Chapter 5:

# Self-Direction for Home- and Community-Based Services

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## Key Points

- Self-direction is a beneficiary-controlled home- and community-based services (HCBS) delivery model that allows the individual to have decision making authority over their HCBS and directly manage their services with assistance.
- States can decide to offer employer authority, a model in which the beneficiary chooses who provides their care and services, or budget authority, a model in which the beneficiary has choice over how their monthly budget is distributed among allowable goods and services in their person-centered service plan, or both.
- States must establish a system of information and assistance, including financial management services (FMS), to support beneficiaries in managing their self-directed care. A range of entities provide information and assistance supports, and the roles of these entities may be difficult to distinguish from one another.
- States have broad flexibility when designing their self-direction programs including: selecting the Medicaid HCBS authorities for administering self-direction; determining which HCBS populations will be offered self-direction options; selecting which services can be self-directed; electing budget authority, employer authority, or both; and allowing family members to be paid caregivers.
- States use a variety of program-specific methods for quality reporting, monitoring, and oversight. States leverage information and assistance roles and FMS agencies to support data collection for these efforts. Data collection processes can vary across state operating agencies.
- Limited data reporting and analysis capacities in self-direction may hinder state and national efforts to ensure quality and conduct effective monitoring and oversight.

# CHAPTER 5: Self-Direction for Home- and Community-Based Services

Medicaid home- and community-based services (HCBS) are designed to allow people with the need for long-term services and supports (LTSS) to live in their homes or a home-like setting in the community. Self-direction is a beneficiary-controlled HCBS delivery model that allows the individual to choose their service providers and have control over the amount, duration, and scope of services and supports in their person-centered service plan (PCSP) (42 CFR 441.740, Murray et al. 2024, ACL 2014).[1] In self-direction, the beneficiary can either hire HCBS workers directly, referred to as "employer authority"; set their workers' hourly wages or purchase approved goods and services that help the beneficiary remain in a home- or community-based setting, referred to as "budget authority"; or both (CMS 2024a).[2] Medicaid is the primary payer of self-directed HCBS, supporting 66 percent of all self-directed services in 2019, although other sources, such as state general revenues, may also pay for self-direction (Edwards-Orr et al. 2020).

Compared with traditional, agency-directed HCBS, self-direction offers beneficiaries increased autonomy in how their HCBS are delivered, as the individuals providing care or services are accountable to the beneficiary or the beneficiary's representative. In an agency-directed model, the service provider coordinates care for the beneficiary, generally establishing a care schedule, assigning an HCBS worker to a beneficiary, managing the HCBS worker, and determining the HCBS worker's wage (DDA 2025, ADMH 2022). In a self-directed model, the beneficiary manages aspects of their care, deciding how, when, and by whom their services are provided (CMS 2024b, Crisp 2017). The flexibility that beneficiaries have in self-direction allows them to tailor care and services to their specific needs, preferences, and routines.

States have considerable flexibility when designing and administering self-direction programs, which has led to an array of different approaches to operating this model both across and within states. States choose which federal authorities to use, which LTSS subpopulations to serve, what services to offer in self-direction, whether or not to allow beneficiaries to have budget or employer authority, and under some authorities whether to allow family members to serve as paid caregivers. States also rely on numerous entities to support the self-directed functions that sustain these programs, including beneficiary advocacy organizations, case management entities, information and assistance support professionals, financial management services (FMS) agencies, managed care organizations (MCOs), and support brokerages.[3]

To understand the statutory and regulatory framework governing self-direction and identify existing data on the model, MACPAC conducted a literature review and interviews with federal and state officials, national subject matter experts, and stakeholders.[4] This chapter synthesizes the findings from MACPAC's work and provides a comprehensive overview of the self-directed HCBS delivery model. The chapter begins with an overview of self-directed HCBS, including the range of federal HCBS authorities that states use to offer self-direction, the statutory and regulatory framework governing the model, and the multitude of actors states may designate to support program administration. Next, we introduce findings that identify variation in the design and administration of self-directed HCBS and administrative complexity in self-direction. The chapter concludes with next steps to further the Commission's work.

## Medicaid Coverage of Self-Directed HCBS

The guiding tenet of self-direction is that HCBS beneficiaries are capable of determining the types of assistance they need to independently reside in their communities (HSRI 2024). This approach differs from agency-directed care when an agency or health care provider takes on the responsibility of managing the care process. Self-direction is a beneficiary-controlled HCBS delivery model that allows the individual, with help to the extent available and necessary from trusted representatives (usually family or friends), to "have decision-making authority over certain services and take direct responsibility to manage their services with

the assistance of a system of available supports" (CMS 2024a). In self-direction, a state can choose to offer employer authority, a model in which the beneficiary chooses who provides their care and services, and budget authority, a model in which the beneficiary has choice over how their monthly budget is distributed among allowable goods and services in their PCSP, or both (42 CFR 441.440, 441.740, Murray et al. 2024, Murray 2024, ACL 2014). Self-directing beneficiaries, or their representatives, can hire, oversee, and terminate paid caregivers, who can be family members, friends, or other acquaintances.

States offer and finance self-direction through an array of HCBS waiver and state plan authorities, including through Sections 1915(c), 1915(i), 1915(j), 1915(k), 1905(a)(24), and 1115 authorities (Appendix 5A). These Medicaid authorities operate under different guidelines, but the Centers for Medicare & Medicaid Services (CMS) has published regulations specifying common requirements across all self-direction models. These models must include a person-centered planning process, a PCSP, information and assistance supports, FMS, a quality assurance and continuous improvement system, and an individualized needs assessment to determine benefit allocations (e.g., authorized aide hours or an individualized budget) (42 CFR 441.474, CMS 2024a).[5] These guidelines support beneficiaries who self-direct, or their representatives, in managing their LTSS.

Self-direction models are available in all 50 states and the District of Columbia, and enrollment has grown substantially over the past decade (Murray et al. 2024, O'Malley Watts et al. 2022). In 2023, more than 1.5 million individuals self-directed their HCBS through programs funded primarily by Medicaid but also through state general revenues, the Veterans Health Administration, and the Older Americans Act (P.L. 89-73, as amended) (Murray et al. 2024). This marks a 23 percent increase in enrollment since 2019 and an 87 percent increase since 2013 (Murray et al. 2024).

States often serve several populations across different Medicaid waiver and state plan programs, including but not limited to older adults, people with physical disabilities or intellectual or developmental disabilities (I/DD), and people with HIV/AIDS (Srinivasan et al. 2024). In a 2023 review of self-direction programs that are funded primarily by Medicaid but also by state general revenue, the Veterans Health Administration, the Older Americans Act, and some other funding streams, 50 states offered self-direction to adults older than age 65 and adults with physical disabilities, and more than half offered self-direction for adults with I/DD, adults with a traumatic brain injury, children with physical disabilities, children with I/DD, and children with traumatic brain injury (Murray et al. 2024).[6] Only a few states (14 percent) have self-direction programs specifically for adults with serious mental illness (SMI) and children with serious emotional disturbance (SEM) (Murray et al. 2024).[7]

## Origins of self-direction

Today's self-directed HCBS programs can be traced back to the 1950s when the U.S. Department of Veterans Affairs pioneered a participant-directed long-term care program: The Aid and Attendance Program (CMS 2024c, Grana and Yamashiro 1987). This program enabled veterans with service-related disabilities to hire personal attendants through a cash benefit (NCD 2013, Grana and Yamashiro 1987). Soon after its inception, the program was redesigned and repurposed to serve a larger population of veterans who needed LTSS after the completion of their military service (VA 2024). This veteran-directed care program is an early example of self-direction, which would be unavailable for civilians until states began offering consumer direction of the Medicaid personal care services benefit option through their state plan in the early 1990s (CMS 2025, 2024a).[8, 9] This optional benefit gives Medicaid beneficiaries increased autonomy over the provision of their personal care services but does not fully convey employer authority to the beneficiary, nor does it provide budget authority (§ 1905(a)(24) of the Social Security Act, CMS 2024a, EOA 2007). During the 1980s and early 1990s, some states incorporated employer authority self-directed services into their Section 1915(c) HCBS waiver programs, authorizing case managers to allow HCBS program participants to employ individual providers, including family members other than spouses or parents of minor children (ASPE 2010).

**Cash and Counseling Demonstration and Evaluation.** In 1995, the Robert Wood Johnson Foundation partnered with the Office of the Assistant Secretary for Planning and Evaluation and began planning the Cash and Counseling Demonstration and Evaluation (EOA 2007, Doty 1998).[10] Authorized

under Section 1115 of the Social Security Act (the Act), the purpose of the Cash and Counseling Demonstration and Evaluation was to assess the feasibility, advantages, and disadvantages of self-direction in the financing and delivery of personal assistance services (PAS) and home care services for Medicaid beneficiaries (Doty 1998). Under the demonstration, Medicaid beneficiaries eligible for PAS and HCBS in three states, Arkansas, Florida, and New Jersey, volunteered to receive a cash allowance with counseling services in lieu of traditional, agency-directed services and supports (Mahoney and Simone 2016, EOA 2007).[11] Beneficiaries in the Cash and Counseling Demonstration and Evaluation reported higher satisfaction and quality of life as well as fewer unmet needs for assistance and fewer adverse health consequences such as bedsores and contractures compared with those receiving agency-directed services (Brown et al. 2007, Dale et al. 2004).

In addition to beneficiary satisfaction, the Cash and Counseling Demonstration and Evaluation assessed the effects on Medicaid costs for demonstration-covered services (Brown et al. 2007, Dale et al. 2004). Overall, personal care and HCBS costs under the Cash and Counseling Demonstration and Evaluation per month of benefits received was higher across all three states and all age groups receiving services when compared with agency-provided services (Brown et al. 2007). Researchers attributed the cost differential in two of the states, Arkansas and New Jersey, to unmet care needs among beneficiaries in the traditional system (Brown et al. 2007, Dale et al. 2004). For example, in Arkansas, nearly one-quarter of beneficiaries who should have been receiving agency-directed services did not receive any personal care services during the first year of the demonstration program (Dale et al. 2004). Among beneficiaries of agency-directed services who did receive personal care services in Arkansas during that first year, they received only 68 percent of the total hours of care for which they were qualified (Dale et al. 2004). However, if all recipients had received the expected number of hours as defined in their care plans, the average personal care expenditures in the Cash and Counseling Demonstration and Evaluation after one year would have been slightly less than the average expenditures for agency-directed personal care services (Dale et al. 2004).

Furthermore, the observed increased costs in the Cash and Counseling Demonstration and Evaluation were partially offset by savings on other Medicaid services (e.g., nursing facility services and home health) (Brown et al. 2007, Dale et al. 2004). In the second demonstration year, the difference in total Medicaid costs between self-directed and agency-directed PAS in Arkansas was statistically insignificant (5 percent), including the offsets (Dale et al. 2004). In Florida, the cost differential between beneficiaries in the Cash and Counseling Demonstration and Evaluation and those receiving agency-provided services was primarily due to a mandate to increase funding for waiver services to beneficiaries with disabilities, which occurred during the Cash and Counseling Demonstration and Evaluation's inception (Brown et al. 2007). Ultimately, the availability of funds and prescription to increase spending for the state's disability population led to a reevaluation of beneficiaries' initial spending plans when beginning the Cash and Counseling Demonstration and Evaluation, which often increased their allowance amounts (Brown et al. 2007).

After the Cash and Counseling Demonstration and Evaluation's success, 11 additional states received replication grants from the Robert Wood Johnson Foundation, and 1 state received a grant from the Retirement Research Fund and implemented budget authority self-directed services programs, mostly under Section 1915(c) HCBS waiver authority, between 2004 and 2009 (Simon-Rusinowitz et al. 2014). By 2011, the demonstration states had more than 20,000 beneficiaries enrolled (Simon-Rusinowitz et al. 2014).

## Federal requirements governing self-direction

States have a range of options to choose from in Title XIX of the Act when designing their self-direction programs. These federal Medicaid authorities dictate the instrumental features of a state's program, such as eligibility, contracting, and payment structures (Bradley et al. 2001). This section provides an overview of the federal requirements that shape the landscape of the self-directed HCBS delivery model (Appendix 5B).

In statute, self-directed HCBS are defined as "services for the individual which are planned and purchased under the direction and control of such individual or

the individual's authorized representative, including the amount, duration, scope, provider, and location of such services" (42 USC § 1396n). Regardless of the Medicaid HCBS authority under which a state authorizes self-direction, all models must meet the following federal requirements:

- person-centered planning process;
- PCSP;
- individualized budget;
- information and assistance in support of self-direction;
- FMS; and
- quality assurances and continuous improvement system.

In self-direction, the beneficiary leads the person-centered planning process. The PCSP focuses on identifying the beneficiary's strengths, preferences, needs, and desired outcomes, while also preparing for contingencies like service interruptions and addressing potential risks (CMS 2024a). The PCSP is a written document outlining the specific services and supports the individual will receive to meet their needs and stay in the community. States offering budget authority develop an individualized budget for the beneficiary based on this plan. States must define how to calculate these budgets and monitor expenditures (CMS 2024a).

States provide information and assistance supports, which include counseling, training, and FMS, for individuals who choose to self-direct their care (CMS 2024a). A support broker or consultant helps individuals navigate the self-direction process, from identifying personnel needs to ensuring services are properly managed (42 CFR 441.450(c), CMS 2024a). FMS agencies assist with managing budgets, handling payroll, paying taxes, and tracking expenses (CMS 2024a). Although some individuals may manage these tasks themselves, most rely on FMS agencies for support. Finally, each state Medicaid agency must maintain a system for quality assurance and improvement, identifying and addressing issues to ensure services are effective. Although quality requirements may vary by state, all states are responsible for monitoring both system performance and individual outcomes (CMS 2024a). Some aspects of self-direction are also found in the broader HCBS system, such as beneficiary choice and control, person-centered planning, the PCSP, and the quality assurance and continuous improvement system. Other elements, such as an individualized budget, individuals determining HCBS worker qualifications and wages, and the availability of information and assistance supports, are unique to self-direction (Murray 2024).

**Medicaid authorities.** Medicaid coverage of self-directed HCBS is authorized under the Act, and as of 2023, nearly all states provide self-direction under Section 1915(c) waivers, and one-third offer self-direction via the state plan (Murray et al. 2024). Under the Act, states have several authorities they can leverage to administer self-directed HCBS, and requirements under these authorities impact a state's self-direction program design (42 USC § 1396n, Murray 2024). For example, states can offer budget authority under Section 1115 demonstrations and Section 1915(c), 1915(i), 1915(j), and 1915(k) Medicaid authorities (Murray 2024). However, budget authority is not available for Section 1905(a)(24) state plan personal care services unless the state plan option is paired with the Section 1915(j) self-directed PAS state plan authority (Murray 2024). States must consider these variations when designing and administering their self-directed programs (Murray 2024) (Appendix 5A).

Section 1915(c) authority is the most common authority through which state agencies offer self-directed HCBS, with 46 states using at least one Section 1915(c) waiver for this purpose in 2023 (Murray et al. 2024). Section 1915(c) waivers allow state agencies to provide self-directed HCBS for individuals with institutional level of care needs (42 USC § 1396n). These waivers cover a broad range of nonmedical, social, and supportive services, such as case management, personal care, and respite care, to help individuals live independently in the community.[12]

Other Medicaid authorities that states use to offer self-direction include Section 1115 demonstration authority as well as Sections 1915(i), 1915(j), 1915(k), and 1905(a)(24) state plan options.[13] Section 1115 demonstrations allow states to conduct pilot projects, including those promoting self-direction in managed care (O'Malley Watts et al. 2017). Section 1915(i) enables states to provide self-directed services for

individuals who meet needs-based criteria that are less stringent than what is required for an institutional level of care (O'Malley Watts et al. 2022). Section 1915(j) allows for self-direction of state plan personal care services and Section 1915(c) waiver services, with provisions for beneficiaries to hire legally responsible relatives or purchase items to support independence (CMS 2024d, Colello 2022). The Section 1915(k) Community First Choice state plan option enables states to provide attendant services for individuals meeting state institutional care criteria, with a 6 percentage point increase in federal matching funds for service expenditures (Colello 2022, CMS 2020). Finally, Section 1905(a)(24) allows states to offer personal care services under a self-directed model, though without budget authority or the ability to hire family members (Murray et al. 2024, MACPAC 2023) (Appendix 5A).[14]

## Employer authority and budget authority

When states design their self-direction programs, they can choose to offer beneficiaries employer authority, budget authority, or both. Employer authority allows beneficiaries to choose and manage their direct care workers, while budget authority lets beneficiaries choose how their monthly budget is distributed among allowable goods and services, such as caregiver pay and items that increase independence or substitute for human assistance (42 CFR 441.740, Murray 2024, Srinivasan et al. 2024). States may elect whether to allow employer or budget authority for specific services (CMS 2024b).

**Employer authority.** Beneficiaries use employer authority to recruit, identify, hire, terminate, train, schedule, supervise, and evaluate the HCBS worker (42 CFR 441.450(j)). Beneficiaries undertake these activities either on their own or with assistance from their representatives, information and assistance support entities, FMS agencies, and MCOs. When a beneficiary has employer authority, they assume the employer responsibilities rather than a provider agency (CMS 2024b). This responsibility includes recruiting, hiring (conducting interviews, performing background checks, and checking references), setting work schedules, identifying training needs, assigning tasks, supervising, evaluating performance, and terminating employees, when required (CMS 2024b). Employer authority is allowable under all Medicaid HCBS authorities.

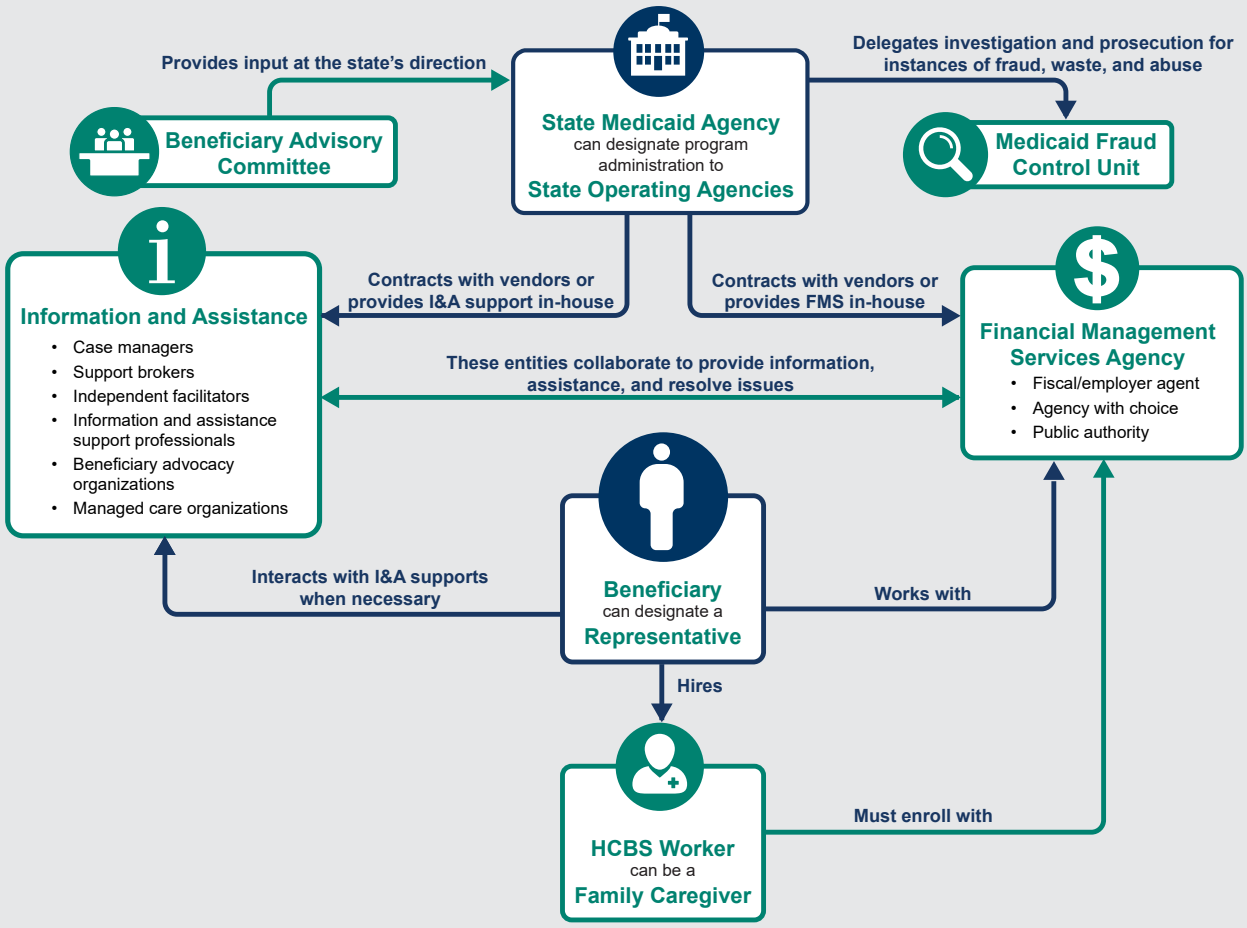
**Budget authority.** Beneficiaries use budget authority to purchase services and supports; determine the amount paid for a service, support, or item; and review, as well as approve, invoices (42 CFR 441.450(j)). For example, a beneficiary with budget authority can set the wage for their HCBS worker. States have also introduced flexibilities that allow beneficiaries to allocate their service funds toward goods and services that promote independence, such as assistive technology or home modifications (Teshale et al. 2021).

Most HCBS authorities allow states to offer budget authority (Appendix 5A). In 2023, 44 states had established at least one self-direction program that included budget authority, and all 10 states with the largest reported growth in enrollment in self-direction allowed budget authority (Murray et al. 2024). Among the 44 states using budget authority, 35 states allowed beneficiaries to purchase goods and services (Murray et al. 2024).

# Key Stakeholders in Program Administration

Self-direction programs include a range of entities that support the beneficiary in managing their care (Figure 5-1). Under self-direction, the beneficiary is typically the legal employer or coemployer of their own staff, and most beneficiaries choose to hire family members, friends, or other people they know to provide their necessary care services (CMS 2007). The state Medicaid agency is responsible for ensuring that a program operates in line with federal regulations, and it can delegate its authority to another entity, such as another state agency, with an agreement specifying the delegated tasks. When another state agency manages a self-direction program, it is referred to as the "operating agency," and the Medicaid agency supervises its operations. States may also employ information and assistance providers or use FMS agencies to provide support services and fulfill administrative responsibilities that are required as part of self-direction (CMS 2024b).

**FIGURE 5-1.** Key Stakeholders in Self-Direction




**Notes:** I&A is information and assistance. FMS is financial management services. HCBS is home- and community-based services.

**Sources:** MACPAC compilation based on review of Sections 1915(c), 1915(i), 1915(j), 1915(k), and 1905(a) of the Social Security Act and the 2024 Section 1915(c) waiver technical guide. We also reviewed relevant regulatory guidance at 42 CFR 441 as well as evidence collected through interviews with experts.

## Beneficiary

The beneficiary is the individual who is eligible for and enrolled in the Medicaid program (CMS 2024b). In a self-direction model, individuals have the opportunity, and the responsibility, to oversee all aspects of service delivery through a person-centered planning process. This oversight could involve employer responsibilities, such as recruiting, hiring, training, and supervising providers, as well as determining the qualifications required for HCBS workers beyond federal and state standards.[15] Additionally, beneficiaries may have financial responsibilities under budget authority, enabling them to manage how Medicaid funds within their budget are allocated and, in some cases, determine the rates for specific HCBS workers within the limits established by the program (CMS 2024e). States are required to support or arrange for the provision of supports that help beneficiaries develop a PCSP and individualized budget, manage and execute services, and carry out employer and budget responsibilities (CMS 2024e). These responsibilities and supports allow beneficiaries to be the primary judges of the quality of the services they direct (CMS 2024e).

## Representative

If a beneficiary is unable or unwilling to self-direct their HCBS, they can choose a representative to assist (ICRC 2017). A representative cannot be paid or serve as the beneficiary's HCBS worker (ICRC 2017). Typically, a representative is a family member or close friend who helps the individual make decisions based on their preferences. Although beneficiaries continue to control how and when their services are delivered, representatives can provide support with tasks that individuals may find challenging, such as reviewing and approving time sheets, addressing worker performance issues, or reminding workers to arrive on time. In some cases, a representative may handle all of these tasks on behalf of the individual.

## HCBS worker

The beneficiary chooses HCBS workers to provide the services outlined in the PCSP. Under certain Medicaid authorities, state Medicaid agencies may require background checks and may establish education, certification, or licensing requirements for caregivers hired under self-direction, but specific requirements vary by state and by the Medicaid authority used to allow self-direction (Teshale et al. 2021).[16] HCBS workers hired through self-direction can include many different kinds of providers, such as direct support professionals, personal care aides, home health aides, and certified nursing assistants (MACPAC 2022).[17] Beneficiaries may hire HCBS workers whom they already know in the community or from agencies with the help of support brokers (CMS 2024a). Some states also maintain and publish HCBS worker registries to help beneficiaries find qualified workers (CMS 2023).

**Family caregivers.** Under certain Medicaid authorities, states determine who can be an HCBS worker in self-direction. Some of the authorities convey authority to the individuals to establish provider qualifications and determine who can be an HCBS worker. Under most authorities, states have the flexibility to allow family members to provide HCBS, which includes legally responsible individuals, with the exception of Section 1905(a)(24) state plan personal care services, unless the state operates a concurrent Section 1915(j) state plan authority (Teshale et al. 2021) (Appendix 5A).

A legally responsible individual is any person who has a duty under state law to care for another person, such as the parent of a minor child or a spouse (CMS 2024b). When acting as an HCBS worker, the legally responsible individual must offer services that go beyond what is typically expected from a spouse or parent, referred to as "extraordinary care" (CMS 2024b).[18]

## State

The state Medicaid agency must maintain a system for quality assurance and improvement, identifying and addressing issues to ensure services are effective (CMS 2024a). The state must also make available information and assistance supports and FMS (CMS 2024a). The state Medicaid agency can delegate the tasks of operating the self-direction program to other state operating agencies, such as the departments overseeing services for people with disabilities, mental health services, and aging services.

States are required to have Medicaid fraud control units as a part of their Medicaid state plans under the Act (42 CFR 1007.3). Medicaid fraud control units operate independent of the state Medicaid agency and the operating agencies and investigate claims of fraud and abuse in the state's Medicaid program, including services provided through self-direction (42 CFR 1007.9).

**Beneficiary advisory board.** Some states have a beneficiary advisory board that provides input to state policymakers on discrete self-directed HCBS topics. The beneficiary advisory board is typically composed of beneficiaries and their family members (DDS 2025a, Wisconsin DHS 2025). A few of the states that we interviewed mentioned leveraging a beneficiary advisory board, although they are not present in all states. Under Section 1915(k) authority, states are required to establish a Development and Implementation Council to consult and collaborate with the state in the development and implementation of the state's Community First Choice benefit (42 CFR 441.575).[19]

## Information and assistance supports

Information and assistance supports must be available to beneficiaries who are self-directing their HCBS, but the amount and frequency of assistance may

vary depending on beneficiary preference (42 CFR 441.464, CMS 2024a). CMS defines information and assistance in self-direction as a system that is "responsive to an individual's needs and desires for assistance in developing a PCSP and budget plan, managing the individual's services and workers and performing the responsibilities of an employer" (CMS 2024a). In practice, information and assistance supports encompass a wide range of services:

- information on how a self-directed service option works;
- education on individual rights and responsibilities;
- access to resources supporting self-direction;
- counseling and coaching;
- training beneficiaries and assisting with issues; and
- access to an independent advocacy system available in the state (CMS 2024a).

The broad definition of information and assistance provides flexibility to states when they design beneficiary supports. Through interviews with state officials, stakeholders, and subject matter experts, we found that many entities may provide information and assistance: case managers, support brokers, independent facilitators, area agencies on aging (AAAs), beneficiary advocacy organizations, information and assistance support professionals, and FMS agencies. The state can perform these information and assistance roles or contract with vendors. All of these roles or entities are not present in every state and may overlap with other information and assistance supports available to self-directing beneficiaries. Below is an overview of each role and its function in providing information and assistance in support of self-directed HCBS.

**Case managers.** The states we interviewed indicated that the case manager shares information about self-direction options with beneficiaries and helps them enroll in self-directed HCBS. According to interviewees, case managers assist with care planning, coordination, and assessment; support beneficiaries with resources and counseling; and train them in their employer responsibilities. In other cases, case managers refer the beneficiary to other information and assistance supports roles (e.g., a support broker or an information and assistance support professional) that provide these supports (CMS 2024b). Case managers have regular check-ins with beneficiaries and help them complete paperwork. Although case managers form a part of the information and assistance support system in self-direction, a case manager's role may be broader than serving self-direction users exclusively, extending to beneficiaries receiving HCBS in a traditional service delivery model.

**Support brokers.** A support broker (also referred to as a "counselor," "consultant," "coach," "independent facilitator," or "information and assistance specialist") is generally selected by the beneficiary and takes direction from them (CMS 2024b, Mahoney et al. 2021). A support broker helps beneficiaries navigate the self-direction process, from identifying personnel needs to ensuring services are properly managed (CMS 2024a, Mahoney et al. 2021). Support brokers monitor service delivery and help address concerns regarding quality or safety, liaising between the individual and their FMS agency or performing other information and assistance supports functions (CMS 2024a). Compared with a case manager, state officials shared that the support broker generally provides more day-to-day supports and handles payment and time sheet issues, but both functions work closely with each other.

**Independent facilitators.** In addition to a support broker, some states have independent facilitators.[20] According to state officials and advocacy organizations, the independent facilitator liaises between the support broker and FMS agency. The role is intended to reduce the workload for support brokers and focuses on helping beneficiaries with administrative tasks like time sheets and troubleshooting as issues arise. They can also support HCBS worker recruitment.

**Information and assistance support professionals.** States may designate information and assistance support professionals as a separate entity to assist in developing the PCSP and the individual service budget and to manage services and employer responsibilities, according to subject matter experts (CMS 2024a). None of the state agencies we interviewed indicated that they designate a separate entity to provide only information and assistance support.

**FMS agencies.** According to interviewees, in addition to their primary role as a fiscal intermediary, FMS agencies may also provide information and assistance supports. For example, we heard that FMS agencies commonly provide support brokerage services. Some states delegate support brokerage services to FMS agencies and provide payment for those services, while other FMS agencies are providing these services more informally.

**AAAs and Aging and Disability Resource Centers.** Interviewees shared that AAAs and Aging and Disability Resource Centers (ADRCs) provide options counseling, self-direction program referrals, and in some instances case management and waiver service coordination. AAAs are funded outside of Title XIX through the Older Americans Act. However, they can be funded by Medicaid in support of self-direction through a contractual agreement. States or vendors contract with AAAs to provide information and assistance supports, but sometimes AAAs provide informal supports as well. AAAs may work closely with other entities providing information and assistance and FMS agencies.

**Beneficiary advocacy organizations.** Advocacy organizations provide resources and education to beneficiaries on self-direction and advise state agencies through input from beneficiaries and community members with lived experience, according to interviewees. They may help support beneficiaries or connect them to additional resources if issues arise when self-directing. They can also advocate for beneficiaries when their service hours or budget allotment are adjusted.

## FMS

Under most authorities, beneficiaries cannot receive direct cash payments, so the FMS agency acts as a fiscal intermediary between the Medicaid program, beneficiary, and HCBS worker (§§ 1115, 1905(a)(24), 1915(c), and 1915(i) of the Act). FMS agencies receive funds from the state and use those funds to pay the beneficiary's HCBS worker for services rendered in accordance with their PCSP (42 CFR 441.454, 441.545, CMS 2024f) (Appendix 5A). In addition to handling payroll, FMS agencies must assist beneficiaries in understanding their billing and documentation responsibilities, perfoming tax and employment benefits services, purchasing goods and services, and monitoring the beneficiary's self-directed budget (42 CFR 441.484, CMS 2024g). Although some beneficiaries choose to manage some of these tasks themselves or with their authorized representative, most rely on an FMS agency for support (CMS 2024a).

In self-direction programs with budget authority, the FMS agency monitors and reports on individual beneficiaries' expenditures (42 CFR 441.484, Murray 2024). FMS agencies must verify that spending on goods and services and payment rates are approved in the PCSP before issuing payment (Murray 2024). Additionally, FMS agencies must track a beneficiary's expenditures and notify the beneficiary and other relevant third-party administrators, such as a case manager or support broker, when funds are being expended too rapidly or are being underused (42 CFR 441.484, Murray 2024).

States can choose from different FMS agency models and may choose more than one model. The primary models are the fiscal/employer agent (F/EA) model and the agency with choice (AwC) model (CMS 2024b, 2024g). Although less common, one state in our case study uses a public authority to provide training for HCBS workers and manage criminal background checks while the state pays the workers (CMS 2024g).

**F/EA.** Under this model, the beneficiary is the common law employer (i.e., employer of record or legally responsible employer) of the HCBS worker. Of the FMS models, this one places the greatest level of responsibility and risk on the beneficiary. They are directly liable for performing employment-related tasks, including hiring, supervising, and firing their employees (CMS 2024b). The FMS agency supports the beneficiary in fulfilling their employer-related obligations by processing payroll and taxes. The agency can either be nested within the state (i.e., government F/EA) or be a contracted entity (i.e., a vendor F/EA), but both perform the same functions (CMS 2024b). All the states we spoke with selected a vendor F/EA model, which is the most common of the two approaches (CMS 2024b, Murphy et al. 2011).

**AwC.** In the AwC model, the FMS agency is the common law employer (i.e., employer of record or legally responsible employer) of the HCBS worker, and the beneficiary is considered their coemployer (i.e., managing employer) (CMS 2024b). In this model,

the beneficiary manages the worker in their day-to-day activities, but the FMS agency is responsible for all of the employment-related functions for the beneficiary's workers. In addition to processing payroll and taxes, under the AwC model, provider agencies can help a beneficiary find an HCBS worker, help with interviewing and hiring processes, and train and manage the HCBS worker (DDS 2025b). Under this model, the FMS agency can offer beneficiaries a list of HCBS workers to choose from who are already enrolled with the FMS agency.

**Public authority.** Public authority is considered a multiple-employer model with three different employers (CMS 2024h). In this model, the beneficiary is the employer for hiring, supervising, and firing their HCBS worker (CMS 2024h). The state is responsible for processing payroll in this model, and the public authority or workforce council (usually at the county level) works with unions to negotiate the wages, benefits, and working conditions for HCBS workers and serves as the employer of record. The public authority also generally maintains an HCBS worker registry that is available to beneficiaries.

### MCO

Through our interviews, including with MCOs, we found that the role of an MCO in self-direction may be similar to some of the information and assistance supports functions. MCOs perform functional needs assessments and assess a beneficiary's ability to self-direct based on the waiver requirements (42 CFR 438.208(c)(3)(ii)). In some states, the MCO uses these assessments to determine the services and service hours that a beneficiary can self-direct, ensuring they stay within state spending caps. Additionally, MCOs process service authorizations, perform back-end claims payment and encounter filing with the state, and provide case management and service coordination. The MCOs we interviewed shared that they also engaged in quality monitoring and oversight: monitoring compliance with electronic visit verification (EVV) and reporting critical incidents and suspicious activity.

When self-directed HCBS are administered in a managed care environment, the MCO collaborates with other information and assistance roles and FMS agencies to support self-direction. For example, once the beneficiary has been assessed and has developed their PCSP, the MCO can share this information with the FMS agency to help with the beneficiary's enrollment processes. In addition to collaboration during the beneficiary enrollment process, MCO case managers work closely with FMS agencies to support beneficiaries and identify issues quickly. One MCO we interviewed shared that they established a daily feed with an FMS agency to share authorizations, which allows them to rapidly address provider payment challenges caused by authorization issues.

## State Design Considerations

States have broad flexibility when designing their self-direction programs, including (1) selecting specific HCBS authorities for administering self-direction; (2) determining which HCBS populations to offer self-direction options; (3) selecting which services can be self-directed; (4) electing budget authority, employer authority, or both; and (5) allowing family members to be paid caregivers.

### Medicaid HCBS authorities

States select administrative authorities based on their policy and programmatic goals as well as the authorities the state uses to operate its existing agency-directed HCBS programs. Federal officials shared that self-direction is currently available in more than half of all Section 1915(c) waivers, or about 150 waivers. In general, state officials said they prefer Section 1915(c) waivers for their flexibility in serving specific populations, setting enrollment limits, limiting availability based on geography, and selecting which services can be self-directed. Federal officials highlighted that these flexibilities help states better manage the costs of operating self-directed HCBS programs. One state Medicaid agency mentioned that Section 1915(c) waivers provide a more defined framework for self-direction and that the flexibilities to set enrollment caps and tailor the model to specific populations made it easier for the state to manage costs and conduct oversight. Although less common, some of the states we interviewed used other authorities such as Section 1915(k) authority, which offers an enhanced federal match, or Section 1115 demonstrations due to the flexibility to target different eligibility groups.[21]

## Populations that self-direct

Self-direction programs serve different populations in each state. An inventory that included 80 percent of all self-directed LTSS programs funded through Medicaid or state revenues between 2010 and 2011 found that about 60 percent (129 programs) of the identified self-directed programs (212 programs) served two or more LTSS subpopulations (Sciegaj et al. 2014). Few programs targeted a single population in this inventory, and the majority of programs served older adults (Sciegaj et al. 2014).

A more recent analysis conducted by AARP found that all 50 states and the District of Columbia have options to self-direct for adults older than age 65 and adults with physical disabilities (Murray et al. 2024). More than 90 percent of states offer self-direction for adults with I/DD and adults with traumatic brain injury (Murray et al. 2024). In contrast, self-direction for adults with SMI is less available across states, with less than half (24 states) offering self-direction for this population (Murray et al. 2024). However, some states are working toward incorporating more self-direction for behavioral health needs. For example, Texas is working to expand self-direction to individuals with SMI (Texas HHSC 2021).

Across case study states, we found that many beneficiaries succeed in self-directing their HCBS with an appropriate level of supports and a contingency plan. State officials, researchers, consumer advocates, and other stakeholders identified certain beneficiaries who may require additional supports to be able to self-direct effectively, including people with few natural supports, those experiencing homelessness, those who have low technological literacy or lack access to technology, those who live in rural areas, and those with low English proficiency.[22] Interviewees emphasized that these populations can still effectively self-direct their HCBS with the appropriate supports and plans in place. For example, one interviewee shared that individuals with dementia may still be able to self-direct but need a contingency plan for when they can no longer safely direct their services. Conversely, interviewees noted that beneficiaries with strong natural supports, such as older adults with adult children or strong social networks, are generally well equipped to successfully self-direct their HCBS with fewer additional supports.[23]

## Self-directed services

State agencies have the flexibility to select which services are available for self-direction. Nationwide, the most commonly self-directed services include personal care, transportation, and respite (ASD 2023). Case study states most commonly offered the following services under their self-directed HCBS programs: respite; personal care assistance; personal care; homemaker; peer support; transportation; skilled nursing; private duty nursing; supported employment; equipment, technology, and modifications; and individual goods and services. Several researchers and state officials said that states are more likely to allow personal care services, such as bathing and dressing, to be self-directed due to their intimate nature. Forty states offered self-direction for home-based services in at least one of their waivers, and 22 states offered self-directed day services in at least one of their waivers (MACPAC 2024). No state offering round-the-clock services under a Section 1915(c) waiver offered a self-direction option for that service (MACPAC 2024).

The National Core Indicators–Aging and Disabilities Adult Consumer Survey, which gathers data on experience of care from older adults and individuals with disabilities, found that 91 percent of the surveyed self-direction participants felt they had the amount of control they desired over their services in the 2023–2024 survey (HSRI and ADvancing States 2025). Additionally, in the 2022–2023 survey year, just under 80 percent of surveyed self-direction participants felt that the services and supports they wanted to self-direct were always available, and in the 2023–2024 survey year, this share increased to 84 percent (HSRI and ADvancing States 2025, 2024).

Interviewees identified two approaches states generally take to determine which services to offer under self-direction: (1) choose from the services available under the state's traditional service delivery model, or (2) develop a new suite of self-directed services, often in response to advocacy. Two states we spoke with offer the same services across both agency and self-directed models for their I/DD population. Officials from one state noted that a benefit of this approach is that a beneficiary can receive care from an agency during the day, while a family caregiver works another job, and then receive self-directed

services in the evening when the caregiver is home, blending both traditional and self-directed HCBS. In contrast, a national advocacy organization described the second approach as developing a "separate parallel ecosystem of self-direction." In these cases, state agencies said that stakeholder input influenced which services were allowed to be self-directed.

Additionally, two state Medicaid agencies shared that they consider the level of training or licensing required to provide specific services when defining which services can be self-directed. One state shared that they avoid offering self-direction for services that necessitate complex certification or licensing requirements for HCBS workers. Another agreed, sharing that some services require more extensive training for workers, so they preferred to offer only less-complex services such as respite, personal attendant, personal assistance, and community transportation under the self-directed model.

## Budget and employer authorities

A notable flexibility that states might draw on as they design self-directed HCBS programs is whether to offer beneficiaries employer authority, budget authority, or both. Under employer authority, beneficiaries receive help to recruit, hire, and supervise HCBS workers. Beneficiaries act as common law employers or coemployers of these HCBS workers, rather than provider agencies assuming full employer responsibilities. Under budget authority, beneficiaries are responsible for managing individualized budgets set by the state Medicaid or operating agencies or a delegated entity. These agencies determine how to use budget authority in their program design, such as permitting beneficiaries to make decisions about purchasing goods and services authorized in PCSPs and manage the funds in their individualized budget, which may include shifting funds between services (CMS 2024b). Interviewees said employer authority tends to be easier for self-directed beneficiaries to understand and requires fewer state administrative resources than budget authority. However, offering both budget authority and employer authority options gives beneficiaries more choices and control.

**Employer authority.** States can allow beneficiaries to function as either common law employers or coemployers of their HCBS worker. Under the common law employer approach, beneficiaries are considered legally responsible employers of hired workers (CMS 2024b). Two state operating agencies emphasized the importance of ensuring self-directing beneficiaries understand their responsibilities and their risks when they are common law employers. For example, beneficiaries, who are functioning as employers, and their fiscal agents are jointly liable for employer taxes, including state, federal, and local taxes. Another state agency added that navigating state labor laws and ensuring an adequate level of knowledge and understanding of employer burden can be a challenge for beneficiaries who are self-directing, but FMS agencies and support brokers can assist beneficiaries in managing these employer-related responsibilities.

Under the coemployment approach, beneficiaries are supported by an agency that functions as the common law employer for workers recruited by beneficiaries. In this model, the beneficiary shares employer responsibilities, acting as the managing employer that provides on-the-job instruction and oversight (CMS 2024b). The coemployer model emerged in one state because state officials found it difficult to engage self-directing beneficiaries under the common law employer model: beneficiaries wanted more control of services but did not want all of the employer responsibilities. Similarly, a beneficiary advocacy organization in a different state said coemployment might be the right model for beneficiaries who do not want the full array of employer responsibilities.[24]

Even within a single self-directed HCBS program, states' selection of employer authority might vary by service and credentialing considerations. State agencies might offer employer authority based on what is practical for a given service. For example, a state Medicaid agency decided against allowing employer authority for home modifications due to concerns around verifying employee credentials for that service. Similarly, a national advocacy organization described how states consider which services can be delegated to non-licensed workers under self-direction to fill gaps in the traditional service delivery system. For example, a state operating agency found that employer authority is useful for homemaker, personal care, or transportation services but potentially less effective for clinical therapeutic intervention services, which require the beneficiary to hire a specialized or licensed provider.

**Budget authority.** Stakeholders noted that budget authority has become an increasingly popular option among both states and beneficiaries. Researchers and state officials agreed that budget authority provides beneficiaries with the most choice. Another researcher also highlighted that states with the largest increase in self-direction enrollment from 2019 to 2023 are those that allow budget authority.

When states implement budget authority, they must establish a process for determining individualized budgets, which can vary across and within states. CMS officials indicated that the process should be based on the needs and preferences outlined in the PCSP and level of care assessments (CMS 2024b). One state agency official shared plans to implement a standardized assessment tool across its self-direction programs to measure what services are needed and how frequently and analyze the data to develop individualized budgets. Another state Medicaid official noted it updated its budget determination process to ensure consistency across self-directed beneficiaries with similar care needs. Two states shared that since using budget authority can be complex for self-direction beneficiaries, they simplified their budget determination process by establishing minimum and maximum HCBS worker wages for specific self-directed services. Subject matter experts and state Medicaid agency officials cautioned that allowing self-directed beneficiaries to set wages for workers could create disparities between self-directed and agency-directed services.

Interviewees raised other challenges associated with the complexities of offering budget authority for self-directed services. One state Medicaid official noted that paying different rates for the same service can be difficult because their administrative systems normally associate a single service type with a single rate, not the variation permitted in self-direction. Other states and stakeholders noted that changes in care or budget assessments often lead to new budgets for consumers.

## Family caregivers

States have the authority to determine who can provide HCBS under self-direction programs. In many cases, states offer the flexibility to allow family members, which may include legally responsible individuals such as spouses or parents of minor children, to deliver care under certain conditions (Teshale et al. 2021). Allowing family members to be paid caregivers is a benefit of the self-direction model, and many interviewees noted that it has helped address the national workforce shortage. However, interviewees also noted that it can be challenging to establish safeguards around family caregiving that ensure the provision of care while preserving the self-directing beneficiary's choice and control.

All case study states allowed for paid family caregivers in at least one of their self-direction programs. One state historically had not allowed family caregivers to provide services but received CMS approval to lift this restriction after feedback from families in the state. Another state allows family caregivers to be paid employees for most services, except for the live-in caregiver service. A third state we spoke with allows family caregivers to be paid employees but does not permit legally responsible family members to be paid.

State officials and consumer advocates shared that decisions to allow family caregivers to be paid employees are influenced by advocacy as well as recent caregiving flexibilities implemented during the public health emergency. These stakeholders discussed how employment of family caregivers can help address the national HCBS workforce shortage. They also noted that family caregiving can help provide culturally competent care. One state highlighted that allowing family caregivers to be paid employees allows their self-direction programs to reach diverse cultures and geographic areas in the state.

However, some researchers and state officials raised concerns about whether beneficiaries receive appropriate care when family caregivers are involved. One state Medicaid agency explained that it set strict standards around the hiring of family caregivers when beneficiaries direct their own services but does not set the same standards for family members employed under AwC. In that case, the AwC entity is responsible for overseeing the caregiver's performance. Another agency in that state noted the challenges of balancing program integrity with the need to preserve beneficiary choice and control. Finally, an MCO raised concerns about beneficiaries' reluctance to report critical incidents involving family caregivers. We also heard concerns about the lack of available data on family caregivers that can complicate state efforts to monitor self-directed care.

Issues around family caregivers often centered around compensation, beneficiary choice, and safety. One state shared that determining a family caregiver's compensation can create interpersonal tensions between family members. Additionally, we heard from some interviewees that decision making in self-direction may include family members in addition to the beneficiary, which can be an issue when that family member is also the caregiver.[25] Federal and state officials described this scenario as a potential conflict of interest, distinct from regulatory conflict of interest requirements, in which family members may feel they know what the beneficiary wants and potentially undermine the beneficiary's control and choice.[26] Finally, one state raised a concern about ensuring that family caregivers do not work more than 40 hours per week to avoid overworking and potentially causing a safety issue for the beneficiary and caregiver. The state's data and payrolling system tracks family caregiver hours across multiple beneficiaries to address this issue.

# Considerations for State Administration

Through our interviews, we found that states have ample flexibility in administering their self-direction programs. Most of the states we interviewed administered their programs across multiple state operating agencies, with only one state hosting all of their self-direction programs under the state Medicaid agency. When administering information and assistance supports, states vary in how they define and structure the functions and in their collaboration across these entities. The roles of information and assistance support entities often overlap and may be difficult to clearly distinguish from one another.

Interviewees shared that FMS agencies may have a range of responsibilities, which vary by state and potentially even within a single state. States also employ different contracting strategies, and one state shared that two of its operating agencies provide FMS through its regional offices. Among states that contract with FMS agencies, state Medicaid and operating agencies can hold multiple FMS agency contracts to enhance beneficiary choice or only one FMS agency contract for a more streamlined approach.

State officials shared a variety of program-specific methods that states use for quality reporting, monitoring, and oversight in discussions around information and assistance supports, FMS provision, and managed care. Primarily, we found that states leverage information and assistance roles and FMS agencies to support those efforts. However, existing systems are generally not designed to stratify the data by self-directed and agency-directed beneficiaries. Limited data reporting and analysis capacities in self-direction may hinder state and national efforts to ensure quality and conduct effective monitoring and oversight.

## Collaboration across programs

Some states administer self-directed HCBS solely through the state Medicaid agency, while others delegate program administration across multiple state agencies. Among the states we interviewed, the majority administer self-direction across multiple agencies. For example, one state we spoke with administers seven different self-direction programs across three agencies: the state Medicaid agency, the state's agency for developmental disabilities, and the department of aging (Box 5-1). This multiagency structure can lead to variation in how the different self-direction programs are administered within a state, an observation that multiple state officials noted. For example, some state operating agencies have different fiscal intermediaries than the state Medicaid agency.

The variation in how different state agencies administer self-direction requires collaboration across those agencies, something that generally works smoothly but can produce some challenges. In one state, officials noted that their self-direction programs are population specific; therefore, each is administered slightly differently, which requires collaboration across operating agencies. Officials in another state Medicaid agency emphasized the extensive collaboration and involvement in program administration across all the state's operating agencies. However, officials in a third state Medicaid agency said they experienced challenges working with operating agencies and getting responses in a timely manner when the state Medicaid agency needed to act quickly to implement new CMS requirements. They shared that any policy or operational changes that the state Medicaid agency wants to make require extensive negotiation and coordination with the operating agencies.

## **BOX 5-1.** Self-Direction Case Study State: Ohio

Ohio operates Section 1915(c) waivers, which allow for self-directed home- and community-based services (HCBS), offering both budget and employer authority for a range of services and allowing family caregivers to be paid. The Ohio Department of Medicaid (ODM), Ohio Department of Aging (ODA), and Ohio Department of Developmental Disabilities (DODD) operate and oversee these programs for approximately 2,000 beneficiaries (Murray et al. 2024). This system is illustrated in the figure below.

ODM has jurisdiction over the Section 1915(c) Integrated Care Delivery System Waiver (or MyCare Ohio Waiver) and operates it in coordination with ODA, which gives beneficiaries dually eligible for Medicare and Medicaid who are age 65 and older and beneficiaries age 18 to 64 with physical disabilities the ability to self-direct their services through a managed care delivery system that is available in certain counties.

In addition, ODM has a new self-direction benefit under the Section 1915(c) Ohio Home Care Waiver program that is designed for beneficiaries younger than age 60 with physical disabilities or unstable medical conditions. Depending on the waiver, beneficiaries receive their case management through a case management entity or one that contracts with Area Agencies on Aging (AAAs) or through a managed care organization or one that contracts with AAAs.

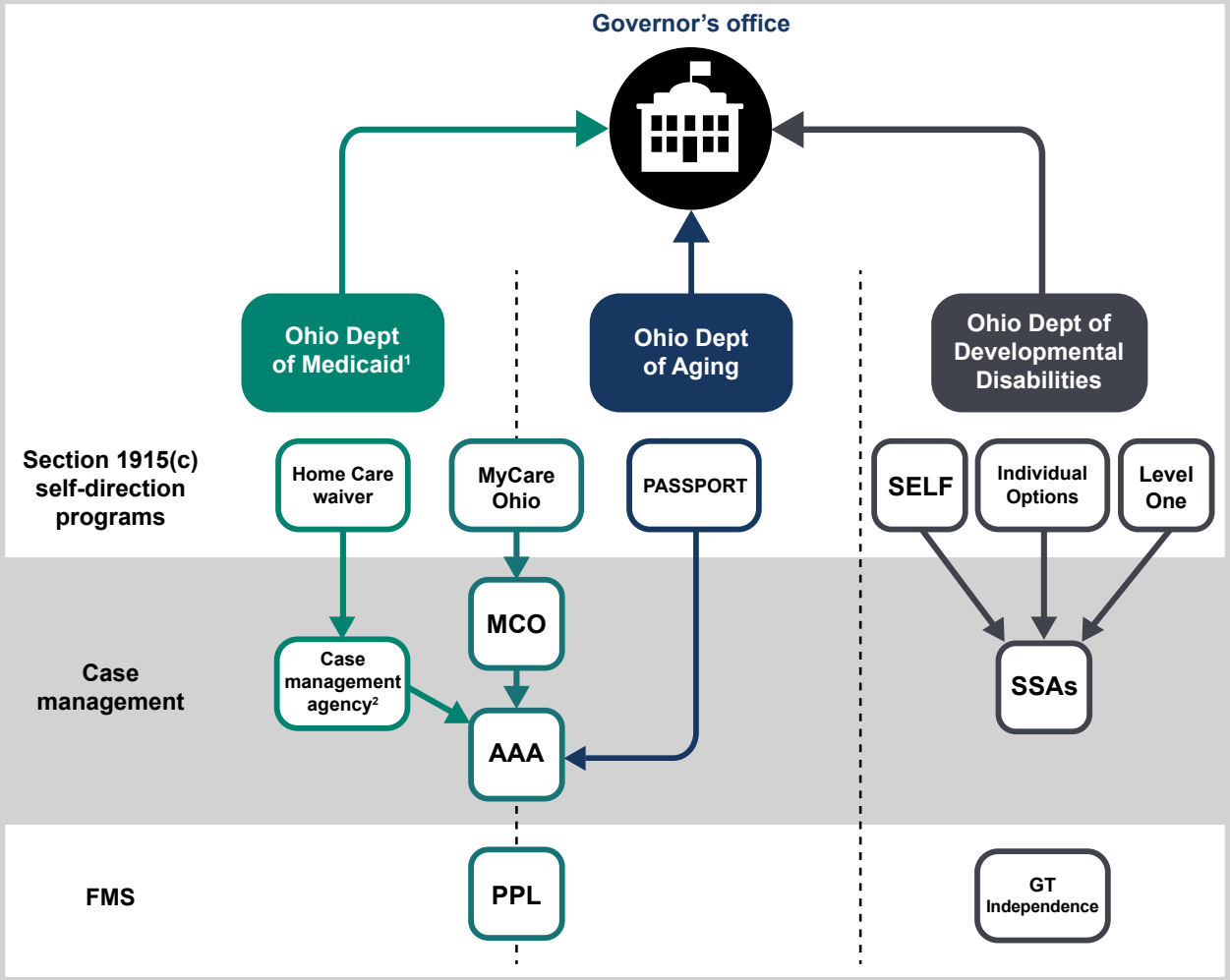
ODA also operates an HCBS waiver program—the Section 1915(c) PASSPORT waiver—which covers self-direction for beneficiaries with physical disabilities (age 60 to 64) and beneficiaries age 65 and older who may be dually eligible but are not enrolled in the Section 1915(c) MyCare Ohio Waiver. Similar to the programs under ODM, beneficiaries in the PASSPORT waiver program receive case management through AAAs. ODA and ODM share a contract with the same financial management services (FMS) agency for their FMS in these programs, Public Partnerships LLC.

Although each waiver program has distinct rules and requirements, many members naturally age out of the Section 1915(c) Home Care waiver or become dually eligible while on the PASSPORT waiver and transition into the Section 1915(c) MyCare Ohio waiver. The waivers are designed to help with this progression. For example, the services available through MyCare Ohio are inclusive of all the services offered under the Home Care waiver and PASSPORT. In addition, beneficiaries transitioning from either waiver to MyCare Ohio can retain their previous caregivers to support continuity of care.

Separately, DODD operates three Section 1915(c) waivers that offer self-direction for beneficiaries with intellectual and developmental disabilities—the Self Empowered Life Funding (SELF), Level One, and Individual Options waiver programs. These programs offer different services for self-direction, different levels of employer and budget authority, and varying budget determination methodologies. For example, the Section 1915(c) SELF waiver program, which is restricted to beneficiaries who want to self-direct, offers the greatest breadth of self-directed services, allowing the purchase of goods and services within an individualized budget. The Level One waiver program also allows for the purchase of goods and services but offers fewer services for self-direction. The Section 1915(c) Individual Options Waiver is the most restrictive, only offering transportation and self-directed homemaker/personal care services. Both the Section 1915(c) SELF waiver and Level One waiver have the same established budget amounts for individual services, while the Section 1915(c) Individual Options waiver uses an assessment process to develop personalized budgets for beneficiaries. Regardless of the waiver, case management services are provided via services and supports administrators at the county boards of developmental disabilities, and FMS are provided through a vendor, GT Independence.

**Source:** Murray et al. 2024.

## BOX 5-1. (continued)




**Notes:** Dept is department. MyCare Ohio is Integrated Care Delivery System waiver. SELF is Self Empowered Life Funding waiver. MCO is managed care organization. AAA is area agency on aging. SSA is services and support administrator. FMS is financial management services. PPL is Public Partnerships LLC.

[1] ODM also offers limited self-direction in the OhioRISE waiver for beneficiaries younger than age 20 with serious emotional disturbance, which is not pictured in this graphic since it is limited to self-directing secondary flex funds through budget authority.

[2] ODM contracts with two case management agencies for the Ohio Home Care Waiver. One case management agency contracts with AAAs to provide case management, and the other provides the service themselves and not through AAAs.

**Sources:** Interview with Ohio state officials and a review of Ohio's Section 1915(c) waivers.

## Information and assistance entities

State agencies must establish roles and responsibilities for state staff and third-party entities that provide information and assistance to Medicaid beneficiaries in support of self-direction. States either perform these functions directly or contract them out to third-party entities. Third-party entities can include MCOs and FMS agencies or state-supported HCBS providers such as AAAs and ADRCs. States may enlist multiple third-party entities to support their self-direction programs or limit the number of support entities, and both approaches have benefits and challenges. When working with third-party entities, state agencies define their expectations through vendor contract requirements. Several interviewees noted that state agencies may require that third-party entities, such as MCOs, FMS agencies, and AAAs, contract with each other to facilitate collaboration. Researchers, federal officials, national advocacy organizations, and national associations mentioned substantial variation in the level of collaboration and interactions between third-party entities in self-direction programs both within and across states.

State agencies vary in how they structure and define the roles of third-party entities in their information and assistance support systems. Information and assistance support entities can include information and assistance support professionals, case management entities, support brokerages, AAAs, beneficiary advocacy organizations, FMS agencies, and MCOs. Interviewees noted that their roles often overlap and may be difficult to clearly distinguish from one another.

**Defining roles and structuring information and assistance supports.** In setting up a system of information and assistance supports for beneficiaries using self-direction, state agencies may establish multiple distinct roles that various third-party entities fulfill or establish a stand-alone service that does not necessarily overlap with other roles. Stakeholders had different views on how to set up a system of information and assistance supports. Some expressed a preference for a more streamlined approach with stand-alone roles, while others preferred a layered system in which gaps are covered by allowing more than one entity to fulfill the same role. Regardless of the approach, stakeholders agreed that establishing clearly defined roles and responsibilities for third-party entities is critical.

The states in our case studies all established multiple roles in their information and assistance systems, and state officials generally noted that this approach works well; other stakeholders noted some challenges. Advocacy organizations shared that providing information and assistance supports through multiple independent entities diffuses responsibilities and causes roles to overlap unnecessarily. For example, some self-direction programs include an additional support broker role, which interviewees noted can provide self-direction-specific information and can also overlap with other roles, such as that of case managers.

A national advocacy organization shared that states typically choose entities to provide information and assistance based on existing structures and entities that beneficiaries are already familiar with, such as AAAs and ADRCs. These entities provide resources and education to beneficiaries in self-direction. State officials in one case study state primarily used AAAs to provide information and assistance supports for beneficiaries in one of their self-direction programs. According to an FMS agency we interviewed, AAAs can help them reach communities or regions with lower rates of self-directed HCBS referrals and enrollment. Leveraging these trusted organizations that are part of the service infrastructure for older adults and people with disabilities and that already have connections to community resources could help beneficiaries navigate the complicated self-direction landscape.

Among interviewees, findings around whether states should rely on existing entities to provide information and assistance supports were mixed. According to subject matter experts, beneficiaries who rely on existing entities to provide information and assistance may receive more streamlined information than through support brokerages or FMS agencies that are not already part of the broader service array for the HCBS population. In contrast, advocates noted that when multiple entities, in addition to existing ones, provide information and assistance support, beneficiaries may receive inconsistent or disparate information. Despite the advantage of leveraging existing networks, interviewees from two states

noted that relying on established entities for options counseling can pose a challenge as they generally have less knowledge of self-direction compared with their understanding of the agency-delivery model, sometimes creating a bias toward agency-delivered services.

Since existing entities in a state may have less program-specific knowledge and large caseloads, some state agencies establish a support broker role that is specific to self-direction. By focusing solely on the self-direction programs available in a state, according to interviewees, the support broker helps beneficiaries navigate self-direction. The services a support broker provides vary by state and program, ranging from providing information and assistance to beneficiaries on the services that are available for self-direction to tailored, one-on-one coaching on managing HCBS workers. Some states offer support brokerage functions as a waiver service paid out of beneficiaries' direct budgets; other states provide this support as an administrative function. An FMS agency shared that when support brokerage services are offered as a waiver service rather than an administrative service, uptake may be lower because the payment for the support broker comes out of a beneficiary's individualized budget.

Although support brokers generally have more program-specific knowledge than other information and assistance support entities that serve the general HCBS population, there are challenges. According to interviewees, adding another role diffuses responsibility in the information and assistance supports system and increases variation in the quality of supports across different entities. For example, interviewees noted major variation in support brokers' training and the resulting quality of services that they provide. A support brokerage in one of the case study states noted that although they are required by the state Medicaid agency to have trainings for support brokers, their contracts with the Medicaid agency do not include specific training standards. As a result, each support brokerage in the state trains their employees differently. This variation in training can lead to variation in service quality but also allows these entities increased flexibility to design their trainings to meet internal standards for quality service delivery.

Across the case study states, the support broker roles were the least routinely defined, and case management entities and beneficiary advocacy organizations shared that they often perform the role of a support broker, providing coaching for beneficiaries in self-direction. Support brokers have program-specific knowledge that other information and assistance support professionals may not. As a result, other information and assistance support entities may struggle to provide these supports in addition to performing their other roles. These challenges with the support broker role are apparent across the different models that state agencies select to structure support broker services: (1) contracting with independent support brokers as a designated role, (2) establishing a support brokerage role nested within the FMS agency, and (3) incorporating the support brokerage services under case management.

Under the first model, in which the independent support broker is a designated role, one subject matter expert shared that although independent support brokers typically spend considerable time with beneficiaries, they add another entity to the information and assistance supports system, which requires information sharing across entities to be effective. A separate support brokerage entity is less streamlined and can diffuse responsibility across the information and assistance support system, such as the responsibility for supporting beneficiaries in acting as an employer. This expert also observed a trend toward more agency-based support brokerage approaches, since ensuring quality and removing underperforming support brokers is easier in an agency-based model. An interview with an FMS agency that serves multiple states corroborated this finding, sharing that support brokerage services were rarely a stand-alone support in the states they served.

In the second model, states pay the FMS agencies a separate fee to provide support broker services. An FMS agency interviewee shared that they prefer to host the support brokerage function within the FMS agency since FMS agencies have extensive knowledge of the self-directed program compared to independent support brokers. A state Medicaid agency agreed that it is helpful to have the support broker function within the FMS agency's scope because care coordinators or case managers may not have the capacity to provide these supports. The FMS agency representatives also noted that it is not always clear what services and supports a support broker is

providing in states where that function is separate from the FMS agency. In these cases, the FMS agencies often find themselves educating the support brokers or providing some of these supports without explicit compensation. Despite potential advantages to this model, a subject matter expert noted that an FMS agency's support brokerage services are generally provided virtually or via phone conversations, which may reduce accessibility for some beneficiaries with low technological literacy or limited internet access.

In the third model, case managers provide the support broker services, but attitudes about this model were mixed. One state Medicaid agency shared that they have consultants who are expected to provide both case management and support brokerage services. However, stakeholders disagreed with state officials on this model's effectiveness. One advocacy organization in the same state shared that their staff often have to educate case managers on various aspects of the self-direction model. An MCO responsible for providing case management in a different state shared a similar challenge with integrating the case management and support broker roles. The MCO shared that their case managers struggle to perform both roles simultaneously and suggested establishing designated support brokers. In another state where case managers perform some support brokerage functions, state officials shared that they did not think it would be more effective for an external entity to perform those duties.

**Collaboration across the information and assistance support system.** Researchers, federal officials, national advocacy organizations, and national associations mentioned varying levels of collaboration in self-direction among information and assistance entities. One researcher described interactions between third-party entities as often minimal and of poor quality. The interviewee said that the most effective collaboration typically begins in response to an adverse event, adding that high turnover rates of third-party employees inhibit well-coordinated operations. In contrast, a state Medicaid agency official highlighted contracting requirements among information and assistance entities, FMS agencies, and MCOs as a tool to help with collaboration.

MCOs regularly interact with other information and assistance support entities and with FMS agencies. For example, one MCO shared that they collaborate with the combined support brokerage and FMS function through biweekly meetings. The MCO has access to the support broker portal, so they can see real-time notes, and employ a liason team to document interactions between the MCO and the FMS agency. During biweekly meetings, the MCO and the FMS agency escalate concerns and troubleshoot compliance issues. The FMS agency also shares files and data with the MCO, including records of beneficiaries completing trainings, which are a prerequisite for MCOs to authorize care for a beneficiary. The MCO then transfers their authorizations back to the FMS agency. The FMS agency also shares EVV data and claims data with the MCO and escalates potential fraud, waste, and abuse issues with the MCO. However, MCOs shared that there are challenges to collaborating directly with an FMS agency, since both the FMS agency and the MCO can, in some cases, contract exclusively with the state agency and not with each other. However, MCOs can mitigate this issue by maintaining continuous communication with partners and with the state. Both MCOs we spoke with said they have regularly scheduled standing meetings with their state Medicaid agency, describing these collaborative relationships as helpful to the operation of their self-directed programs.

## State approaches to FMS

States may choose to have one, multiple, or no FMS agencies. For example, according to one of the FMS agency interviewees, one state they work in has about 200 FMS agency contracts, while another state we interviewed has only one (Texas HHSC 2025). State decisions regarding FMS structure, such as the choice to contract with one or multiple agencies or to allow MCOs to hold FMS contracts, represent a trade-off between minimizing administrative oversight and allowing beneficiary choice. One state agency noted that it can be challenging to establish a standardized and streamlined approach to the information and assistance that multiple FMS agencies provide. This challenge highlights a need for a more centralized system, especially when multiple information and assistance entities are collaborating. An MCO working in a state with only one FMS agency identified benefits to this approach, stating that it is easier to collaborate with other MCOs in the state and troubleshoot similar

challenges with just one FMS agency. However, the MCO noted that this approach has trade-offs. For example, increasing competition among multiple FMS agencies within the state could result in higher-quality FMS. Another MCO and some state officials noted that having multiple FMS agencies in a state gives beneficiaries more opportunities to match their needs with services—for example, choosing an FMS agency that offers more beneficiary supports.[27]

One state we interviewed only uses an FMS agency for some of its self-direction programs, whereas others operate via a county-based model. The state Medicaid agency and an operating agency we spoke with in that state both prefer the latter model. In particular, officials with the state Medicaid agency said that its data system operated by the counties functions like an FMS agency, and thus, they do not need a separate FMS agency.

## Quality reporting, monitoring, and oversight

Over the course of discussions around information and assistance supports, FMS provision, and managed care, we identified a variety of methods that states use to administer their self-direction programs through quality reporting, monitoring, and oversight. However, data are limited, and states primarily rely on information and assistance entities and FMS agencies to support these functions. At the federal level, it is not possible to identify total spending and enrollment that is specific to self-directing Medicaid beneficiaries. At the state level, officials rely on information from contracted entities to support their oversight processes, but poor data systems infrastructure and limited interoperability can pose challenges.

**Entities supporting monitoring and oversight.** States rely on information from contracted entities for their oversight and monitoring processes. One subject matter expert suggested that FMS agencies play a major role in monitoring and overseeing the total service hours a beneficiary receives and in reporting this information to the state. For example, three FMS agencies that serve multiple states and state agency officials said that FMS agencies share data with the state to support oversight activities, including authorizations and claims data, summary notes from service visits, and payment information. FMS agencies also noted that they develop data dashboards for states. This data sharing supports quality reporting, monitoring, and oversight. Another state Medicaid agency highlighted that their FMS agency developed system flags to notify them when an HCBS worker is being paid over an established threshold, either signaling that they may be working too many hours and the beneficiary needs additional training to effectively manage their service hour allotment or prompting investigations to ensure beneficiaries are receiving the services outlined in their PCSPs.

States also rely on other information and assistance support functions and internal processes to support quality reporting, monitoring, and oversight. For example, one state shared that it receives weekly utilization reports that its support brokers and regional offices monitor.[28] Other states identified internal quality monitoring processes that ensure HCBS workers are up to date on any required state certifications or licensing. However, state officials may face challenges to these existing quality reporting, monitoring, and oversight processes as their self-direction models grow. State officials noted that adapting to substantial increases in enrollment strained their monitoring and oversight capabilities.

**Data systems.** At the federal level, stratifying self-directing Medicaid beneficiaries from the broader HCBS population can be a challenge. Subject matter experts shared that they cannot comprehensively identify spending in self-direction or Medicaid-specific enrollment. CMS does not require personal identifiers for beneficiaries self-directing their services in the Transformed Medicaid Statistical Information System (T-MSIS), which further limits analysis (Doty 2025, Srinivasan et al. 2024).

Among states, reporting and monitoring capabilities may present challenges to effective data collection efforts in self-direction. Several interviewees cited poor data systems infrastructure and limited interoperability among entities as key barriers to administration of self-direction programs. Also, in one state, officials noted that data collection processes vary across operating agencies. One state Medicaid agency said they need a robust data infrastructure to validate hours for reimbursement accurately. Another state Medicaid agency struggled with

stratifying self-directing beneficiaries in data analysis and reporting. One MCO that supports self-direction program monitoring identified an inability to directly access the FMS agency's EVV data system portal as a major delay in their monitoring processes. Due to the delays in transferring the FMS agency's EVV data to the MCO, they said that it can be weeks or months before they know that a beneficiary is not getting their prescribed care.

Many interviewees referenced EVV as a method to ensure quality and conduct program monitoring and oversight in self-direction, but EVV systems are new, and a few states are still in the implementation phase. After an audit by the Office of Inspector General at the U.S. Department of Health and Human Services found that self-directed personal care services were particularly susceptible to fraud, through the enactment of the 21st Century Cures Act (P.L. 114-255), federal officials implemented EVV requirements (OIG 2015, 2012). EVV is a tool for states to detect and address potential instances of fraud, waste, and abuse (CMS 2018).[29] Subject matter experts, state interviewees, and federal officials specifically identified the global positioning system tracking requirement as well as required check-ins and checkouts in EVV as some of the most challenging aspects of the system for HCBS workers to implement. Still, multiple stakeholders have found EVV to be useful in monitoring for instances of fraud, waste, and abuse. One MCO noted that global positioning system data in EVV are especially useful in flagging potential fraud. For example, if a service is logged as being provided in an out-of-state location, the MCO would pull records, question, and exchange files to ensure program integrity.

Given some of the challenges states face in effective monitoring, some interviewees acknowledged the future implications of the CMS final rule on ensuring access to Medicaid services and the requirements it established in supporting quality monitoring of self-direction programs (CMS 2024h). In the final rule, states must report on the length of time it takes for a self-directing beneficiary to receive services from the day that they were enrolled in the program (42 CFR 441.311(d)(2), CMS 2024h). Officials from one state Medicaid agency said that the final rule will help assist with quality reporting, monitoring, and oversight through this requirement. The final rule also includes provisions on rate transparency and reporting requirements that directly impact certain self-directed services, including homemaker, home health aide, personal care, and habilitation services (Appendix 5B) (CMS 2024h). Officials from the same state Medicaid agency also said that the final rule will help them create more standardized program administration processes across the different state operating agencies. Federal officials said that states will need to ensure that self-directing HCBS beneficiaries and their HCBS workers understand that these requirements, such as critical incident reporting requirements, are applicable to them.

## Looking Ahead

Self-direction of HCBS continues to evolve as a model that can offer Medicaid beneficiaries choice while alleviating the burdens of the national HCBS workforce shortage. This study identifies considerations that states can take into account when they design and administer these programs. State agencies implement flexible statutory and regulatory requirements differently, depending on Medicaid authority, HCBS subpopulation, budget authority, employer authority, and other factors. The variation reflects the flexibility states have to tailor their self-directed HCBS programs to meet their programmatic priorities.

## Endnotes

[1] A PCSP is a document describing the services and supports that are important for the individual to meet the needs identified in the functional assessment as well as what is important to the individual with regard to preferences for the delivery of HCBS (42 CFR 441.301(c)(2)).

[2] Sometimes the budget authority model is referred to as the "Cash and Counseling" model. In this study, we reviewed self-direction programs that offer employ authority, budget authority, or both.

[3] States are mandated through 42 CFR 441.740(e) to offer the following functions in support of self-direction for their applicable programs: information and assistance; FMS; and voluntary training on how to select, manage, and dismiss providers.

[4] Mathematica, in partnership with MACPAC, conducted interviews with representatives from the Direct Care Workforce Strategies Center, National Council on Aging; Center for Medicaid and CHIP Services, Division of LTSS; National Academy for State Health Policy; Applied Self-Direction; AARP; Pennsylvania State University; Alabama Medicaid Agency; Alabama Department of Mental Health, Developmental Disabilities Division; California Department of Health Care Services; California Department of Social Services; California Department of Developmental Services; MassHealth; Massachusetts Department of Developmental Services; Ohio Department of Medicaid; Ohio Department of Developmental Disabilities; Ohio Department of Aging; Tennessee Division of TennCare; Tennessee Department of Intellectual and Developmental Disabilities; Wisconsin Department of Health Services, Division of Medicaid Services; The Arc of Massachusetts; CareSource; Community Living Alliance; Consumer Direct Care Network; GT Independence; Justice in Aging; Lutheran Social Services Connections; Massachusetts Regional Self-Direction Managers (regional offices); Public Partnerships LLC; San Diego County IHSS Office; Top of Alabama Regional Council of Governments; Wellpoint; and Wisconsin Board for People with Developmental Disabilities.

[5] The individualized budget is required only when a beneficiary has budget authority.

[6] These data do not include self-directed programs that exclusively offer respite.

[7] Slightly less than half of states have self-direction programs available for adults with SMI and children with SED; however, this program count appears larger than it is because state plan Medicaid authorities do not allow for population targeting (Murray et al. 2024). Therefore, although someone with SMI or SED could potentially qualify for such self-direction programs, they often do not meet the institutional level of care or functional needs requirements to be eligible, as the nature of their disability is different.

[8] Offering personal care services has been a state plan option since the mid-1970s, when it was established administratively under the authority of the Secretary of Health and Human Services (ASPE 2010). However, it was not formally added to the list of services in the Medicaid statute until 1993 (ASPE 2010).

[9] Consumer direction is outlined in the state Medicaid manual at Section 4480: “A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of the personal care services and, if necessary, fire the provider. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications . . . and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services” (CMS 2025).

[10] The Robert Wood Johnson Foundation sponsored another demonstration program separate from, but philosophically related to, the Cash and Counseling Demonstration and Evaluation. From 1994 to 2001, the Robert Wood Johnson Foundation gave grants to local and state government agencies initially in New Hampshire and subsequently in 18 other states for “self-determination” projects targeting adults with I/DD. Conceptually, self-determination is not quite the same as self-direction, but, over time, the two have come to be seen as closely intertwined. The self-determination projects emphasized a person-centered planning process that encompassed not just the development of a Medicaid-funded service plan but sought to identify the goals, preferences, and developmental potential of individuals with I/DD to enable them to experience meaningful and fulfilling lives (Conroy et al. 2002).

[11] Originally, the Office of the Assistant Secretary for Planning and Evaluation and the Robert Wood Johnson Foundation selected four states to participate in the Cash and Counseling Demonstration and Evaluation. However, in 1999, New York left the demonstration due to difficulties in recruiting (Mahoney and Simone 2016).

[12] When this authority is paired with Section 1915(a) or Section 1915(b) authority, states can offer self-direction within managed care systems (CMS 2024i, Doty et al. 2010).

[13] Section 1115 demonstrations are authorized by the Balanced Budget Act of 1997 (P.L. 105-33), while the Section 1915(i) and Section 1915(k) Community First Choice state plan options were established by the Deficit Reduction Act of 2005 (P.L. 109-171) and the Patient Protection and Affordable Care Act (P.L. 111-148, as amended), respectively.

[14] Under Section 1905(a)(24) state plan personal care services, a state may employ a self-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of the personal care services, and, if necessary, fire the provider. The state Medicaid agency maintains responsibility for ensuring the provider meets state provider qualifications and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the state may either provide personal care services without self-direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services.

[15] The federal government sets certain conditions of participation for personnel who provide certain services. For example, home health aides must have a minimum of 75 training hours (42 CFR 484.80). States may establish additional standards for personnel who provide such services, such as home health aides (42 CFR 484.80). In self-direction, the beneficiary can define further training and certification requirements for these personnel who provide HCBS beyond federal and state minimum standards (CMS 2024b). Regulations at 42 CFR 440.70(d) specify that home health agencies participating in the Medicaid program must also meet the Medicare conditions of participation, which are set forth in regulations at 42 CFR 484 (CMS 2017).

[16] In addition to training and certification requirements for HCBS workers that a state deems appropriate, in self-direction, the beneficiary or representative must identify the specific training needed to meet their needs for assistance as part of the PCSP (CMS 2024b). A state may not allow the HCBS worker qualifications to be solely specified in the PCSP or by the participant and must establish the essential minimum qualifications that an HCBS worker must meet to be deemed qualified and ensure the requirements are met when HCBS are provided (CMS 2024b).

[17] Direct support professionals are a type of HCBS worker that supports people with disabilities to remain engaged with their community and provides caregiving and support with activities of daily living (ODEP 2025). Job development staff or job coaches are an example of direct support professionals (ODEP 2025).

[18] Section 1915(c) waiver technical guidance from CMS defines "extraordinary care" as care that exceeds the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age and that is necessary to ensure the health and welfare of the participant and avoid institutionalization (CMS 2024b). For example, a legally responsible individual supporting a teenage child enrolled in a waiver with activities of daily living such as bathing and dressing could constitute extraordinary care, as teenage children without a disability or chronic illness do not typically require such support. States that do allow legally responsible individuals to provide personal care or similar services must specify the situations in which payment may be approved for the delivery of exceptional care and describe how the state ensures that services provided by this individual are in the participant's best interest (CMS 2024b).

[19] The regulations at 42 CFR 441.575 specifically require that the majority of the Development and Implementation Council members be composed of individuals with disabilities, elderly individuals, and their representatives. The regulations require the state to consult and collaborate with the council when developing and implementing a state plan amendment to provide Community First Choice services and supports.

[20] Through interviews with state officials, we found that some states may refer to their support brokers as "independent facilitators." This definition is focusing on independent facilitators in states that have separate support broker and independent facilitator functions.

[21] Several states operate self-direction programs across multiple HCBS authorities. Some states shared that operating multiple authorities can present administrative challenges. Another state plans to phase out legacy Section 1915(c)-only waivers and enroll all self-directed beneficiaries in programs operating under both Section 1915(c) and 1915(j) to improve program flexibilities.

[22] Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of HCBS state plan or waiver services and supports (42 CFR 441.301, 441.725). Individuals who provide natural supports may include but are not limited to family members, neighbors, friends, and other personal associations and relationships.

[23] Federal officials noted that self-direction is not as prevalent for the older adult population, as many individuals receive

residential or assisted living services, so they have limited opportunities for self-direction.

[24] Under the Fair Labor Standards Act, the AwC FMS agency can be considered a third-party employer and be required to pay overtime (Appendix 5B).

[25] A beneficiary's paid provider is not allowed to also serve as the beneficiary's representative who makes decisions for, or in coordination with, the beneficiary (42 CFR 441.505, 441.480).

[26] Section 1915(c), 1915(i), 1915(j), and 1915(k) authorities have conflict of interest requirements in place to ensure the independence of individuals performing case management or assessment functions from those who provide HCBS to participants (42 CFR 431.301(c)(1)(vi), 441.468(d), 441.555(c), 441.730(b)).

[27] FMS agencies may offer some additional supports to compete with other FMS agencies in a state for clients.

[28] Regional offices are state-run centers that oversee self-direction programs in their area and communicate with information and assistance support entities and FMS agencies. In some cases, they may hold contracts with FMS agencies or information and assistance support entities. A state agency, such as the state Medicaid agency or operating agency, oversees the regional offices.

[29] Section 1903(l)(5)(A) of the Act (42 USC 1396) defines EVV as "a system under which visits conducted as part of such [personal care and home health care] services are electronically verified with respect to (i) the type of service performed; (ii) the individual receiving the service; (iii) the date of the service; (iv) the location of service delivery; (v) the individual providing the service; and (vi) the time the service begins and ends."

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# APPENDIX 5A: Statutory Authorities Used for Self-Directed Medicaid Home- and Community-Based Services

States cover self-directed Medicaid home- and community-based services through one or more statutory authorities, including waivers and state plan options (Table 5A-1).

**TABLE 5A-1.** Statutory Authorities for Self-Directed Medicaid Home- and Community-Based Services

| Type of authority | Authority | Description | Budget authority | Employer authority | Permits payment of relatives | Permits payment of legally responsible individuals | Total states using authority for self-direction |
|---|---|---|---|---|---|---|---|
| Waiver | Section 1915(c) | Allows states to offer a wide range of home- and community-based services (HCBS) to individuals who meet an institutional level of care. Also allows states to forgo certain Medicaid requirements to target HCBS benefits to specific populations, cap the number of beneficiaries who receive these benefits, and create waiting lists for people who cannot be served under the enrollment cap. | Yes, but no direct cash payments. | Yes | Yes | Yes | 46 |
| | Section 1115 | Not specific to HCBS, Section 1115 demonstration authority is a broad authority that allows states to test new delivery models that advance the goals of the Medicaid program. | Yes, but no direct cash payments. | Subject to specific requirements in approved demonstration | Yes | Yes | 14 |

**TABLE 5A-1.** (continued)

| Type of authority | Authority | Description | Budget authority | Employer authority | Permits payment of relatives | Permits payment of legally responsible individuals | Total states using authority for self-direction |
|---|---|---|---|---|---|---|---|
| State plan | Section 1905(a)(24) | Allows states to cover personal care services but does not give beneficiaries using self-direction the authority to manage their own individual service budget. | No | Yes | No | No | – |
| | Section 1915(i) | Allows states to offer HCBS to people who need less than an institutional level of care, the typical standard for Medicaid coverage of HCBS. States can also establish specific criteria for people to receive services under this authority. | Yes, but no direct cash payments. | Yes | Yes | Yes | 4 |
| | Section 1915(j) | Gives authority for self-directed personal assistance services (PAS), providing beneficiaries with the ability to hire and direct their own PAS attendant. States may also give beneficiaries the authority to manage their own individual service budget. This authority is used in conjunction with state plan PAS or other HCBS authorities such as Section 1915(c) waivers. | Yes, required. Cash payments are allowed to beneficiaries. | Yes | Yes | Yes | 7 |
| | Section 1915(k) | Known as Community First Choice (CFC), this option provides states with a 6 percentage point increase in the federal medical assistance percentage (FMAP) for PAS. | Yes, cash payments are allowed to beneficiaries. | Yes | Yes | Yes | 8 |

**TABLE 5A-1.** (continued)

**Notes:** Under self-direction, beneficiaries, or their representatives if applicable, have decision making authority and responsibility for managing all aspects of their service delivery in a person-centered planning process with the assistance of a system of available supports.

– Dash indicates data were not available on that authority.

**Sources:** CMS 2024; Murray et al. 2024; Sections 1115, 1905(a)(24), 1915(c), 1915(i), 1915(j), and 1915(k) of the Social Security Act; 42 CFR 440.70(b).

# APPENDIX 5B: Final Rules and Guidance

The Centers for Medicare & Medicaid Services (CMS) has issued a variety of final rules and guidance documents that establishes a comprehensive regulatory framework through which states administer their Medicaid self-directed home- and community-based services (HCBS). These rules and accompanying guidance have a direct impact on self-direction program design and administration and intend to enhance choice, control, and flexibility for beneficiaries self-directing their services.

**Revised Section 1915(c) waiver application (2004–2007).** CMS refined the criteria and guidance to states surrounding self-direction in its Section 1915(c) HCBS waiver application and instructions, technical guide, and review criteria (CMS 2024a). These modifications were designed to encourage states to include self-direction across their HCBS waiver programs (CMS 2009a). Revisions pertaining to self-direction included the incorporation of employer authority and budget authority into the application as well as requirements for the inclusion of information and assistance supports (CMS 2024a). These changes to the waiver application ultimately replaced the Independence Plus framework, which states previously had to use when implementing self-direction under a Section 1115 demonstration or a Section 1915(c) waiver, streamlining the waiver application and review process (CMS 2024a, 2002).

**Federal guidance on the implementation of Section 6087 of the Deficit Reduction Act of 2005 (P.L. 109-171) (2007).** In this state Medicaid directors' letter, CMS provides guidance on state requirements for administering self-directed personal assistance services (PAS) via a Section 1915(j) state plan authority (CMS 2007). These guidelines include an overview of payment methodology options under Section 1915(j) authority, minimum state assurances, reporting requirements, and state flexibilities regarding eligibility, conditions for disenrollment, and options for individual budget authority (CMS 2007). The guidance emphasizes that self-direction participants in a Section 1915(j) state plan or Section 1915(c) waiver program have access to counseling on self-directed options before enrollment in addition to a support system that can "inform, counsel, train, and assist participants with their employer-related responsibilities, including managing their workers and budgets and performing their fiscal and tax responsibilities" (CMS 2007). The guidance also directs states to submit an annual report on the total number of enrollees self-directing their services under Section 1915(j) state plan authority as well as total expenditures (CMS 2007). States must also conduct an evaluation every three years that compares beneficiaries' health and wellness in this state plan option with those who elected not to participate in self-directed PAS (CMS 2007). Although self-directed PAS under Section 1915(j) authority is a state plan option, the guidance clarifies that it does not need to be available throughout the entire state, and the state may limit the population eligible to self-direct and the number of individuals self-directing (CMS 2007). Last, the state may allow beneficiaries to have budget authority under this state plan option, and beneficiaries are not required to use a financial management services (FMS) agency if they are using the cash option (CMS 2007).

**Self-directed PAS program state plan option, final rule (2008).** Through this final rule, CMS provides guidance to states in administering self-directed PAS under Section 1915(j) of the Social Security Act, as authorized by the Deficit Reduction Act of 2005 (CMS 2008a). This rule establishes the framework for self-directed PAS, including requirements for person-centered planning, a risk management system, using budget authority, and using FMS (CMS 2008a).

Specifically, the final rule implemented a series of requirements that states must meet before pursuing self-directed PAS under this provision. First, states must have an existing personal care services benefit or be operating an HCBS waiver program before implementing self-directed PAS under this state plan option (CMS 2008a, 2008b). Second, all enrollment in the program must be voluntary, and for beneficiaries who choose to later disenroll from the program, a traditional, agency-delivered HCBS option must be available (CMS 2008a, 2008b). Last, states need to have quality assurances and other safeguards that ensure the health and welfare of beneficiaries participating in the self-direction state plan option (CMS 2008a, 2008b). These must also include a

support system to provide "sufficient information, training, counseling, and assistance to participants" so they may manage their budgets and services (CMS 2008b). Key components of this support system include support brokers or consultants and FMS agencies (CMS 2008a).

**Federal guidance on the implementation of Section 6087 of the Deficit Reduction Act of 2005.** In a second state Medicaid directors' letter on the optional choice to self-direct PAS, CMS provides additional clarification on beneficiaries' use of their individual budget authority for "permissible purchases" (CMS 2009b). This guidance also applies to the purchase of "individual directed goods and services" under a Section 1915(c) waiver. The key criterion beneficiaries must adhere to when purchasing these goods and services with their individual budget authority is that "the purchase be related to a need or goal identified in the participant's State-approved person-centered service plan" (CMS 2009b). The guidance directs states to make available supports brokers or consultants for self-direction participants under these authorities to provide appropriate information, counseling, training, and assistance, as needed or desired by participants, to enable participants to effectively direct the service planning and budget planning process, develop their service plans and individualized budget plans, and manage and direct their service and budget plans (CMS 2009b). State Medicaid agencies must also design procedures for effective oversight of spending on goods and services, including an annual reassessment of participants, which incorporates their use of goods and services to supplant human assistance needs (CMS 2009b).

**Community First Choice option, final rule (2012).** This final rule implements the Community First Choice state plan option under Section 1915(k) of the Social Security Act, as authorized under the Patient Protection and Affordable Care Act (P.L. 111-148, as amended) (CMS 2012a). The Community First Choice state plan option provides home- and community-based attendant services and supports at a 6 percentage point increase in the federal medical assistance percentage (FMAP) (CMS 2012a). Among other major provisions, this rule expands opportunities for self-direction, allowing beneficiaries to select and manage their attendant services and supports (CMS 2012a). The final rule mandates that states use a person-centered service plan that is based on a functional needs assessment (CMS 2012a). The person-centered service plan must also allow attendant services to be provided in either a traditional service-delivery model or a self-directed model within a defined service budget (CMS 2012a). Additionally, the final rule clarifies definitions of self-direction and the "self-directed model with service budget," also referred to as "individual budget authority" (CMS 2012a).

**HCBS, final rule (HCBS Settings Rule of 2014).** This final rule defines and describes state plan Section 1915(i) HCBS, offering new flexibilities for providing services for the elderly and people with disabilities (CMS 2014a). In addition to establishing requirements around the qualities of settings eligible for Medicaid reimbursements under HCBS programs, including settings requirements for Community First Choice, the rule requires states to implement person-centered planning processes, which are critical for self-direction programs (CMS 2014a). The rule amends Section 1915(i) of the Social Security Act outlining minimum supports for self-direction participants, including information and assistance, FMS supports, and the availability of an independent advocate to assist with access to and oversight of self-directed HCBS (CMS 2012b). Last, it defines both employer authority and budget authority (CMS 2014a, 2012b).

**Self-direction and the implementation of the Fair Labor Standards Act regulation changes (2014).** Pursuant to changes in the Fair Labor Standards Act, states operating self-direction models with a "third party joint employer" must ensure that direct care workers' (DCWs) work meets the minimum wage and overtime requirements (CMS 2014b). This guidance provides an overview of the "economic realities test," so states may determine which of their self-directed programs are impacted by the regulatory changes in the Fair Labor Standards Act. The guidance also identifies reimbursement options for third parties when a DCW provides services to multiple beneficiaries (CMS 2014b). For example, reimbursing a DCW for overtime or travel when split across multiple self-directing beneficiaries may be challenging (CMS 2014b). Additionally, these costs may not be deducted from an individual beneficiary's budget or the administrative costs for a third party (CMS 2014b). The reimbursement frameworks include both a capitated and fee-for-service approach.

**Medicaid and CHIP managed care, final rule (2016).** This rule updates regulations governing Medicaid managed care, including specific provisions that impact self-directed HCBS. The rule encourages states to include self-direction within their managed care system (CMS 2016). It also bolsters existing principles of self-direction by mandating person-centered planning for all managed long-term services and supports beneficiaries (including those in self-direction) and including consumer protections and supports (CMS 2016). These protections require managed care organizations to provide beneficiaries with clear information about self-direction options, access to adequate networks of qualified providers, and a robust grievance and appeals process (CMS 2016). It also mandates separation between the roles of care planning and service delivery to ensure beneficiaries have guidance and support in directing their services that are free from potential conflicts of interest (CMS 2016).

**Ensuring access to Medicaid services, final rule (2024).** This rule aims to ensure access to Medicaid services, and its provisions regarding rate transparency and reporting requirements directly impact self-directed homemaker, home health aide, personal care, and habilitation services (CMS 2024b). The rule mandates that at least 80 percent of all Medicaid payments must be spent on compensation to direct care workers for homemaker services, home health aide services, and personal care services (CMS 2024b). States must report on the percentage of payments for homemaker, home health aide, personal care, and habilitation services that are spent on compensation for DCWs at the provider level (CMS 2024b). For self-direction, the state must report separately on the compensation for self-directed services but exclude payment data for self-directed services for which individuals have budget authority (CMS 2024b). Last, the reporting and payment adequacy requirements apply only to services provided through Section 1915(c) waivers; Section 1915(j), 1915(k), and 1915(i) state plan authorities; and managed care delivery systems authorized under Section 1115(a), but they do not apply to Section 1905(a) state plan services (CMS 2024b).

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