

# Origins and Benefits of Self-direction

## *Home and Community-based Services (HCBS) Self-direction Series*

### Origins and History of Self-direction

#### **HCBS Self-direction Series**

This briefing paper series is designed for policymakers and stakeholders, to inform conversation and policy regarding HCBS self-direction and the direct service workforce. This brief is the first of four in the series and focuses on the origins and history of self-direction, self-directed options under Medicaid, self-direction's role in long-term services and supports (LTSS) rebalancing, and its benefits for individuals, families, and direct service workers.

The Centers for Medicare & Medicaid Services (CMS) define self-directed Medicaid services as a service delivery model in which “participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports.”<sup>1</sup> Self-directed services may include, but are not limited to, homemaker, home health aide, personal assistance/personal care, respite, supported employment, and environmental modification services. Participants who self-direct their services may have decision-making authority over who provides their services (i.e., employer authority), how their Medicaid funds are spent (i.e., budget authority), or both. Typically, states may provide the option to self-direct Medicaid services through section 1915(c) HCBS waiver programs, the section 1915(i) HCBS state plan option, the section 1915(j) Self-Directed Personal Assistance Services state plan option, and the section 1915(k) Community

First Choice state plan option.<sup>1</sup> The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency-delivery model, and may help people who use Medicaid-funded HCBS to access a new pool of workers. This is an important consideration as states explore strategies to ensure an adequate direct service workforce and advance individual choice and preference in the delivery of Medicaid HCBS.

The origins of self-direction can be traced to the implementation of the U.S. Department of Veterans Affairs Aid and Attendance Pension Benefit shortly after World War I and the founding of the Independent Living Movement in the 1960s and 1970s.<sup>2,3</sup> Beginning in the 1990s, a number of states began to offer “consumer-directed” personal care services pursuant to section 1905(a)(24) of the Social Security Act, the optional state plan personal care services benefit.<sup>1</sup> The Robert Wood Johnson Foundation awarded grants for Self-Determination demonstrations in 19 states from 1997 to 2001; they later implemented the Cash and Counseling demonstration and evaluation in three states (Arizona, Florida, and New Jersey) and replicated it in 12 additional states from 1996 to 2013.<sup>4</sup> Following these projects, self-direction emerged as an important option for the delivery of Medicaid-funded HCBS. Since then, there have been a number of federal and privately funded initiatives that have advanced the development and implementation of self-directed service options nationally, including the passage of the Developmental Disabilities Assistance and Bill of Rights Act in 2000, the Deficit Reduction Act (DRA) in 2005 (which authorized sections 1915(i)

and 1915(j) in the Medicaid program), and the Affordable Care Act (ACA) in 2010 (which authorized section 1915(k)).<sup>1,3,5</sup>

### Self-direction Fast Facts<sup>6</sup>

- Medicaid is the primary funding source for self-directed services. Medicaid accounted for 66 percent of self-directed services funding in 2019. Each of the Medicaid HCBS authorities has differences in what is allowed in a self-directed services program.
- Every state and the District of Columbia has implemented at least one Medicaid waiver program or state plan option with a self-directed option, with most states offering self-directed services statewide.
- In 2019, there were 1,234,214 participants served (a 16.5 percent increase over 2016) across 267 Medicaid waiver programs with self-directed options.<sup>7</sup>
- In 2019, participant enrollment in Medicaid waiver programs with self-directed options ranged from 166 in South Dakota to 606,078 in California.

CMS initiatives and activities have been integral to the development and growth of self-directed services nationally:

- **1998-2000:** CMS approved section 1115 research and demonstrations for the three Cash and Counseling grantee states.<sup>8</sup>
- **2002:** CMS announced the Independence Plus initiative to streamline approval of states' waiver program applications for self-directed services.
- **2003:** CMS awarded Systems Change Independence Plus grants to 12 states to develop Medicaid-funded self-directed services.
- **2004-2007:** CMS revised the section 1915(c) HCBS Waiver Application and Instructions, Technical Guide, and Review Criteria to incorporate both employer and budget authority, require the provision of information and assistance in support of self-direction, and eliminate the need for a separate Independence Plus waiver for states to implement self-directed services. CMS also implemented a web-based electronic waiver application.
- **2007-2014:** CMS issued the final rule for the sections 1915(j) Self-Directed Personal Assistance Services, 1915(i) HCBS, and 1915(k) Community First Choice state plan options, significantly expanding opportunities for states to implement self-direction under Medicaid.<sup>3</sup> Each Medicaid funding authority has different self-direction guidelines, but all authorities share some common requirements, including: (1) a person-centered planning process, (2) a service plan, (3), information and assistance in support of self-direction, (4) financial management services (FMS), (5) a system for continuous quality assurance and improvement, and (6) an individualized budget, if in a self-directed program with budget authority.<sup>1</sup>
- **2007-present:** CMS continues to sponsor technical assistance to state agencies developing and pursuing self-directed Medicaid-funded HCBS.<sup>9</sup>

## Self-directed Services under Medicaid

By choosing to self-direct their services, participants take direct responsibility to manage their services using a person-centered planning process and the assistance of a system of available

supports. For example, a supports broker, consultant, or counselor is made available to participants who choose to self-direct their services. This individual acts as a liaison between the participant and Medicaid and provides overall self-direction support (e.g., assistance with directing services, identifying information and resources to meet Medicaid requirements).<sup>1</sup> FMS also are a support made available to participants to assist them in exercising employer and budget authority. Although participants can perform some or all FMS functions themselves, typically, FMS entities perform these functions for them. For example, FMS entities assist participants with (1) understanding billing and documentation responsibilities, (2) performing payroll and other employer-related duties, such as managing federal, state, and local, as applicable, employment tax filings and payments, processing direct service workers' timesheets, and facilitating the purchase of workers' compensation insurance and other required insurances, (3) purchasing approved goods and services, (4) tracking and monitoring individual budget expenditures, and (5) identifying expenditures that are over or under the budget.<sup>1</sup>

### Employer and Budget Authority

- As described in 42 Code of Federal Regulations (CFR) section 441.740, **employer authority** allows participants to select and manage providers or direct service workers as specified in the participant's person-centered service plan either as a common law or joint employer. This encompasses employer-related tasks, such as recruiting, hiring (e.g., interviews, background checks, reference checks), establishing work schedules, determining training needs, assigning tasks, supervising and evaluating performance, and discharging workers, when necessary. Some participants may also negotiate direct service workers' wages and benefits. However, this may be limited in states where participants must abide by collective bargaining agreements with unions representing direct service workers.
- **Budget authority**, as described in 42 CFR section 441.740, allows participants to develop an individualized budget as specified in the participant's person-centered service plan. The individualized budget identifies the dollar value of the services selected and managed by the participant. Participants may also purchase items or goods (e.g., lift chairs, microwave ovens) that are not typically covered under Medicaid and can be purchased from non-traditional sources. Each Medicaid authority with the option to self-direct establishes its own policies related to allowable self-directed purchases.<sup>1</sup>

## Highlighted Benefits of Self-direction

Self-directed services may: (1) significantly reduce the unmet need of participants, (2) result in positive health outcomes for participants, and (3) improve quality of life for participants and their caregivers.<sup>10</sup> **Exhibit 1** summarizes benefits of self-direction for individuals, families, and direct service workers.

## Exhibit 1. Benefits of Self-direction

Benefits to Individuals and Their Families	Benefits to Direct Service Workers
<ul style="list-style-type: none"> <li>▪ <b>Affords opportunity to customize HCBS</b> to meet a person’s goals, desires, and support needs</li> <li>▪ <b>Provides choice and control over the services received</b>, including recruitment, work schedules, service delivery, wages, benefits, training, and discharge (when necessary)</li> <li>▪ <b>Enables the hiring of relatives with options to hire legally responsible individuals</b> (e.g., spouse or parent of a minor child) <b>when permitted by the state</b>, for services identified in a person-centered service plan. This can often result in better, more consistent care by people with whom the individual is most comfortable</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Provides options to work for individuals of their choice</b>, such as a relative or friend who needs supports</li> <li>▪ <b>Affords opportunity to develop close personal relationships</b> with the individual they are caring for due to permanent assignment</li> <li>▪ <b>Fewer workers’ compensation insurance claims</b> for HCBS programs under self-directed options<sup>11</sup></li> <li>▪ <b>Allows relatives to recoup a portion of lost income</b> while caring for their relative</li> <li>▪ <b>Provides flexible wage ranges</b> enabling direct service workers to receive wage rates higher than those typically paid by agency providers</li> </ul>

Self-direction is an important service delivery model for states to consider as they seek to rebalance their LTSS toward HCBS and experience a demand for services that exceeds the capacity of the direct service workforce.

**For more information, please view the other briefs in this HCBS self-direction series:**

*Key Components of Self-directed Services*

*Operational Considerations for Self-directed Service Delivery Models*

*Self-direction Research Compendium*

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## References

- <sup>1</sup> Centers for Medicare & Medicaid Services. (n.d.). *Self-Directed Services*. Department of Health and Human Services. Retrieved from <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html>.
- <sup>2</sup> National Council on Disability. (2013). *The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities*. Retrieved from <https://ncd.gov/publications/2013/05222013A>.
- <sup>3</sup> National Resource Center for Participant-Directed Services. (2010). *Developing and Implementing Self-Direction Programs and Policies: A Handbook*. Retrieved from <https://www.appliedselfdirection.com/sites/default/files/Participant%20Direction%20Handbook.pdf>.
- <sup>4</sup> The 12 replication states included Alabama, Iowa, Illinois, Kentucky, Michigan, Minnesota, New Hampshire, New Mexico, Pennsylvania, Rhode Island, and Washington.
- <sup>5</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402, 106<sup>th</sup> Congress. (2000). Retrieved from [https://acl.gov/sites/default/files/about-acl/2016-12/dd\\_act\\_2000.pdf](https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf). Among these initiatives is the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), passed by Congress in 2000. The act's stated purpose is for "individuals with developmental disabilities and their families [to] participate in the design of and access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs..." According to the DD Act, "the term 'self-determination activities' means activities that result in individuals with disabilities, with appropriate assistance, having – (A) the ability and opportunity to communicate and make personal decisions; (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; (C) the authority to control resources to obtain needed services, supports, and other assistance; (D) opportunities to participate in, and contribute to, their communities; and (E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities." DD Act grantees carry out a variety of activities related to self-determination.
- <sup>6</sup> Edwards-Orr, M., Morris, M., DeLuca, C., Sciegai, M., & Ujvari, K. (2020). *2019 National Inventory of Self-Directed Long-Term Services and Supports Programs*. AARP Public Policy Institute. Retrieved from <https://www.appliedselfdirection.com/resources/2019-national-inventory-self-direction-programs>
- <sup>7</sup> Applied Self Direction counted all self-directed service options operating under a single Medicaid waiver program as one single program.
- <sup>8</sup> Arkansas' Independent Choices Program implemented in 1988, New Jersey's Personal Preference Program implemented in 1999, and Florida's Consumer-Directed Care Program implemented in 2000.
- <sup>9</sup> Centers for Medicare & Medicaid Services. (2020). *Welcome to HCBS-TA*. Department of Health and Human Services. Retrieved from <https://www.hcbs-ta.org/>.
- <sup>10</sup> Brown, R., Lepidus-Carlson, B., Dale, S., Foster, L., Phillips, B., & Schore, J. (2007). *Cash and Counseling: Improving Lives of Medicaid Beneficiaries Who Need Personal Care and Home- and Community-Based Services*. Mathematica Policy Research. Retrieved from <https://www.mathematica.org/our-publications-and-findings/publications/cash-and-counseling-improving-the-lives-of-medicaid-beneficiaries-who-need-personal-care-or-home-and-communitybased-services>.
- <sup>11</sup> National Resource Center for Participant-Directed Services. (2010). *Managing Changes: Introducing Consumer Direction to Aging Network Management*. Retrieved from <https://www.appliedselfdirection.com/sites/default/files/Managing%20Changes%20Q%26A.pdf>.