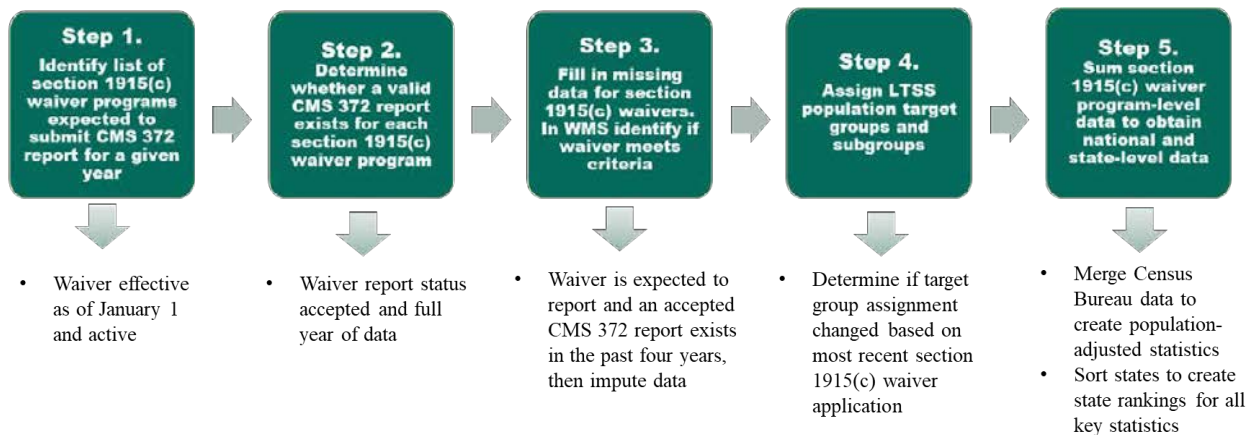
## Methods

Overall, our analytic approach comprised five main steps:

1. Identify list of section 1915(c) waiver programs expected to have annual CMS 372 reports in 2015, 2016, and 2017.
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 expected to have a CMS 372 report in a given year but did not have a report.
4. Assign LTSS population target groups and subgroups.
5. Sum section 1915(c) waiver program-level data to obtain state and national-level data, merge Census Bureau data to create population-adjusted demographic and expenditures statistics, and sort states by statistics to create state rankings.

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

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



**Step 1. Identify list of section 1915(c) waiver programs expected to have annual CMS 372 reports in 2015, 2016, and 2017.** As noted previously, CMS 372 annual reports are generally required of all section 1915(c) waiver programs within 18 months of the close of their “waiver program year.” A waiver program year may begin and end on any day of the calendar year. The start of the section 1915(c) waiver program year generally corresponds to the anniversary of the historical effective or current effective date, with the end date falling 365 or 366 days later.

To determine whether a state was expected to submit a CMS 372 report in 2015, 2016, and 2017 for a section 1915(c) waiver program, we first compared the historical effective and current effective dates of the section 1915(c) waiver program to the first day of the calendar year (for example, January 1, 2016). 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 programs effective date is January 1, 2016), then the state is not expected to submit a report until the anniversary of the waiver program effective date in the subsequent year. For the section 1915(c) waiver programs that started during the calendar year (after January 1), the states are not expected to report for that year (Personal communications between S. Cummins and K. Liao, April 17, 2020).

Generally, it is expected that each CMS 372 submission represents a full year of data; that is, a waiver with an effective date of March 26 reporting for waiver program year ending in 2016 should reflect the period of March 26, 2015 through March 25, 2016. However, if the waiver had a termination date prior to the end of the calendar year (for example., December 31, 2016), 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, 2016, was terminated on November 20, 2017, the state would submit data for report year 2017 for the period between the anniversary of the waiver effective date and waiver termination date (that is, from December 26, 2016–November 20, 2017).

**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 if 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 it met the following criteria:

- Report status of “Accepted,” indicating CMS 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>16</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. Following this review, we excluded reports that were:

- Duplicate entries with a status of “TE” (temporary extension) if a state had a duplicate record and both a “Lag” and “TE” entry appeared in the export. A report type of “TE” indicates a temporary extension to states who receive an extension as the state’s waiver is renewed. The accepted report with status of “Lag” was kept for analysis.
- Entries with partial year data but for which there was no termination date.
- Entries covering more than one year of data.

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 did not exclude the record. 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 expected to have a CMS 372 report in a given year but did not have a report.** After applying the criteria in Step 2, some waiver programs that we expected to report in a given year did not have a valid report. In order to provide a reasonable approximation of participation, service use, and expenditures for these section 1915(c) waiver programs, we used the most recent available accepted report meeting the Step 2 criteria to impute current year information. When there were no available accepted, valid reports within the past four years, we did not impute current year information from the year of the waiver program report (i.e., from 2012 through 2014 for waiver report year 2016). In the case of New Jersey section 1915(c) waiver program 0031, the most recent accepted, valid report was from 2011 and therefore did not use these data to estimate results for 2016 and 2017. For this reason, we do not report any information for New Jersey in these years, and show the state as NR = Not reported.

The proportion of active waivers in 2015, 2016, and 2017 for which data is estimated from prior year 372 reports is shown below in Table A.6. For these waivers, 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. Individual waiver programs for which we estimated data from prior years are noted with a footnote in Appendix B tables.

**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. To ensure target group assignments reflected information reported in the current section 1915(c) waiver program applications, we utilized the Waiver Characteristics Data file to verify selected LTSS target groups and subgroups. In general, the LTSS population groups used in this report align with those used in past years. However, for a small number of section 1915(c) waiver programs that represented unique mixes of LTSS participants from

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

different subgroups, which could not be easily categorized into the standard target groups, we created a new LTSS target group, entitled “Multiple Subgroups.” Waiver programs in this group might include a mix of section 1915(c) waiver program participants who are older adults, with physical disabilities, have brain injuries, or have HIV/AIDS, for example. Additional details are provided in the Table I.1.

**Table A.6. CMS 372 data entry, by waiver program report year**

Waiver program year	Waivers expected to report	Waivers with no Accepted, Valid CMS 372 Report	Waivers with no Accepted, Valid CMS 372 Report within 5 years
2015	287	24	9
2016	279	22	7
2017	278	46	3

**Step 5. Sum section 1915(c) waiver program-level data to obtain state and national-level data, merge Census Bureau Data to create population-adjusted demographic and expenditures statistics, and sort states by statistics to create state rankings.** Following Steps 1–4, we established the final dataset of section 1915(c) waiver programs for each year, including their actual or imputed CMS 372 data, and target group assignment. We used this dataset to create aggregated results including counts of unduplicated participants and total waiver program expenditures at the state and national level, and for each of the seven LTSS target population subgroups. We then calculated the proportion of section 1915(c) waiver program participants per 1,000 residents for each year using the Census Bureau national and state-level population estimates for 2015, 2016, and 2017. We ranked states from highest to lowest for all key results. These results can be found in Appendix B.

### 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. There are nonetheless subject to important limitations. First, the accuracy of these analyses are a reflection of the validity of the underlying data, which are the responsibility of states, CMS, and the U.S. Census Bureau. Second, section II of this report uses national data from 2012, 2013, and 2014, which was obtained from prior reports analyzing CMS 372 report data, and we did not attempt to recreate or validate those results. Third, we analyze changes in expenditures from year to year, but in alignment with past report methodology, do not adjust for inflation. Fourth, to provide a complete picture of trends in section 1915(c) waiver programs, we estimate missing data using the most recently accepted CMS 372 report in the four years prior to the waiver program report year of interest. However, these data may not be reasonable proxies for the actual waiver program report year in which there was missing data. We imposed a restriction of four years on any estimation of current year data. Fifth, to avoid overcounting or undercounting, apart from section 1915(c) waiver programs that terminated, we excluded CMS 372 report submissions with partial year data or more than 12 months of data, as we report data for a full waiver program year. It is important to note that in some cases, a CMS 372 report with more than 12 months of data may represent a legitimate extension of a waiver program year, due to a forthcoming revision that resets the effective date.

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

