

Report to the Ranking Member,
Committee on Finance, U.S. Senate

August 2018

MEDICAID HOME- AND COMMUNITY- BASED SERVICES

Selected States' Program Structures and Challenges Providing Services

Accessible Version

GAO Highlights

Highlights of [GAO-18-628](#), a report to the Ranking Member, Committee on Finance, U.S. Senate

Why GAO Did This Study

The need for LTSS to assist individuals with limited abilities for self-care is expected to increase, in part due to the aging of the population. Medicaid is the nation's primary payer of LTSS, with spending estimated at \$167 billion in 2016. State Medicaid programs are generally required to cover LTSS provided in institutions, such as nursing homes, but coverage of the same services outside of institutions—that is, HCBS—is generally optional. In recent years there have been efforts to shift the balance of LTSS away from institutions through the expanded use of HCBS. National spending for HCBS has increased and now exceeds that for services in an institution. However, the extent to which Medicaid programs cover HCBS varies by state, as does the structure of states' HCBS programs.

GAO was asked to review the approaches states use to provide coverage for HCBS in the Medicaid program. For selected states, this report describes (1) decisions that influenced the structure of Medicaid HCBS programs, and (2) challenges providing HCBS to Medicaid beneficiaries and efforts to respond to these challenges. GAO reviewed information and conducted interviews with officials from a nongeneralizable sample of five states, which GAO selected to obtain variation in the percentage of total Medicaid LTSS expenditures used for HCBS, geography, and other factors. GAO also reviewed information and interviewed officials from four MCOs—two in each of the two selected states that used managed care to provide HCBS. The MCOs varied in enrollment size and population served.

View [GAO-18-628](#). For more information, contact Carolyn L. Yocom at (202) 512-7114 or yocomc@gao.gov.

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What GAO Found

All state Medicaid programs finance coverage of long-term services and supports (LTSS), which help beneficiaries with physical, cognitive, or other limitations perform routine daily activities, such as eating, dressing, and making meals. When these services are provided in beneficiaries' homes or other community settings instead of nursing homes, the services are known as home- and community-based services (HCBS). The structure of the 26 HCBS programs we reviewed in five states—Arizona, Florida, Mississippi, Montana, and Oregon—reflected decisions about which populations to cover, whether to limit eligibility or enrollment, and whether to use managed care.

- **Populations:** Four of the five states had multiple HCBS programs that targeted specific populations. For example, Mississippi had separate HCBS programs for aged or physically disabled individuals and individuals with intellectual or developmental disabilities. The fifth state, Arizona, had one program that targeted two specific populations.
- **Eligibility:** All five states had at least one HCBS program that limited eligibility to beneficiaries whose needs would otherwise require care in a nursing home or other institutional setting.
- **Enrollment:** Four of the five states limited enrollment in one or more of their HCBS programs; 19 of the 26 programs had enrollment caps, and 12 of these programs maintained a waiting list.
- **Managed care:** Two of the five states used managed care to provide HCBS, paying managed care organizations (MCO) a fixed fee for each beneficiary rather than paying providers for each service delivered.

State and MCO officials identified several challenges providing HCBS and described their efforts to respond to them:

- **HCBS workforce:** Officials cited challenges recruiting and retaining HCBS providers, particularly given the low wages these providers typically receive. To respond to this, officials from Mississippi, Montana, and two of the MCOs reported offering providers higher payment rates.
- **Complex needs:** Officials described challenges serving beneficiaries with complex medical and behavioral health needs, including individuals who display aggressive or other challenging behaviors. Officials from Montana and one MCO reported responding to this challenge by providing behavioral health training for providers.
- **HCBS funding:** State officials reported that limitations on overall HCBS funding levels posed a challenge, which they responded to by providing their state legislatures with information on the projected need for HCBS to inform future funding decisions, and leveraging other available resources, such as federal grants.

The Department of Health and Human Services provided technical comments on a draft of this report, which GAO incorporated as appropriate.

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Abbreviations

ADL	activities of daily living
CMS	Centers for Medicare & Medicaid Services
HCBS	home- and community-based services
HHS	Department of Health and Human Services
IADL	instrumental activities of daily living

LTSS	long-term services and supports
MCO	managed care organization
MLTSS	managed long-term services and supports

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August 30, 2018

The Honorable Ron Wyden
Ranking Member
Committee on Finance
United States Senate

Dear Mr. Wyden:

In the coming decades, the need for long-term services and supports (LTSS) to assist individuals with limited abilities for self-care is expected to increase, in part due to the aging of the population. Medicaid, a federal-state health financing program for low-income and medically needy individuals, is the nation's primary payer of LTSS. LTSS comprise a broad range of health care, personal care, and supportive services to help individuals with physical, developmental, or cognitive disabilities maintain their quality of life. For example, LTSS can help individuals perform routine daily activities, such as eating, dressing, bathing, and making meals. Many individuals prefer to receive LTSS in home- and community-based settings, rather than receiving care in a nursing home or other institutional setting, because it can help them maintain their independence and participate in community life to the fullest extent possible. LTSS delivered outside of institutional settings are known as home- and community-based services (HCBS), and include adult day care, personal care services, and services provided in assisted living.

While state Medicaid programs are required to finance coverage for beneficiary care in nursing homes, coverage for most HCBS is optional, which creates incentives for Medicaid to deliver LTSS in institutional settings. In recent years the Congress, the Centers for Medicare & Medicaid Services (CMS)—the federal agency within the Department of Health and Human Services (HHS) responsible for overseeing states' Medicaid programs—and states have taken steps to expand the use of

HCBS and shift the provision of LTSS away from institutional settings.¹ For example, the Patient Protection and Affordable Care Act, enacted in 2010, created new options and provided additional funding for states to make HCBS available to eligible Medicaid beneficiaries. In concert with these efforts, the proportion of LTSS spending for HCBS has increased nationwide. In fiscal year 2016, the most recent year of data available, Medicaid spent an estimated \$167 billion on LTSS.² Of that amount, 57 percent—or \$94 billion—was spent on HCBS. However, the extent to which states cover HCBS in their Medicaid programs varies, as does the proportion of LTSS spending used for HCBS; the proportion of Medicaid LTSS spending on HCBS ranged from 27 percent to 81 percent among states in 2016, a three-fold difference.

States have a number of different options to provide Medicaid coverage of HCBS. As a result, states vary in the structure of their HCBS programs. States can provide certain types of HCBS under their state Medicaid plans.³ In addition, states may seek permission from CMS to provide HCBS under waivers of traditional Medicaid requirements; for example, in order to provide services to a specific population, such as individuals with intellectual or developmental disabilities, or to limit the number of beneficiaries who can receive HCBS.

Given the variety of options available for providing HCBS and the wide variation in HCBS spending among states, questions arise about how states are structuring their HCBS programs, as well as challenges they may face in providing access to these services. You asked us to review

¹Increasing access to HCBS is also important for states to be able to comply with the Supreme Court's 1999 decision in *Olmstead v. L.C.*, in which the Court held that unjustified institutionalization of a person based on disability violates Title II of the Americans with Disabilities Act. *Olmstead v. L.C.*, 527 U.S. 581 (1999). In particular, the Court held that states must provide community-based care for persons with disabilities who are otherwise entitled to institutional services when such services are appropriate, the individual does not oppose such treatment, and the community-based care can be reasonably accommodated, taking into account the resources available to a state and the needs of others with disabilities.

²Steve Eiken, Kate Sredl, Brian Burwell, and Angie Amos, *Medicaid Expenditures for Long-Term Services and Supports in FY 2016* (IBM Watson Health, 2018).

³A state Medicaid plan (1) describes the groups of individuals to be covered and the methods for calculating payments to providers; (2) establishes criteria and requirements for providers to be eligible to receive payments; (3) describes the categories of services covered, such as inpatient hospital services, nursing facility services, and physician services; and (4) must be approved by CMS in order for the state to receive matching funds for the federal share of Medicaid payments it makes.

the approaches states use to provide coverage for HCBS in the Medicaid program. This report describes

1. decisions that influenced the structure of selected states' Medicaid HCBS programs, and
2. selected states' challenges providing HCBS to Medicaid beneficiaries and efforts to respond to these challenges.

To address these objectives, we selected a nongeneralizable sample of five states: Arizona, Florida, Mississippi, Montana, and Oregon. We selected these states to obtain variation in several factors, including geographic location, the percentage of the state's population that resides in a rural area, the proportion of the state's LTSS spending for HCBS, and the state's use of various HCBS authorities and managed care.⁴ We focused our work on the optional authorities the selected states used to provide HCBS within Medicaid, including waivers and state plan options.⁵ For the selected states, we reviewed documentation for the 26 HCBS programs operated under these authorities at the time of our review, including waiver applications, state plan amendments, and information about program enrollment and waiting lists. We also conducted interviews with state Medicaid officials in the five selected states and, as applicable, officials from other state agencies, such as state aging or behavioral health agencies that operate Medicaid HCBS programs, to understand how states structured and delivered their HCBS benefits and any challenges faced in providing HCBS.⁶ Additionally, we interviewed officials from two managed care organizations (MCO) in each of the two states (Arizona and Florida) that used a managed care delivery system to provide LTSS, also referred to as managed long-term services and supports (MLTSS). We selected the MCOs to include an MCO that serves a large proportion of LTSS Medicaid beneficiaries in the state and to

⁴Under managed care, states contract with managed care organizations or other health plans to provide or arrange for medical services, and prospectively pay the plans a fixed fee per enrollee, typically per month.

⁵We excluded the Program of All-Inclusive Care for the Elderly, which is a Medicare program and a state Medicaid option that provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals who are generally dually eligible for Medicaid and Medicare.

⁶Each state is required to designate a single state agency to administer or supervise its Medicaid program, and states may designate other state and local agencies to administer and oversee components of their programs, including their HCBS. We spoke with officials from other state agencies that operated Medicaid HCBS programs in three of the five selected states—Florida, Mississippi, and Oregon.

achieve diversity in population served.⁷ To gather additional information on factors and challenges that affect Medicaid HCBS programs, we also interviewed CMS officials, the CMS contractor who produces an annual report on LTSS expenditures in Medicaid, and representatives from two aging and developmental disability professional groups.

We conducted our performance audit from July 2017 through August 2018 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Individuals who have a limited ability to care for themselves due to physical, cognitive, or mental disabilities or conditions may require a range of LTSS that include hands-on assistance with, or supervision of, daily tasks. Individuals with LTSS needs range from young children to older adults, and they have varying degrees of difficulty performing without assistance (1) activities of daily living (ADL), such as bathing, dressing, toileting, and eating, or (2) instrumental activities of daily living (IADL), such as preparing meals, housekeeping, using the telephone, and managing money; they may require full or partial assistance to complete some—or all—of the ADLs and IADLs.

LTSS are generally provided in two settings: (1) institutional settings, such as nursing facilities and intermediate care facilities for individuals with intellectual disabilities; and (2) home and community settings, such as homes or assisted living facilities.⁸ LTSS provided in home- and community-based settings comprise a wide range of services and

⁷In Arizona, the Department of Economic Security, a state agency, has had a capitated managed care contract to provide HCBS to Medicaid beneficiaries with intellectual or developmental disabilities for over 20 years; therefore, for the purposes of this work, we refer to the department as an MCO rather than as a state agency.

⁸Assisted living facilities provide a residential alternative to nursing home care for individuals who prefer to live independently but need assistance to maintain their independence. For past GAO work on state Medicaid programs covering assisted living services, see GAO, *Medicaid Assisted Living Services: Improved Federal Oversight of Beneficiary Health and Welfare is Needed*, [GAO-18-179](#) (Washington, D.C.: Jan. 5, 2018).

supports to help individuals remain in or return to their homes or communities. HCBS include personal care services to provide assistance with ADLs or IADLs, adult day care services, certain home modifications that allow beneficiaries to remain in their home, non-medical transportation, respite care for caregivers, and case management services to coordinate services and supports.⁹ Direct care workers—personal care aides, homemakers, companions, and others—provide the majority of the paid care for individuals with LTSS needs.

Medicaid Coverage of HCBS

Medicaid provides states with a number of options for providing HCBS, including through state plan benefits and through waivers and demonstrations. Since 1975, states have had the option to offer personal care services under their state Medicaid plan, which covers assistance with ADLs and IADLs, either at home or in another location.¹⁰ States also have the option to cover HCBS for Medicaid beneficiaries through waivers and demonstrations, under which states may, for example, provide services not otherwise covered by Medicaid to designated populations who may or may not otherwise be eligible for Medicaid services. States have the option to seek approval for waivers and demonstrations that allow them to target HCBS to specific populations or conditions, limit the availability of those services geographically, and limit the number of individuals served through the use of enrollment caps—actions that are generally not otherwise allowed under Medicaid, but may enable states to control costs. Table 1 below summarizes key characteristics of selected state plan and waiver authorities that states can use to provide HCBS.

⁹Respite care provides a range of services to beneficiaries when unpaid caregivers are absent or need relief.

¹⁰For past GAO work examining CMS oversight of states' provision of Medicaid personal care services, which can be offered under multiple authorities, see *Medicaid Personal Care Services: CMS Could Do More to Harmonize Requirements across Programs*, [GAO-17-28](#) (Washington, D.C.: Nov. 23, 2016) and *Medicaid: CMS Needs Better Data to Monitor the Provision of and Spending on Personal Care Services*, [GAO-17-169](#) (Washington, D.C.: Jan. 12, 2017).

Table 1: Selected Optional Authorities for Providing Medicaid Home- and Community-Based Services (HCBS)

Title	Authorizing statute ^a	Date enacted	Type of authority	Allows targeting to specific populations	Allows capped enrollment	Limited to individuals who need an institutional level of care ^b	Number of states using authority ^c
State plan personal care services	1905(a)(24)	1975 ^d	State plan	n/a	n/a	n/a	29
HCBS waiver ^e	1915(c)	1981	Waiver	applicable	applicable	applicable	48
State plan HCBS	1915(i)	2006	State plan	applicable	n/a	n/a	14
Participant-directed personal assistance services ^f	1915(j)	2006	State plan	applicable	applicable	n/a	8
Community First Choice	1915(k)	2010	State plan	n/a	n/a	applicable	8
Medicaid demonstration ^g	1115	1965	Waiver	applicable	applicable	n/a	12

Legend: ✓ = applicable to the authority; — = not applicable to the authority

Source: Social Security Act and Centers for Medicare & Medicaid Services (CMS). | GAO-18-628

^aAuthorizing statute refers to sections of the Social Security Act.

^bIndividuals who need an institutional level of care are those who meet the state's eligibility requirements for services in an institutional setting, such as a nursing facility.

^cInformation from CMS on state use of HCBS authorities is as of December 2017.

^dStarting in 1975, states have had the option of offering personal care services as a Medicaid state plan benefit. In its present form, section 1905(a)(24) of the Social Security Act, enacted in 1993, authorizes states to provide personal care services as a covered service in their state Medicaid plans.

^eFederal law requires 1915(c) waivers to be cost neutral—that is, states must show that the average Medicaid expenditures for services provided under a waiver are equal to or less than the average for the same population to be served in an institution. See 42 U.S.C. § 1396n(c)(2)(D).

^fThe participant-directed personal assistance services option allows beneficiaries to express choice and control over the budget, planning, and purchase of personal care and related services. This is not a standalone option for states, but, instead, must be offered in conjunction with either state plan personal care services or a 1915(c) HCBS waiver.

^gPer Department of Health and Human Services policy, section 1115 demonstrations must be budget neutral; that is, the federal government should spend no more under a state's demonstration than it would have spent without the demonstration.

The 1915(c) waiver, named for the statutory provision authorizing it in the Social Security Act, is the primary means through which states provide HCBS coverage for Medicaid beneficiaries. Added as an option in 1981, these waivers account for the majority of Medicaid HCBS expenditures.¹¹ Under 1915(c) waivers, states may cover a broad range of services for

¹¹According to CMS, of the about \$94 billion spent on HCBS in fiscal year 2016, over half (about \$48 billion) was spent on 1915(c) waiver services. See Eiken, Sredl, Burwell, and Amos, *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*.

participants, as long as these services are required to prevent institutionalization. Therefore, to be eligible, individuals must demonstrate the need for an institutional level of care by meeting state eligibility requirements for services in an institutional setting, such as a nursing facility. Prior to 2014, states were required to have multiple 1915(c) waivers if they chose to target different populations—using, for example, one waiver for individuals with developmental disabilities and another for individuals with physical disabilities. However, beginning in March 2014, CMS permitted states to combine target groups within a single 1915(c) waiver as long as the services offered were the same for all groups.¹²

States' 1915(c) waivers are required by federal law to be cost neutral; that is, states must show that the average Medicaid expenditures for the services provided under the waiver are equal to or less than what average expenditures would be if that same population were to be served in an institutional setting.¹³ States may apply cost neutrality in the aggregate across all waiver participants—meaning that some individuals can be more costly to serve in home- and community-based settings than in an institution—or individually, meaning that spending for each waiver participant can be no more than what it would cost to serve the individual in an institution. States also have the option to limit the number of beneficiaries served under a 1915(c) waiver by establishing a predefined enrollment cap. States with enrollment caps may establish a waiting list, and a nationwide survey of state Medicaid officials estimated that there were over 600,000 individuals on waiting lists for 1915(c) waiver services in 2015.¹⁴

The newest Medicaid option for covering HCBS—the Community First Choice state plan option under section 1915(k) of the Social Security Act—was established by the Patient Protection and Affordable Care Act in 2010. Under this option, states must provide personal care services to assist beneficiaries with ADLs and IADLs and services to support the acquisition of skills necessary for beneficiaries to accomplish these daily

¹²See State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 3015 (Jan. 16, 2014).

¹³42 U.S.C. § 1396n(c)(2)(D).

¹⁴Terence Ng, Charlene Harrington, MaryBeth Musumeci, and Petry Ubri, *Medicaid Home- and Community-Based Services Programs: 2013 Data Update* (Menlo Park, Calif.; Kaiser Family Foundation, 2016).

activities, among other things.¹⁵ The Community First Choice option also allows for the coverage of other services, such as the costs associated with moving a beneficiary from an institution to a home- or community-based setting. Like the 1915(c) waiver, this option is limited to individuals who meet the state's institutional level-of-care criteria, but unlike the 1915(c) waiver, enrollment in a 1915(k) Community First Choice program cannot be capped. States that offer this benefit receive a 6 percentage point increase in their federal medical assistance percentage for services provided under this option.¹⁶

Medicaid Spending on LTSS

Medicaid spending on LTSS is significant, representing about 30 percent of total Medicaid program spending in fiscal year 2016, and the percentage of LTSS spending used for HCBS has grown over time.¹⁷ CMS's annual reports on LTSS expenditures have shown that national spending for HCBS as a percentage of LTSS spending surpassed the percentage spent on institutional care in fiscal year 2013 and has continued to grow, climbing to 53 percent in fiscal year 2014, 54 percent in 2015, and 57 percent in 2016.¹⁸ At the state level, 29 states spent more

¹⁵The other services states are required to cover are (1) back-up systems, such as personal emergency response systems or pagers, to ensure continuity of services; and (2) voluntary training on how to select, manage, and dismiss care providers. The Community First Choice state plan option requires that the services provided to beneficiaries be based on an individualized assessment of their needs.

¹⁶The federal government and states share in the financing of Medicaid expenditures, with the federal government matching most state expenditures for services on the basis of a statutory formula, known as the federal medical assistance percentage. The federal share of Medicaid expenditures typically ranges from 50 to 83 percent.

¹⁷Eiken, Sredl, Burwell, and Amos, *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*.

¹⁸CMS officials said the agency uses these LTSS expenditure reports, in part, to track progress on two HCBS-related goals under the Government Performance and Results Act: (1) to increase the percentage of Medicaid spending on LTSS for HCBS to 65 percent by 2020; and (2) to increase the number of states with more than 50 percent of Medicaid LTSS spending used for HCBS by 2020.

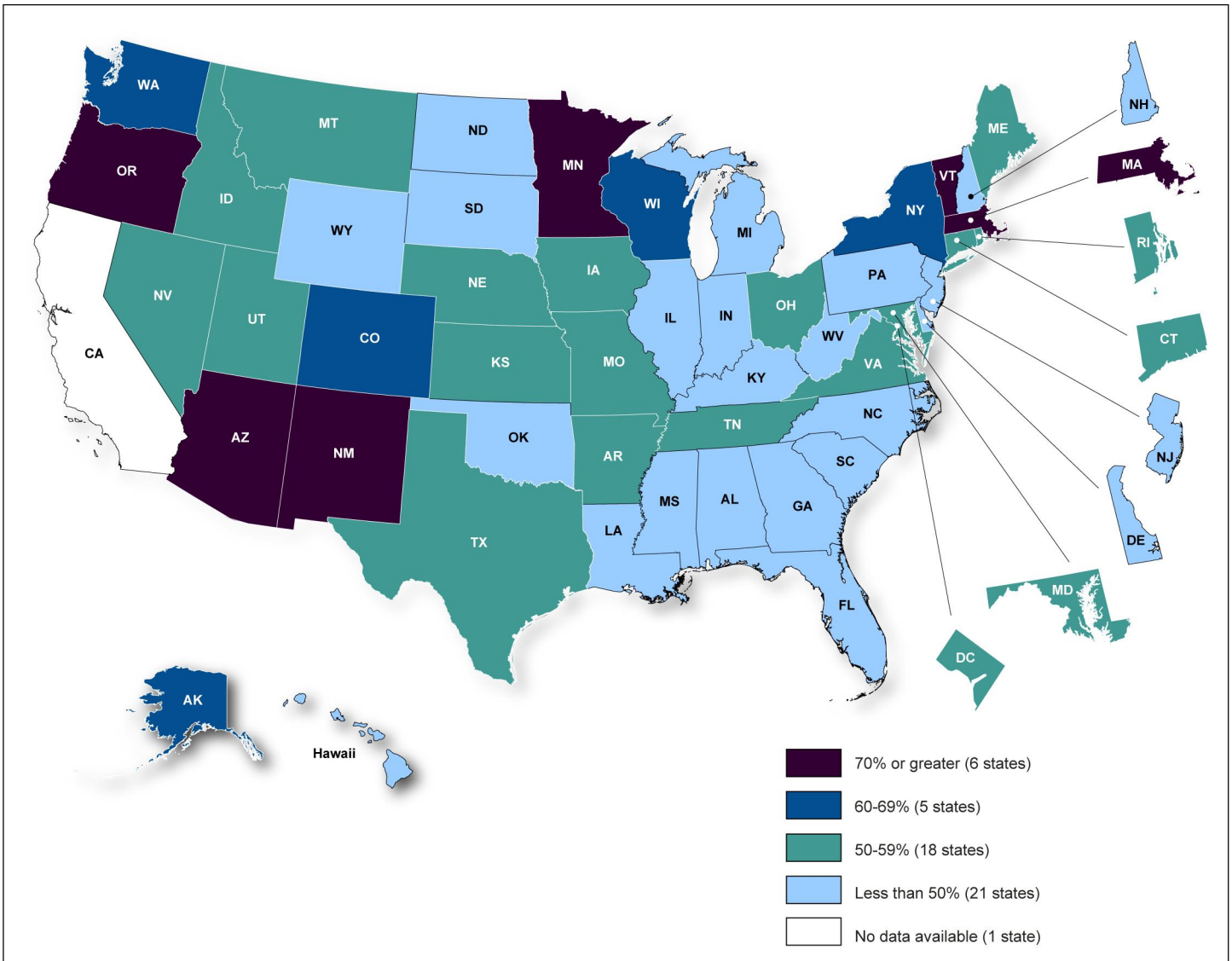
on HCBS than institutional care in fiscal year 2016, but the percentage of HCBS spending varied widely across states.¹⁹ (See fig. 1.)

¹⁹For the purpose of this report, we refer to the District of Columbia as a state.

CMS's LTSS expenditure reports also suggest that the percentage of LTSS spending for HCBS varies by population, with a greater proportion of HCBS spending for individuals with intellectual or developmental disabilities than for older adults and individuals with physical disabilities. However, CMS does not collect LTSS expenditure data by population, and therefore it is difficult to estimate population spending with precision.

CMS has also produced four reports that examine the percentage of Medicaid LTSS beneficiaries served (as opposed to spending) in home- and community-based settings. The most recent report, based on calendar year 2013 data, showed that almost all states served a majority of their LTSS beneficiaries in home- and community-based settings, with a nationwide average of 72 percent. See Steve Eiken, *Medicaid Long-Term Services and Supports Beneficiaries in 2013* (Truven Health Analytics, 2017). CMS officials told us that HCBS accounted for a higher percentage of beneficiaries than spending because HCBS users have a lower average cost per person than beneficiaries in institutional settings.

Figure 1: Percentage of Medicaid Long-Term Services and Supports (LTSS) Spending on Home- and Community-Based Services, by State, Fiscal Year 2016



Sources: GAO analysis of Centers for Medicare & Medicaid Services data; Map Resources (map). | GAO-18-628

Note: The Centers for Medicare & Medicaid Services' annual report on 2016 LTSS expenditures does not provide a percentage for California because a significant portion of its data was missing. South Carolina and Michigan were also missing some data on managed care expenditures.

As states' options for providing HCBS within Medicaid and spending on HCBS have grown, Congress has also authorized temporary programs aimed at increasing the provision of HCBS.

- Money Follows the Person was established by the Deficit Reduction Act of 2005 as a demonstration grant program to support states' transition of eligible individuals who want to move from institutional settings back to the community. As of September 2016, CMS had awarded a total of about \$3.7 billion in grant funding to 44 states. According to CMS, as of December 2016, funding from the program had been used to support the transition of more than 75,000 individuals back into the community. Authorization for the Money Follows the Person program expired at the end of fiscal year 2016, but states have through fiscal year 2018 to transition new beneficiaries and through fiscal year 2020 to spend any remaining grant funds.
- The Balancing Incentive Program was created by the Patient Protection and Affordable Care Act to help states rebalance their provision of LTSS toward greater use of HCBS. Under the program, states that spent under 25 percent of their LTSS expenditures on HCBS in fiscal year 2009 qualified for a 5 percentage point increase in their federal medical assistance percentage for state HCBS expenditures. States that spent between 25 and 50 percent were eligible for a 2 percentage point increase. In return, states agreed to increase the percentage of LTSS spending for HCBS to achieve a specific benchmark.²⁰ Under the program, CMS provided \$2.4 billion in enhanced federal matching payments over 4 years (October 2011 – September 2015) to 21 states. According to CMS, 15 of the 21 states met their balancing benchmark by September 2015, when the program ended.²¹

HCBS Delivery Systems

States can choose among delivery systems, such as fee-for-service and MLTSS (i.e., managed care), to provide HCBS. Under fee-for-service, states pay providers directly and on a retrospective basis for each covered service they deliver. In contrast, in MLTSS, states contract with MCOs to provide a specific set of covered services to beneficiaries in

²⁰States were also required to undertake certain structural reforms as part of the Balancing Incentive Program, such as the creation of “no wrong door” systems to enable consumers to access all LTSS from a single point of entry.

²¹Of the remaining six states, three states ended their participation in 2014 before completing the program and three states did not meet their balancing benchmark by September 2015. After the program ended, participating states were permitted, with CMS approval, to expend remaining funds through September 2017.

return for one fixed periodic payment per beneficiary, typically per member per month.²² These payments are referred to as capitation payments. The use of MLTSS has increased over time; MLTSS spending rose from \$10 billion in fiscal year 2012 to about \$39 billion in 2016.²³ According to a 2018 CMS report, 24 states had implemented 41 MLTSS programs as of August 2017, and there were about 1.8 million Medicaid beneficiaries enrolled in MLTSS programs.²⁴

Selected States' HCBS Program Structures Reflect Decisions about Populations to Cover, Whether to Limit Eligibility or Enrollment, and Managed Care Preferences

The structure of the 26 HCBS programs we reviewed in selected states reflected decisions about which populations states wanted to cover, whether to limit eligibility for or enrollment in HCBS programs, and whether the state wanted to provide HCBS through managed care (i.e., MLTSS). In two states, settlements resulting from litigation also affected the structure of HCBS programs.

Decisions about Which Populations to Cover

Four of our five selected states—Florida, Mississippi, Montana, and Oregon—had multiple HCBS programs (21 in total) that targeted specific populations. The fifth state, Arizona, used one program to provide HCBS to individuals who are aged or disabled and those with intellectual or developmental disabilities. The remaining four programs were not

²²States may have different types of managed care arrangements in Medicaid; in this report, we are referring to comprehensive, risk-based managed care, the most common type of managed care arrangement. MLTSS programs can also include prepaid inpatient health plans and prepaid ambulatory health plans.

²³Eiken, Sredl, Burwell, and Amos, *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*, 9. Due to challenges with collecting MLTSS data, CMS's contractor reported that this is a conservative estimate of overall MLTSS expenditures.

²⁴The estimate of the number of MLTSS enrollees was based on data from 2016 and 2017. See Elizabeth Lewis, Steve Eiken, Angela Amos, and Paul Saucier, *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update* (Truven Health Analytics, 2018).

targeted to specific populations. (See appendix I for a list of the HCBS programs and populations served in each of the selected states.)

- All four of Florida's HCBS waiver programs targeted specific populations, such as individuals with intellectual or developmental disabilities and individuals with familial dysautonomia.²⁵ Florida's HCBS program for intellectually and developmentally disabled individuals included an individual budgeting model through which the beneficiaries and their guardians could choose which services they received and which providers would deliver the services. Such individual budgeting also allowed beneficiaries the flexibility to make adjustments in services and providers as their needs changed.
- All of Mississippi's six HCBS programs provided services to targeted populations, including the aged or disabled and individuals with severe orthopedic and neurological impairment. Two of the programs were targeted to individuals with intellectual or developmental disabilities, including a state plan benefit that provided services that help beneficiaries develop daily living and social skills, as well as opportunities to participate in community activities, and promote an individual's ability to obtain and maintain employment.²⁶
- Four of Montana's six HCBS programs targeted specific populations, including those with severe disabling mental illness and children with autism. Officials from Montana told us that one of the reasons for implementing the program for children with autism was to provide early intensive treatment to lessen the degree of services needed later in life.²⁷ In addition to its programs for specific populations, Montana also operated two programs that provided personal care

²⁵Familial dysautonomia is a genetic disorder that affects the nervous system and can cause many symptoms, including reduced sensitivity to temperature changes and pain, kidney and heart problems, erratic or unstable blood pressure, and increased risk of bone fractures.

²⁶Mississippi implemented a 1915(i) state plan HCBS program to provide day habilitation, prevocational, and supported employment services for individuals with intellectual or developmental disabilities. Day habilitation includes services provided in a setting outside the home that are focused on the improvement of skills needed for the individual to function as independently as possible. Prevocational and supported employment services help individuals apply for and maintain gainful employment.

²⁷In response to 2014 CMS guidance that clarified policy regarding the requirement to provide necessary diagnostic and treatment services for children with autism spectrum disorder, the Montana HCBS program for children with autism is being phased out and replaced with state plan services. Officials told us that the tentative plan is to terminate the program in July 2019, although no date had been set as of December 2017.

services to a broader Medicaid population requiring assistance with ADLs and IADLs—the personal care state plan benefit and the Community First Choice program. Montana officials told us that one of the factors the state considered when implementing the Community First Choice program was the 6 percent enhanced federal match for this program; before implementing the program, Montana projected that the increase in federal funds would allow the state to serve an additional 150 beneficiaries per year.²⁸

- Oregon had nine different HCBS programs, seven of which targeted specific populations, including children with LTSS needs and different populations of individuals with intellectual or developmental disabilities. Like Montana, Oregon also had two personal care services programs that served all eligible Medicaid beneficiaries—a state plan benefit and a Community First Choice program. Oregon officials explained that they were also attracted to the Community First Choice option due to the enhanced federal match, as well as the opportunity to expand the array of services available. For example, in addition to providing personal care services, Oregon’s Community First Choice program also covers costs associated with transitioning beneficiaries from institutions to home- or community-based settings, such as the first month’s rent, utility deposits, bedding, and basic kitchen supplies.

Decisions about Whether to Limit Eligibility or Enrollment

All five of the selected states had at least 1 HCBS program that limited eligibility to individuals who require an institutional level of care. Specifically, 22 of the 26 HCBS programs we reviewed limited eligibility to this population. The remaining 4 programs—in Mississippi, Montana, and Oregon—were state plan HCBS or personal care services programs, which were operated under authorities that do not permit limiting enrollment to individuals with an institutional level-of-care need.

Four of the selected states—Florida, Mississippi, Montana, and Oregon—had enrollment caps for 1 or more of their HCBS programs, namely all of

²⁸CMS’s 2015 report to Congress on the Community First Choice program presents a number of reasons states were motivated to add this option to their state plans. See Department of Health and Human Services, *Community First Choice: Final Report to Congress as Required by the Patient Protection and Affordable Care Act of 2010 (P.L. 111–148)* (Washington, D.C.: December 2015).

the 19 HCBS programs operated under 1915(c) waivers.²⁹ Some of the state officials we spoke with told us that they used historical data on utilization, cost-of-care per person, and the annual number of requests for enrollment, as well as information on available funding, when determining their enrollment caps. However, states can also obtain CMS approval to change their enrollment caps over time to respond to increased demand or to include additional populations. Oregon officials told us that the state has generally been able to increase the enrollment cap for the aged or disabled program as needed in order to meet demand.³⁰ Montana officials told us that the enrollment cap for their HCBS program for individuals with intellectual or developmental disabilities—originally limited to children—was increased when the state decided to expand the program to serve adults.

The four selected states maintained waiting lists for 12 of the 19 HCBS programs that limited enrollment through enrollment caps.³¹ However, because states differed on whether they determined eligibility before adding individuals to the waiting list, information on the number of individuals on these waiting lists is not comparable across states.³² For example, Florida did not screen for eligibility prior to placing individuals on the waiting list of its aged or disabled waiver, which totaled over 48,000 individuals as of December 2017. By contrast, individuals on Montana's much smaller aged or disabled waiting list were pre-screened for

²⁹According to a 2016 report produced under contract with CMS, 1915(c) waivers are attractive to states in part because of the ability to limit enrollment, which allows states to more easily control costs. See Audra Wezlow, Steve Eiken, and Kate Sredl, *Improving the Balance: The Evolution of Medicaid Expenditures for Long-Term Services and Supports (LTSS), FY 1981-2014* (Truven Health Analytics, 2016).

³⁰Officials explained that if the state were to reach the enrollment cap as specified in the approved waiver application, they would submit a waiver amendment to CMS to request an increase.

³¹Of the remaining seven programs, four were in Oregon, where, as discussed above, state officials reported being able to increase the enrollment caps as needed. The others included two Florida programs that focused on individuals with very specific diseases and a program for children with autism in Montana that is being phased out and thus no longer maintains a waiting list.

³²A 2017 report produced under contract with CMS also found that waiting lists were not comparable across states and detailed other limitations of using waiting lists to measure access to HCBS. For example, waiting list numbers may include individuals who are not eligible for or who no longer need HCBS and may not reflect increases in the number of people receiving HCBS. See Paul Saucier, Jessica Kasten, and Angie Amos, *Do Managed Care Programs Covering Long-Term Services and Supports Reduce Waiting Lists for Home and Community-Based Services?* (2017).

eligibility. In addition, states varied on whether and how they set priorities for enrollment in the waiver for individuals on the waiting list.³³ For example, the Montana aged or disabled waiver set priorities for an individual's enrollment according to various state criteria, including risk of institutionalization, and an assessment of informal supports. By contrast, in Mississippi, individuals on the intellectual or developmental disabilities waiting list generally gained enrollment into the waiver in order of their date of eligibility.³⁴

Decisions about Whether to Use MLTSS

Two of the selected states we reviewed—Arizona and Florida—used MLTSS for one HCBS program. Officials from these states told us the ability to use managed care contracts to (1) set incentives aimed at transitioning individuals from institutions to home- and community-based settings and (2) increase oversight of providers were important factors in choosing MLTSS to provide HCBS.

- **Setting incentives for transitions.** State officials told us that they used contract incentives to shift services from nursing facilities to community-based care in their MLTSS programs.³⁵ Specifically, Arizona and Florida used blended capitation rates, meaning that the rate or amount the states pay MCOs to cover expected costs for each LTSS beneficiary is the same for all beneficiaries regardless of whether they are in a nursing home or in a home- and community-based setting. Because HCBS is generally less expensive than LTSS delivered in institutional settings, blended rates can create a financial advantage for the MCO to serve as many beneficiaries as possible in

³³CMS requires states that maintain a waiting list to have policies that govern the selection of individuals for entrance to the program when capacity becomes available. For example, states could enroll individuals from the waiting list based on the date of the individual's application or based on the individual's need for services as determined through an assessment process.

³⁴Although individuals primarily gained enrollment into the waiver in order of their date of eligibility, Mississippi also set aside a certain number of spaces for individuals transitioning from institutions and individuals in emergency situations.

³⁵Arizona officials told us that, as of September 2017, 73 percent of Arizona's aged or disabled LTSS beneficiaries were served in HCBS settings, compared with 54 percent in Florida in December 2017. Oregon officials said that while the state does not use MLTSS, they track beneficiaries served in home- and community-based settings. Officials said that as of January 2018, nearly 88 percent of Oregon's aged and disabled LTSS recipients were served in home- and community-based settings.

home- and community-based settings. Three of the MCOs we spoke with provided examples of how they have responded to these incentives to provide HCBS. For example, an official from one MCO told us that the MCO had created new positions for “transition clinicians,” registered nurses who use their medical knowledge to systematically evaluate beneficiaries in an institution to determine if they may be a candidate for transition to a community-based setting. The official explained that after the transition clinician identifies a potential candidate, the clinician will evaluate other factors, including the candidate’s current housing options and level of familial support, in order to ensure that necessary resources are in place when the beneficiary leaves the institution. In addition, the official said they facilitated transitions by providing beneficiaries leaving nursing facilities with a one-time \$2,500 transition allowance that can be used for expenses such as security or utility deposits, furniture, or new resident fees at an assisted living facility.

- **Oversight of MCOs.** According to officials from Arizona and Florida, the states chose to use MLTSS because it afforded better oversight of providers and had the potential to improve patient outcomes. Specifically, officials said that managing a limited number of MCOs, who in turn have contracts with HCBS providers, allows for better oversight and outcomes, and has led to service delivery improvements, compared to paying providers on a fee-for-service basis.³⁶ For example, Florida officials explained that they recently consolidated three smaller fee-for-service programs into their MLTSS program. Prior to that consolidation, the three fee-for-service programs provided HCBS to approximately 7,500 individuals with AIDS, traumatic brain injury/spinal cord injury, and individuals with cystic fibrosis. Officials said that they did not believe providers in these smaller fee-for-service programs were providing good care, based on service utilization analyses that showed some beneficiaries were not accessing any services beyond one case management service per month. Furthermore, the officials also told us that it was harder to assess quality of care in the fee-for-service programs compared to MLTSS. Officials said that now that these beneficiaries receive care under the MLTSS waiver, there is more accountability and improved quality of care.

³⁶Representatives from an aging and disability group we spoke to told us that it can be difficult for a state Medicaid agency with a limited staff to manage thousands of fee-for-service providers and that providing oversight and ensuring accountability of a limited number of MCOs can seem like a more manageable task.

Representatives from aging and developmental disability professional groups we interviewed said that states may also choose to implement MLTSS programs to achieve greater budget predictability and control costs. CMS's recent report on the growth of MLTSS also notes states' desire for improvements in quality of care and outcomes; increased access to HCBS providers; and better care coordination, among other factors.³⁷ We have previously reported that although MLTSS can provide states with the opportunity to enhance and encourage the provision of HCBS, oversight at the state and federal levels is critical to ensure that individuals with LTSS needs are able to obtain needed care in a timely fashion.³⁸ In addition, our prior work on MLTSS payment rates found that five states—including Arizona and Florida—set clear financial incentives in their MCO payment rates for greater use of community-based care, while one state's rate structure included higher payments for beneficiaries receiving institutional care. This state's rate structure could have created an incentive for MCOs to move higher-cost beneficiaries from the community to an institution. Additionally, we found that most of the states reviewed for that prior work were not specifically linking payments with MLTSS program goals such as beneficiary outcomes and that federal oversight of states' MLTSS payment structures was limited. We made several recommendations to improve CMS's oversight of states' payment structures for MLTSS. CMS agreed with our recommendations and reported actions it planned to take to address them.³⁹

Officials from the three selected states that do not use MLTSS cited various reasons for this, such as stakeholder opposition and state law restrictions on enrolling individuals receiving LTSS in managed care. For example, officials in Oregon explained that stakeholders objected to the profit motive they assumed an MCO would have, which the stakeholders

³⁷Elizabeth Lewis, Steve Eiken, Angela Amos, and Paul Saucier, *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update* (Truven Health Analytics, 2018).

³⁸GAO, *Medicaid Managed Care: CMS Should Improve Oversight of Access and Quality in States' Long-Term Services and Supports Programs*, [GAO-17-632](#) (Washington, D.C.: Aug. 14, 2017). We recommended that CMS take steps to identify and obtain key information to oversee states' efforts to monitor beneficiary access to quality services, including, at a minimum, obtaining information specific to network adequacy, critical incidents, and appeals and grievances. CMS agreed with our recommendation and cited actions it planned to take to address the recommendation.

³⁹GAO, *Medicaid Managed Care: Improved Oversight Needed of Payment Rates for Long-Term Services and Supports*, [GAO-17-145](#) (Washington, D.C.: Jan. 9, 2017).

believed would compromise quality of care and reduce beneficiaries' choice of providers. Officials in Montana said that because the state was rural and had relatively few Medicaid beneficiaries, MLTSS would not be cost effective.

The Effects of Litigation on the Structure of HCBS Programs

Officials from two of the selected states—Oregon and Mississippi—told us that settlements resulting from litigation have shaped the structure of their HCBS programs for certain populations. Oregon officials explained that a legal settlement in 2001 resulted in the creation of an additional HCBS program for individuals with intellectual or developmental disabilities and the elimination of an HCBS waiting list for this population. In Mississippi, officials explained that as a result of a legal settlement in 2005, the state increased enrollment in certain HCBS programs. As a result of the settlement, officials said that state case managers contacted all 1,900 individuals who resided in institutions at the time to determine their interest in living in a home- and community-based setting. Those who expressed interest were evaluated to determine if they could live outside an institution and whether adequate familial or other support was available. Based on this information, and as a result of additional funding from the state legislature as a result of the lawsuit, the state was able to add new beneficiaries to several of its HCBS programs.

Selected States Described Challenges Providing HCBS, Such As Workforce Issues, and Steps Taken to Respond to These Challenges

Officials from the five selected states and MCOs we interviewed described challenges with providing HCBS, including workforce issues, such as recruiting and retaining direct care workers; serving beneficiaries with complex medical and behavioral health needs; and other challenges. The officials also reported taking steps to respond to these challenges.

HCBS Workforce Challenges

Officials from all five selected states and three of the four MCOs we interviewed described workforce challenges, such as recruiting and retaining direct care workers and ensuring the availability of HCBS providers in rural and remote areas. For example, officials from Montana and Oregon noted that the low wages paid to direct care workers, who provide hands-on care and assistance with ADLs and IADLs, contribute to workforce shortages. According to the officials, direct care workers can typically earn more by working at a fast food restaurant. Officials from Montana and Mississippi and officials from three of the MCOs said the workforce shortages are often worse in rural or remote areas, where travel across long distances is common. For example, the state officials said that it can be hard to find a provider willing to drive a long distance each way to work for only a few hours.

To respond to these workforce issues, officials from Montana and Mississippi and two MCOs reported offering higher payment rates to providers. In 2017, the Montana legislature approved special funding to raise the hourly wage for direct care workers providing care in certain Medicaid HCBS programs in state fiscal year 2019.⁴⁰ Officials from Mississippi said that based on a study of provider reimbursement rates in one of their HCBS waiver programs, the state raised payment rates for agencies that employ direct care workers and other providers in 2017. Officials said they hoped the increase would create an incentive to recruit and develop providers in more rural areas. Officials from Arizona and Montana and one MCO also mentioned that Medicaid's participant-directed options—which allow beneficiaries to draw paid caregivers from among their family members, friends, and neighbors—had helped to address HCBS workforce shortages. Arizona officials said that roughly half of beneficiaries in its HCBS program who were receiving personal care services got their care from family members, including spouses and parents of adult children living in the home.

Serving HCBS Beneficiaries with Complex Needs

Officials from four of the five selected states and all four MCOs we spoke with said they faced challenges providing HCBS for beneficiaries with

⁴⁰This funding, however, is contingent upon the state's general revenues meeting specific targets.

complex medical or behavioral health needs. Officials we interviewed said that complex medical conditions can be hard to accommodate in home- and community-based settings. For example, officials from Mississippi and one MCO mentioned difficulties finding appropriate placements for individuals requiring ventilator services. State and MCO officials also reported that complex conditions that affect beneficiaries' behavior, such as co-occurring developmental disabilities and behavioral health conditions, dementia, and traumatic brain injury can also create challenges for providing HCBS, particularly when beneficiaries display aggressive or other challenging behaviors. Officials from one MCO explained that these beneficiaries' challenging behaviors can cause friction between beneficiaries and their providers and make it harder for beneficiaries to sustain good relationships with providers.

Officials from the selected states and MCOs we interviewed said that they have responded to the challenge of serving HCBS beneficiaries with complex medical or behavioral health needs by (1) supporting the development of locations in the community to serve individuals with specific complex needs, (2) training providers, and (3) increasing care coordination.

- Officials from one MCO said that they worked with nurses in the community to support the development of adult foster homes as an alternative to institutional care for beneficiaries who require ventilator services. Similarly, Montana officials said they had reached out to community partners, such as assisted living facility owners, to educate them on what Medicaid can and cannot pay for in order to aid them in developing multiple funding streams for specialized programs for individuals with traumatic brain injury.
- Montana officials and officials from an MCO said they had offered behavioral health training for providers; Montana offered a mental health first aid class for providers, and MCO officials reported sending behavioral health specialists into assisted living facilities to help train staff on handling challenging behaviors in an effort to avoid beneficiaries being moved out of the assisted living facility and into an institutional setting.
- Regarding care coordination, Arizona officials reported that the state is planning to offer beneficiaries with intellectual or developmental disabilities the choice of a model of care that integrates medical care, behavioral health care, and certain LTSS, under a single, comprehensive managed care contract beginning in October 2019. Officials from one MCO said this model of care will help better identify

needs and coordinate care, for example, for children with autism and a co-occurring behavioral health condition.

Limited Funding for HCBS Programs

Officials from four selected states and officials from one of the MCOs in the fifth state told us that limits on funding for HCBS programs were a challenge, particularly in the context of the growing number of individuals with LTSS needs.

- Officials from Mississippi said that lack of funding from the state legislature had affected the enrollment of beneficiaries in certain HCBS waivers.⁴¹ Specifically, officials said that the state was unable to enroll as many beneficiaries in certain waivers as were approved by CMS, and that only a limited number of beneficiaries had been added to these programs for the past 2 or 3 years.
- Officials from one MCO in Arizona said that state budget constraints had led to past reductions in the amount of certain HCBS, such as respite care.
- Oregon officials said that the state experienced budgetary pressures as a result of implementing its 1915(k) Community First Choice state plan program, namely, that the increase in federal funding the state received did not fully cover the increased cost of serving all eligible beneficiaries as required under this option.⁴²
- Florida officials said that the state has experienced rapid growth in the population with LTSS needs and that this growth, combined with medical advances that prolong life and reduce attrition from waiver programs, had contributed to a growing waiting list for HCBS.

⁴¹Representatives from a developmental disability professional group we spoke with said that economic conditions in a state can affect how much state legislatures appropriate for HCBS. Representatives from an aging and disability professional group we interviewed said that advocacy from individuals with LTSS needs and their families and from the nursing home industry can also influence funding decisions.

⁴²Oregon officials said that the state had underestimated the increase in caseload and spending that would occur from implementing their 1915(k) program. Officials noted that services provided under 1915(k) are based on beneficiaries' assessed level of need and are not subject to a cap on the number of hours of care provided. This is in contrast to Oregon's personal care state plan benefit, for which there is generally a cap of 20 hours of personal care services per beneficiary per month.

Officials who cited HCBS funding as a challenge said that they responded to these challenges by, among other things, providing information to their legislatures on the projected need for HCBS to inform future funding decisions. For example, Florida officials said that they educate the legislature about funding needs by conducting estimating conferences that produce information that is provided to the Governor and both legislative houses to use when deciding funding amounts. The information provided includes the growth in the population of frail elders, the projected demand for Medicaid, the cost of providing HCBS, and the cost avoidance achieved by keeping people out of nursing homes.⁴³

State officials have also leveraged alternative funding sources—including federal grants—to help respond to funding limits for HCBS. Officials from Montana and Mississippi said that CMS’s Money Follows the Person grant program—which provided state Medicaid programs with funding for beneficiaries to transition out of institutions—had helped them to serve more individuals in home- and community-based settings.⁴⁴ Montana officials noted that Money Follows the Person provided the state with extra help to transition beneficiaries who were the most difficult to serve and often had multiple co-occurring conditions from institutions to community-based settings. Mississippi’s Money Follows the Person program—Bridge to Independence—resulted in a total of 540 beneficiaries moving from institutions to home- and community-based settings, according to state officials. Mississippi officials also noted that they maximize HCBS waiver funding by leveraging other potential funding sources, such as charitable organizations, that could pay for items such as a wheelchair ramp for a beneficiary before waiver funds were expended.

Other Challenges

State and MCO officials also mentioned other challenges providing HCBS:

⁴³According to Florida officials, the state’s MLTSS program had resulted in \$716 million in avoided institutional costs from 2014 through 2016. Cost avoidance of \$200 million per year was projected beyond 2016.

⁴⁴Mississippi also participated in the Balancing Incentive Program, which provided funding for states to increase their percentage of LTSS spending for HCBS, among other things.

- **Affordable housing.** Officials from Mississippi and Montana and one MCO cited the lack of affordable housing as a barrier for beneficiaries wishing to transition out of an institution. The MCO officials we spoke with said their transitions team, which assists beneficiaries who are moving out of an institution into the community, includes a housing coordinator whose job it is to track available housing and help beneficiaries find housing they can afford.
- **Limits on HCBS spending per beneficiary.** Officials from one MCO said that the state's limit on HCBS waiver spending per beneficiary—requiring that spending for HCBS does not exceed the cost of institutional care—was a challenge, particularly for beneficiaries with high needs.⁴⁵ The officials indicated that the MCO tracks HCBS spending for each beneficiary and reviews plans of care when a beneficiary reached 80 percent and 95 percent of the spending limit. Beneficiaries whose spending exceeds 100 percent for more than a 6-month period can choose to move to an institutional setting, or to continue to receive more limited HCBS that do not exceed the cost of care in an institution. In cases where the MCO believed the beneficiary could not be safely served in the community at that level of spending, officials said that beneficiaries and their families were required to sign a form acknowledging the safety risks.

Agency Comments

HHS provided technical comments on a draft of this report, which we incorporated as appropriate.

As discussed with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days after its issuance date. At that time, we will send copies of this report to the Secretary of Health and Human Services and other interested parties. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

⁴⁵While not required, two of the selected states—Mississippi and Arizona—have chosen to limit HCBS spending per beneficiary to a maximum of the average cost of institutional care. This per beneficiary cost limit applies to all beneficiaries in Arizona's program, and to enrollees in two of Mississippi's five 1915(c) waiver programs. Mississippi's three other waiver programs address the cost neutrality requirement for 1915(c) waivers in aggregate—that is, by ensuring that expenditures across all waiver participants are equal to or less than the average cost for the same population to be served in an institution.

If you or your staff members have any questions, please contact me at (202) 512-7114 or yocomc@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. Major contributors to this report are listed in appendix II.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Carolyn L. Yocom". The signature is fluid and cursive, with a long horizontal stroke at the end.

Carolyn L. Yocom
Director, Health Care

Appendix I: Home- and Community-Based Services Programs in Selected States

Table 2: Characteristics of Key Medicaid Home- and Community-Based Services (HCBS) Programs in Selected States, Fiscal Year 2018

State	Program name	Authorizing statute ^a	Target population	Enrollment cap	Waiting list
Arizona	Arizona Medicaid Section 1115 Demonstration	1115	Aged or disabled; individuals with intellectual or developmental disabilities	N/A	N/A
Florida	Long-Term Care Waiver	1915(c) ^b	Aged or disabled ^c	62,500	Yes
Florida	Developmental Disabilities Individual Budgeting Waiver	1915(c) and 1915(j)	Individuals with intellectual or developmental disabilities	38,018	Yes
Florida	Familial Dysautonomia Waiver	1915(c)	Individuals diagnosed with familial dysautonomia	15	No
Florida	Model Waiver	1915(c)	Children under 21 years of age with degenerative spinocerebellar disease	20	No
Mississippi	Elderly and Disabled Waiver	1915(c)	Aged or disabled	21,000	Yes
Mississippi	Assisted Living Waiver	1915(c)	Aged or disabled	1,100	Yes
Mississippi	Independent Living Waiver	1915(c) ^b	Individuals 16 years of age and older with severe orthopedic or neurological impairment	5,500	Yes
Mississippi	Intellectual Disabilities/ Developmental Disabilities Waiver	1915(c)	Individuals with intellectual or developmental disabilities	3,100	Yes
Mississippi	Traumatic Brain Injury/Spinal Cord Injury Waiver	1915(c) ^b	Individuals with traumatic brain injury or spinal cord injury	3,000	Yes
Mississippi	State Plan HCBS	1915(i)	Individuals with intellectual or developmental disabilities	N/A	N/A
Montana	Big Sky Waiver	1915(c)	Aged or disabled	2,580	Yes
Montana	Home and Community-Based Waiver for Individuals with Developmental Disabilities	1915(c)	Individuals with intellectual or developmental disabilities	2,750	Yes
Montana	Children's Autism Waiver	1915(c)	Children with autism from 15 months to 7 years of age	52	No ^d
Montana	Behavioral Health Severe and Disabling Mental Illness HCBS Waiver	1915(c)	Adults with severe disabling mental illness	235	Yes

**Appendix I: Home- and Community-Based
Services Programs in Selected States**

State	Program name	Authorizing statute ^a	Target population	Enrollment cap	Waiting list
Montana	State Plan Personal Care Services	1905(a)(24)	N/A	N/A	N/A
Montana	Community First Choice	1915(k)	N/A	N/A	N/A
Oregon	Aged and Physically Disabled Waiver	1915(c) ^b	Aged or disabled	39,480	No
Oregon	Medically Fragile (Hospital) Model Wavier	1915(c) ^b	Children from birth to 17 years of age who meet the hospital level of care and need specialized services to remain in, or return to, the family home	105	No
Oregon	Medically Involved Children's Waiver	1915(c) ^b	Children from birth to 17 years of age who meet the nursing facility level of care and need specialized services to remain in, or return to, the family home	220	Yes
Oregon	Behavioral Intermediate Care Facility for Individuals with Intellectual Disabilities Model Waiver	1915(c) ^b	Children from birth to 17 years of age who require specialized behavioral services to remain in, or return to, the family home	160	Yes
Oregon	Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) Comprehensive Waiver	1915(c) ^b	Individuals with intellectual or developmental disabilities	15,320	No
Oregon	Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) Support Services Waiver	1915(c) ^b	Individuals 18 years of age or older with intellectual or developmental disabilities	9,152	No
Oregon	State Plan HCBS	1915(i)	Individuals 21 years of age and older with chronic mental illness	N/A	N/A
Oregon	State Plan Personal Care Services	1905(a)(24)	N/A	N/A	N/A
Oregon	Community First Choice	1915(k)	N/A	N/A	N/A

Legend: N/A = not applicable

Source: GAO review of state HCBS program documents and interviews with state officials | GAO-18-628

^aAuthorizing statute refers to sections of the Social Security Act.

^bIn addition to the 1915(c) waiver, this state uses a 1915(b)(4) Selective Contracting Waiver. This waiver allows the state to restrict the providers from whom the Medicaid beneficiary may obtain services, as long as these restrictions do not substantially impair access to services of adequate quality where medically necessary. Florida also has a 1915(b)(1) waiver, which allows the state to mandate beneficiary enrollment in managed care.

^cThis includes individuals with AIDS, individuals with cystic fibrosis, and individuals with traumatic brain or spinal cord injuries, who were added to this program in January 2018.

^dOfficials informed us that this waiver is being phased out in July 2019, therefore the waiting list is no longer being maintained.

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

Carolyn L. Yocom, (202) 512-7114 or yocomc@gao.gov

Staff Acknowledgments

In addition to the contact named above, Michelle Rosenberg, Assistant Director; Hannah Locke, Analyst-in-Charge; Romonda McKinney Bumpus; Krister Friday; Vikki Porter; and Jennifer Whitworth made key contributions to this report.

Related GAO Products

Medicaid Assisted Living Services: Improved Federal Oversight of Beneficiary Health and Welfare Is Needed. [GAO-18-179](#). Washington, D.C.: January 5, 2018.

Medicaid: CMS Should Take Additional Steps to Improve Assessments of Individuals' Needs for Home- and Community-Based Services. [GAO-18-103](#). Washington, D.C.: December 14, 2017.

Medicaid Managed Care: CMS Should Improve Oversight of Access and Quality in States' Long-Term Services and Supports Programs. [GAO-17-632](#). Washington, D.C.: August 14, 2017.

Medicaid: CMS Needs Better Data to Monitor the Provision of and Spending on Personal Care Services. [GAO-17-169](#). Washington, D.C.: January 12, 2017.

Medicaid Managed Care: Improved Oversight Needed of Payment Rates for Long-Term Services and Supports. [GAO-17-145](#). Washington, D.C.: January 9, 2017.

Medicaid Personal Care Services: CMS Could Do More to Harmonize Requirements across Programs. [GAO-17-28](#). Washington, D.C.: November 23, 2016.

Long-Term Care Workforce: Better Information Needed on Nursing Assistants, Home Health Aides, and Other Direct Care Workers. [GAO-16-718](#). Washington, D.C.: August 16, 2016.

Older Adults: Federal Strategy Needed to Help Ensure Efficient and Effective Delivery of Home- and Community-Based Services and Supports. [GAO-15-190](#). Washington, D.C.: May 20, 2015.

Medicaid: States' Plans to Pursue New and Revised Options for Home- and Community-Based Services. [GAO-12-649](#). Washington, D.C.: June 13, 2012.

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