

# Chapter 2: Legal Authority

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## Chapter 2

# Legal Authority<sup>1</sup>

This chapter describes the legal (statutory) authorities under which self-direction may be incorporated into the delivery of Medicaid-funded home and community-based services (HCBS). While the authorities differ, they share common features, including empowering Medicaid program participants and their representatives (hereafter, referred to as participants) to hire their workers, to direct how and when services are provided, and to exercise authority over an individual budget. The chapter also examines options for self-direction in other federal and state long-term services programs.

### A. Medicaid

The federal-state Medicaid program is the largest purchaser of long-term services and supports for people with disabilities and older persons. In 2004, Medicaid accounted for 42 percent of all long-term services expenditures in the United States.<sup>2</sup> Medicaid-funded long-term services include HCBS such as personal care/assistance as well as institutional services (e.g., nursing facility services).

In 2006, Medicaid long-term services expenditures totaled \$99.3 billion.<sup>3</sup> Over the past decade, there has been a major shift in the delivery of Medicaid long-term services away from institutional settings toward expanded use of HCBS. Between 1996 and 2007, the share of Medicaid long-term services spending devoted to HCBS increased from 21 percent to 41.7 percent.<sup>4</sup> In 2007, Medicaid HCBS spending reached \$42.3 billion.<sup>5</sup>

Medicaid's central role in underwriting the costs of HCBS means that federal policies have major implications for the extent to which states may provide participants the opportunity to direct their services. This section discusses:

- How federal Medicaid policies have evolved over the past decade to support self-direction;
- The current federal policy framework for incorporating self-direction into the delivery of Medicaid HCBS; and,
- The five principal federal legal authorities that permit states to employ self-direction in the delivery of Medicaid HCBS.

#### ***Evolution of Self-Direction in Medicaid HCBS***

Medicaid was framed as a program in which service providers manage the delivery of services to participants. However, over the past decade, federal

Medicaid policies have evolved to provide states with several options to offer participants the authority to direct their HCBS.

Self-direction of Medicaid HCBS began in the 1970s when a few states launched Medicaid personal assistance/attendant services programs that offered employer authority (i.e., empowered Medicaid participants to hire, supervise, and dismiss their personal assistants/attendants [hereafter, referred to as workers]).<sup>6</sup>

During the 1980s and 1990s, the number of states that authorized Medicaid participants to manage their workers grew, both with respect to the provision of personal care/assistance services under the Medicaid State Plan and, starting in 1981, services furnished through Section (§) 1915(c) HCBS waivers (hereafter, referred to as §1915(c) waivers). In 1997, the federal Health Care Financing Administration (now the Centers for Medicare & Medicaid Services—CMS) released formal guidance (discussed in more detail below) that acknowledged that states could employ a “consumer-directed service delivery model” for the delivery of personal care/assistance services under the Medicaid State Plan.

Starting in 1995, the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) partnered to sponsor the “Cash & Counseling” demonstrations. The aim of the demonstrations was to test a broader approach to self-direction that gave participants the authority to manage an individual budget and the latitude to use this budget to purchase individually selected goods and services, including but not limited to employing workers. The demonstrations also gave participants the option of receiving allowances in cash that they could keep in personal bank accounts and use to purchase HCBS, or have their funds deposited with an entity that would perform financial transactions under their direction. However, fewer than a dozen participants in all three states selected the cash option.<sup>7</sup>

CMS collaborated with Arkansas, Florida, and New Jersey to design §1115 research and demonstration programs in order to evaluate the benefits of this approach. The demonstrations were launched in the three states between 1998 and 2000 and yielded robust information about the positive benefits of the Cash and Counseling approach to self-direction.<sup>8</sup>

On a parallel track, RWJF also launched its Self-Determination for People with Developmental Disabilities Program in 1995.<sup>9</sup> RWJF awarded grants to 18 states to create pilot programs that gave individuals and families a leadership role in the design of person-centered service plans along with choice and control over an individual budget to carry out the service plan. These pilots also featured the provision of independent counseling services (specifically referred to as Support Broker services) to assist participants in selecting and managing services along with fiscal intermediaries to serve as their agents for employment purposes. The Self-Determination pilots operated within the regulatory confines of the §1915(c)

waiver program and, therefore, did not permit the cashing out of waiver funds.

In response to the favorable early evaluation results from the Cash & Counseling demonstrations, experience garnered through the Self-Determination pilots, and rapidly growing state interest in shifting to the use of self/family-directed budgets, CMS launched its Independence Plus (IP) initiative in 2002. CMS created a stand-alone Independence Plus §1915(c) waiver template that provided states with a tool to incorporate the use of individual budgets, “supports brokerage” services, and participant employment of workers into the delivery of waiver services. CMS also issued a separate Independence Plus §1115 demonstration program template.

In 2005, CMS extensively modified its standard §1915(c) waiver application so that states could include a self-direction option in any §1915(c) waiver. The new waiver application built upon the predecessor Independence Plus waiver template and further clarified the federal policies that apply when a self-direction option is implemented in a §1915(c) waiver. More than 32 states have incorporated self-direction into these waivers.<sup>10</sup>

In the Deficit Reduction Act of 2005 (DRA-2005), Congress added two statutory provisions that offer states additional avenues to incorporate self-direction into the delivery of Medicaid HCBS without having to seek federal waivers.<sup>11</sup> These provisions are discussed in more detail below. DRA-2005 also provided that states may offer participants in Money Follows the Person (MFP) demonstrations the authority to self-direct their HCBS.<sup>12</sup>

In the space of about 10 years, federal Medicaid policy has evolved from the limited recognition that states could allow participants to directly manage their workers, to the establishment of a broad framework under which states may give Medicaid participants more wide-ranging authority to direct their HCBS.

### ***Basic Features of Self-Direction of Medicaid HCBS***

The section following this one describes in detail the legal authorities that permit incorporation of self-direction into the delivery of Medicaid HCBS. While each authority has unique elements, certain basic features of self-direction cut across the authorities. These features include:

- ***Individual Election of Self-Direction.*** When a state offers self-direction of HCBS, it generally must allow participants to opt into or out of directing their services. For the purposes of Medicaid funding, a state must offer a traditional “provider-managed” service delivery option alongside self-direction and ensure there are no service breaks during transition periods. This feature recognizes that not all participants may want to assume the responsibilities that self-direction entails.
- ***Participant-Led Service Planning Process.*** Another important feature is

positioning the participant (or a personally selected personal representative) to lead the service planning process. This includes giving participants the authority to select who participates in the process (e.g., family members and friends), and ensuring that participants' service plans reflect their own preferences and personally selected desired outcomes. Participants are expected to have the authority to select their HCBS in addition to exercising free choice of provider, a longstanding right under federal Medicaid law.<sup>13</sup>

- ***Individual Authority Over Service Delivery.*** Self-direction of Medicaid HCBS also allows participants to determine how and when services are delivered. This includes specifying the elements of the services that will be delivered (within the approved scope of the service(s) that the state offers), scheduling the delivery of services, and establishing any additional special qualifications for the workers or agencies that participants select to provide services.<sup>14</sup>
- ***Individual Budget.*** Under most of the legal authorities, participants may be provided an individual budget that includes some or all of their HCBS funding. Within this budget, participants are afforded the authority (a.k.a., budget authority) to purchase individually selected goods and services. Participants, with the aid of counselors and the financial management services (FMS) entity assume responsibility for managing the individual budget.
- ***Managing Workers.*** All of the legal authorities provide that participants may function as the employers of their workers. This includes exercising authority over the selection, supervision, and management of workers. This dimension of Medicaid self-direction is termed the employer authority. Under this authority, a state may recognize Medicaid participants as the legal (common law) employers of their workers and provide for the use of fiscal/employer agents to pay workers and file payroll taxes on their behalf. A state may also elect to use a co-employer model under which an organization serves as the legal employer of participant-hired workers.
- ***Supports for Self-Direction.*** Federal policy provides that states can obtain Medicaid federal financial participation (FFP) when they provide certain key supports to participants who direct their services. These supports include:
  - ***Financial management services.*** These services include performing financial transactions on behalf of participants (e.g., paying workers that participants employ, deducting payroll taxes, and facilitating the purchase of other goods and services) along with tracking expenditures against the individual budget.
  - ***Assistance in Directing HCBS.*** Medicaid funding is also available to reimburse the costs of personalized assistance to participants in planning and directing their services. Such assistance may include counseling

participants about available services and supports; helping them to acquire the skills to create and manage the individual budget and to manage their individually employed workers; assisting them to locate workers and services; and obtaining other benefits and community resources. This form of assistance is termed “counseling.” (Other terms used include “supports brokerage” or “supports coordination” or “consulting.” This Handbook uses the term “counseling” to describe this support and the term “counselor” to describe the person providing it.)

- **Safeguards.** Finally, states are expected to implement certain basic safeguards on behalf of participants who direct their services. These safeguards include ensuring that services are not interrupted when an individual elects to transition from self-direction to provider-managed services, guarding against the premature depletion of the individual budget, and ensuring that participants have an individualized backup plan to handle service delivery breakdowns.

It is important to point out that, under the applicable authorities, states have considerable latitude in how they implement each of these self-direction features.

### ***Federal Medicaid Statutory Authorities***

There are five principal Medicaid statutory authorities under which states may implement self-direction of HCBS.<sup>15</sup> Four of these authorities are located in Title XIX (Medicaid) of the Social Security Act. In this section, the basic scope of each authority is described with particular attention to how self-direction can be implemented under the authority.

The first three self-directed services options are Medicaid State Plan authorities. The Medicaid State Plan is the fundamental document in which a state describes the groups of participants it will serve under its Medicaid program along with the services it will furnish participants. A state can add self-direction options under the Medicaid State Plan by submitting a State Plan Amendment (SPA) to CMS for review and approval. Once an SPA is approved, it becomes a permanent feature of the state’s Medicaid program unless subsequently altered by the state.

The other two self-directed services options operate under what are termed “waiver authorities.” Under a waiver authority, a state requests waivers of federal statutory provisions in order to furnish services in a fashion not otherwise permitted under the Medicaid State Plan. Section 1915(c) waivers and §1115 waivers, when granted, are for limited periods but can be periodically renewed.

## 1. State Plan Coverage of Personal Care

### *Basic Scope*

Under §1905(a)(24) of the Social Security Act (hereafter referred to as the Act), a state has the option to cover personal care services under its Medicaid State Plan. These services are also sometimes termed “personal assistance” or “attendant care.” Personal care “may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages which enables them to accomplish tasks that they would normally do for themselves if they did not have a disability.”<sup>16</sup> Personal care includes assisting participants in performing Activities of Daily Living (ADLs—e.g., eating, bathing) and Instrumental Activities of Daily Living (IADLs—e.g., meal preparation, shopping, money management). Personal care services also may include prompting or cuing an individual to perform an ADL or IADL.

Personal care may be furnished in participants’ homes or other living arrangements and to support them in the community. For example, some states (e.g., Utah) provide that personal assistance may be furnished to support participants while working. Thirty-six states cover personal care under their Medicaid State Plans.<sup>17</sup> When personal care is covered under the Medicaid State Plan, it must be provided to all Medicaid participants who require such services. A state may not limit the number of persons who can receive these services. However, a state may impose limitations on the amount, frequency, and duration of the services that it provides to eligible participants because personal care is an optional State Plan benefit.

### *Self-Direction of Personal Care Services*

As previously noted, in 1997 CMS issued revised guidance concerning the provision of personal care services under the Medicaid State Plan.<sup>18</sup> In this guidance, CMS confirmed that a state had the option of employing a “consumer-directed model” to deliver personal care where “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 guidance also allowed states to “permit family members or other participants to direct the provider on behalf of the individual receiving the services.”<sup>19</sup>

About one-half of the states that cover personal care under the Medicaid State Plan authorize participant-directed services. In some states (e.g., Maine, Massachusetts), third-party entities (often Independent Living Centers) facilitate self-direction by performing payroll and related employment functions on behalf of participants who select and manage their workers. Elsewhere (e.g., California, Michigan), the state itself or its claims payment contractor performs payroll and tax-filing functions as the beneficiary’s employer-agent. Within the federal

framework of self-direction, participant-directed Medicaid State Plan personal care/assistance services are a long-standing example of affording Medicaid participants the “employer authority” discussed above.

There are two main limitations concerning the extent to which self-direction can be employed in conjunction with the delivery of personal care/assistance under the Medicaid State Plan. In particular:

- When personal care is covered under §1905(a)(24), the budget authority may not be used and personal care assistance dollars may not be redirected or cashed out to purchase other types of goods and services. Medicaid dollars may only be used to pay for the provision of personal assistance.
- Another limitation is that legally-liable relatives (i.e., parents of minor children and the beneficiary’s spouse) may not be paid to provide personal care/assistance. However, other relatives (at a state’s option) can be paid to provide personal care.

These limitations may be overcome when a state elects to furnish self-directed personal assistance services under the provision of §1915(j) of the Act (described below).

## **2. State Plan Coverage of HCBS**

### ***Basic Scope***

Section 6086 of the DRA-2005 added §1915(i) to the Act, effective January 2007.<sup>20</sup> This provision permits a state to offer HCBS in addition to personal care services under its Medicaid State Plan without having to secure federal approval of a waiver. While this optional coverage is similar to the longer-standing HCBS waiver authority (described later), the two authorities differ in important ways.

The §1915(i) authority is a State Plan coverage authority. Like other State Plan services, a state must submit a State Plan amendment to CMS in order to cover HCBS under this authority. Under this authority, a state is permitted to offer services statewide or limit them to geographic regions specified by the state. Unlike the §1915(c) waiver authority, a state does not have to periodically request federal approval to continue the delivery of HCBS under this option. A state may offer services under the §1915(i) authority while continuing to concurrently operate §1915(c) waivers. In other words, employing the §1915(i) authority does not require that a state cease operating its targeted HCBS waivers.

The §1915(i) authority permits a state to cover the services that are specifically identified in the waiver authority under §1915(c) of the Act.<sup>21</sup> Unlike the §1915(c) waiver authority, a state may not cover services that are not specified in §1915(c). A state may also elect to pay relatives—including legally responsible relatives—to provide HCBS.

Unlike the §1915(c) waiver authority, the §1915(i) authority does not require that HCBS be provided only to people who require an institutional level of care. This is an important difference between the two authorities that may prove especially beneficial for participants with mental illnesses.<sup>22</sup> States are limited to offering services to participants whose income does not exceed 150 percent of the federal poverty level.<sup>23</sup>

Another important difference between the two authorities is that, unlike the HCBS waiver authority, under the §1915(i) authority, a state may not limit HCBS to groups of participants with specific diagnoses or conditions to the exclusion of others. Instead, the §1915(i) authority requires that a state establish generic eligibility criteria that apply to all people who seek HCBS. States have latitude in deciding the criteria that they will apply, but the statute specifies that these criteria must be less stringent than the criteria that apply to the provision of Medicaid institutional services. Criteria may be based on functional limitations.

Like the HCBS waiver authority, a state may limit the number of participants who receive HCBS under the new authority. A state is permitted to wait-list participants for services if necessary. In addition, the §1915(i) authority permits a state to modify its eligibility criteria in the event that the state finds that more people qualify than the state estimated. The new authority does not require that a state demonstrate cost neutrality.

CMS permits states to have only one program that uses the §1915(i) authority. CMS published guidance on this authority in the form of a proposed rule in the Federal Register on April 8, 2008 with comments due by June 3, 2008. At the time of publication, the final rule was expected in early 2009. CMS also released a State Plan preprint that states may use to add this coverage to their Medicaid programs.<sup>24</sup> This pre-print borrows elements of the §1915(c) waiver application. So far, only one state—Iowa—has added this coverage, although by report several others are considering taking advantage of this new authority.

### ***Self-Direction of State Plan HCBS***

The §1915(i) authority specifically provides that a state may incorporate a self-direction option for the delivery of State Plan HCBS.<sup>25</sup> Under the statute, self-directed services are defined as HCBS “which are planned and purchased under the direction and control of such individual or the individual’s authorized representative.”

States that elect to incorporate a self-direction option in the provision of State Plan HCBS, must address the following:

- ***Assessment.*** The state must provide for a process to assess the “needs, capabilities, and preferences” of the individual;
- ***Service Plan.*** The state must have a service plan development process that

is “directed by the individual or the individual’s authorized representative; builds upon the individual’s capacity to engage in activities that promote community life and that respects the individual’s preferences, choices, and abilities; and involves families, friends, and professionals as desired or required by the individual or the individual’s authorized representative; . . . . and includes appropriate risk management techniques that recognize the roles and sharing of responsibilities in obtaining services in a self-directed manner; and assure the appropriateness of such plan based upon the resources and capabilities of the individual or the individual’s authorized representative;”

- ***Specification of Self-Directed Services.*** The state must specify which of the HCBS offered under its §1915(i) coverage may be self-directed;
- ***Methods of Self-Direction.*** The state also must specify the methods by which participants may self-direct their services. In its State Plan pre-print, CMS has addressed this element by providing that a state may elect to offer participants the employer and/or budget authority along similar lines as allowed under the §1915(c) waiver authority;
- ***Self-Directed Budget.*** The state *may* offer participants a self-directed budget, which “identifies the dollar value of the services and supports under the control and direction of the individual or the individual’s authorized representative.” When a state offers a self-directed budget, it must specify the methods by which the budget is calculated and provide for a process to adjust the budget based on changes in an individual’s assessment and service plan; and,
- ***Financial Management Services.*** The state may contract administratively for the provision of financial management services to support participants who elect to direct their services.

In most respects, the elements of a self-direction option under §1915(i) closely parallel self-direction in §1915(c) waivers.

### **3. State Plan Coverage of Self-Directed Personal Assistance Services**

#### ***Basic Scope***

Section 6087 of DRA-2005 added §1915(j) to the Act, effective January 2007.<sup>26</sup> This authority permits a state to institute a self-directed services option that includes the disbursement of cash prospectively to participants who direct their personal assistance services.

This authority also allows states to permit participants who self-direct under the §1905(a)(24) authority to use their individual budgets to purchase goods and services other than personal assistance, to the extent that expenditures would otherwise be made for human assistance. (States already have the authority

under §1915(c) to allow waiver participants to purchase a broad range of goods and services.) Absent the §1915(j) authority, self-direction of Medicaid State Plan personal assistance services is limited to use of the employer authority, as previously discussed.

States may use this authority only in programs *already* offered under its Medicaid State Plan or a §1915(c) waiver (i.e., states may not offer self-directed services under the §1915(j) authority except through an existing State Plan Personal Care program or §1915(c) waiver program).

Especially with respect to Medicaid State Plan personal assistance services, this authority is specifically intended to relieve states of the need to operate §1115 Research and Demonstration waivers in order to offer participants wide-ranging authority to direct their personal assistance services, including using personal assistance funds to purchase other goods and services. Elements of this authority are the direct outgrowth of the Cash & Counseling demonstrations.

In September 2007, CMS issued a State Medicaid Director Letter that provides guidance to states concerning this Medicaid State Plan option.<sup>27</sup> The letter is accompanied by a Medicaid State Plan amendment (SPA) pre-print that states may submit in order to invoke this authority.<sup>28</sup> So far, five states—Alabama, New York, Oregon, Florida, and Arkansas—have secured CMS approval of a State Plan amendment under this authority, and several other states have submitted their draft SPAs to CMS for approval.<sup>29</sup>

### **Key Features of the §1915(j) Authority**

The authority defines self-direction as:

*The participant (or in the case of a participant who is a minor child, the participant's parent or guardian, or in the case of an incapacitated adult, another individual recognized by state law to act on behalf of the participant) exercises choice and control over the budget, planning, and purchase of self-directed personal assistance services, including the amount, duration, scope, provider, and location of service provision.<sup>30</sup>*

The authority has the following major features:

- **Disregard of Statewide and Comparability.** The state may elect to make its self-direction option available statewide or only in specified parts of the state, and may limit the number of participants who direct their services under this option.
- **Limitations on Participants Who May Self-Direct.** The state may not offer its self-direction option to participants who reside in a living arrangement that is owned, operated, or controlled by a service provider. The self-direction

option may only be offered to participants who live with their families or in housing that the person controls (either by ownership or lease). States also have the latitude to make self-direction available to all participants (subject to the preceding limits) or only to specified groups of participants.

- ***Election of Self-Direction.*** The state must provide information and counseling to participants about self-direction so they can make an informed choice whether to self-direct. A state also must allow participants to voluntarily terminate self-direction and return to receiving provider-managed services. When a person voluntarily ends self-direction (or the state determines that self-direction should be terminated involuntarily), the state must ensure that the individual continues to receive critical services during the transition period.
- ***Use of a Representative.*** The state may permit participants to appoint a representative to direct services.
- ***Service Plan.*** The state must fashion a person-centered service planning process that includes an assessment of the individual’s needs, strengths, and preferences and “... [a] builds upon the participant’s capacity to engage in activities that promote community life and that respects the participant’s preferences, choices, and abilities; and [b] involves families, friends, and professionals in the planning or delivery of services or supports as desired or required by the participant.”
- ***Quality Assurance and Risk Management.*** The state must develop appropriate quality assurance methods and employ processes that identify and address risks. The risk management plan must be developed in concert with the participant.
- ***Individual Budget.*** The state must provide an individual budget to each participant who elects to self-direct. The amount of this budget must be determined through the uniform application of a methodology developed by the state.
- ***Cash Option.*** The state may elect to disburse cash prospectively to self-directing participants, with which they directly purchase services. Participants who elect this option are also permitted to pay their workers and file the employer share of payroll taxes, subject only to retrospective oversight to ensure compliance with labor/tax requirements. The availability of a cash option is unique to this authority. There is no comparable cash option available under the §1915(c) waiver program or the Medicaid State Plan HCBS coverage.
- ***Purchase of Goods and Services.*** The state may elect to permit participants who self-direct to “to acquire items that increase independence or substitute

for human assistance (such as a microwave oven or an accessibility ramp), to the extent that expenditures would otherwise be made for the human assistance.” In other words, participants may be given the authority to use their individual budgets to purchase goods and services other than personal assistance.

- ***Availability of On-Going Assistance in Self-Direction.*** The state must make ongoing training, assistance, and counseling available to participants who direct their personal assistance, through use of a counselor, financial management services, and other information and assistance methods.
- ***Providers.*** Participants have the authority to “choose as a paid service provider, any individual capable of providing the assigned tasks including legally liable relatives.”
- ***Financial Management Services.*** The state must arrange for the provision of financial management services on behalf of self-directing participants (except those who have elected the cash option, if available). The state may obtain such services from vendors or elect to provide the services itself. The costs of these services are eligible for federal financial participation (FFP) only as an administrative expense.

While this authority shares some of the features of self-direction that are available under the §1915(c) waiver and Medicaid State Plan HCBS options, it goes beyond those options by permitting states to offer participants a cash option.

#### **4. HCBS Waiver Program**

##### ***Basic Scope***

Under the provisions of §1915(c) of the Act, a state may obtain federal waivers to furnish HCBS to participants who require the level of care that is provided in a Medicaid-reimbursable institutional setting but choose to be supported in the community. This waiver authority has emerged as one of the principal vehicles (along with State Plan coverage of personal care/assistance) by which states secure Medicaid federal financial participation in the costs of supporting older persons and participants with disabilities in the community. A state may operate one or several waivers. The §1915(c) waiver authority permits a state to:

- Target HCBS to a state-specified group of Medicaid participants by securing a waiver of comparability;<sup>31</sup>
- Furnish a state-defined package of HCBS to waiver participants; and,
- Specify the number of persons who may participate in a waiver program.

The §1915(c) waiver statute identifies certain services (e.g., case management,

personal care, supported employment, respite) that a state may include in its waiver benefit package. A state may also propose to cover additional services beyond those specified in the Act, subject to CMS review and approval. By operating a §1915(c) waiver, a state may provide: (a) services that it could not otherwise offer under its Medicaid State Plan; (b) services that it could offer under the State Plan but does not; and, (c) services that it offers under the State Plan but in an amount greater than allowed under the State Plan. States principally target waiver services to the following groups of Medicaid participants:<sup>32</sup>

- Older persons
- People with physical disabilities
- People who have experienced a brain injury
- Children with serious emotional disturbances
- Children and adults with intellectual and other developmental disabilities
- Children with special health care needs
- People with AIDS
- Technology-dependent individuals

In order to secure CMS approval of a §1915(c) waiver, a state must demonstrate that the program will be cost-neutral in the aggregate. That is, the state must show that the estimated average annual cost of supporting participants in the waiver will be no greater than the average annual cost of serving them in an institutional setting. Waivers are approved for an initial period of three years and may be renewed for periods of five years, provided that the state has operated the waiver in a satisfactory fashion.

All states except Arizona and Vermont operate §1915(c) waivers.<sup>33</sup> Currently, more than 300 waivers operate nationwide serving more than 1 million individuals. In 2006, §1915(c) waivers accounted for 65 percent of total federal-state Medicaid HCBS expenditures.<sup>34</sup>

### ***Self-Direction of HCBS Waiver Services***

Since the inception of the §1915(c) waiver program in 1981, some states (e.g., Kansas, Oregon, Washington, Wisconsin) have incorporated limited forms of self-direction in their waivers. For example, Kansas gave participants in all its waivers the authority to hire and supervise their workers. Several other states also incorporated the “employer authority” into their waivers. However, especially as an outgrowth of the RWJF-sponsored Cash & Counseling demonstrations and Self-Determination pilots, questions arose concerning how states could incorporate a more wide-ranging approach to self-direction in their

waivers, including permitting participants to exercise choice and control over an individual budget.

As previously noted, in 2002, the CMS Independence Plus initiative spelled out for the first time the essential features for incorporating self-direction into the delivery of waiver services.<sup>35</sup> CMS stressed the use of person-centered planning, provided guidance to states in establishing individual budgets, defined requirements for supporting participants who direct their services (e.g., through the provision of financial management services and counseling services), and provided guidance on how states could permit waiver participants to exercise choice and control over the selection of workers and their individual budgets. As part of the initiative, CMS issued a stand-alone Independence Plus §1915(c) waiver application template for states that were interested in implementing self-direction of waiver services.

In 2004, CMS—in collaboration with several state agency associations that have operational responsibility for HCBS service delivery—undertook a major revision of the standard §1915(c) waiver application.<sup>36</sup> The revised application, released in 2005 (and the most recent update released in 2008), requires states to describe in detail the critical operational features of their waivers and places a stronger emphasis on waiver service quality assurance/quality management than did the previous application.<sup>37</sup> In conjunction with the release of the new application, CMS also released comprehensive technical guidance to states concerning various dimensions of the design and operation of §1915(c) waivers.<sup>38</sup>

An important feature of the revised waiver application is the inclusion of a distinct part (Appendix E) that is devoted to “participant-direction” of waiver services. Appendix E is designed to permit a state to incorporate self-direction into the operation of any §1915(c) waiver. Appendix E built upon the self-direction elements that were contained in the predecessor Independence Plus waiver application template.

When states elect to include a self-direction option in a §1915(c) waiver, they have the latitude to shape the option along several dimensions, including:

- ***Disregard of Statedwideness.*** A state may elect to offer the self-direction option in all parts of the state or limit it to specific areas or regions, for example, to create a pilot in a specific geographic area to evaluate the program design before expanding it statewide.
- ***Disregard of Comparability.*** A state may decide to make its self-direction option available to all waiver participants or limit its availability to specified groups of participants (for example, persons who live with their families or in their own homes, but not persons who are served in provider-operated residential settings).

- ***Direction by a Representative.*** A state may allow services to be directed by a representative selected by the waiver participant.
- ***Specification of Self-Directed Services.*** A state may specify which waiver services—some or all—may be directed by participants.
- ***Election of Employer and/or Budget Authority.*** A state may elect to offer participants the employer authority, the budget authority—or both—over the services they may direct. In each instance, a state may limit the extent of the authority that participants may exercise.
- ***Employer Authority.*** A state has the option to offer the employer authority in the form of a “co-employer” model (a.k.a., agency with choice) where a third party serves as the legal employer of workers that the participant selects to furnish services and/or a “common law employer” model where the participant is the legal employer of workers.
- ***Budget Authority.*** A state is afforded latitude in determining the amount of the individual budget over which the participant may exercise budget authority. In addition, when a state offers budget authority to participants, the state may specify whether participants may modify the allocation of funds among approved services in the budget without prior approval or require that changes be reflected in the person’s service plan before taking effect.
- ***Coverage of Individual-Directed Goods and Services.*** A state may elect to include the coverage of “individual-directed goods and services” in its waiver.<sup>39</sup> Under this service coverage, participants may identify and purchase goods and services from their individual budgets that are not otherwise covered under the waiver or the Medicaid State Plan; for example, appliances that substitute for or reduce the need for paid assistance. A state may elect to limit the availability of this coverage solely to participants who exercise budget authority over the HCBS they direct.<sup>40</sup>

As part of its design of a §1915(c) waiver self-direction option, a state also must address the following topics:

- ***Information About Self-Direction.*** A state must describe how it will inform waiver participants about the benefits and potential risks of self-direction as well as their responsibilities when they elect to direct their HCBS.
- ***Financial Management Services.*** A state must provide for the provision of financial management services (FMS) on behalf of participants who direct their waiver services. The §1915(c) waiver statute does not permit the payment of Medicaid dollars directly to waiver participants through the use of a “cash option.” Thus, the use of an intermediary to perform financial transactions on behalf of participants is necessary. States may offer financial

management services as a waiver service or contract for such services as a Medicaid administrative function.<sup>41</sup>

- ***Assistance in Support of Self-Direction.*** In a similar vein, a state must make information and assistance available to participants who direct their services and wish to avail themselves of such assistance. This assistance may take the form of a distinct waiver service (e.g., by covering counseling), a case management/support coordination activity, an administrative activity, or a combination of all three.
- ***Budget Safeguards.*** A state must put mechanisms in place to flag situations when a waiver participant might prematurely deplete the individual budget and intervene as appropriate.
- ***Transition.*** A state must provide for the transition of waiver participants who voluntarily decide to discontinue self-direction to agency-delivered services. In particular, a state must ensure that such participants continue to receive critical services during the transition period.
- ***Termination from Self-Directed Option.*** Finally, a state must describe the circumstances when it will terminate participants' use of the self-direction option and provide for their transition to agency-delivered services. As with voluntary transitions, a state must ensure the participants continue to receive critical services during the transition period.

Again, it is important to note that states have considerable latitude in determining how they will address these requirements.

Additional §1915(c) waiver operational dimensions relate to self-direction of waiver services. These include service planning (and associated risk assessment processes) and some elements of quality management. CMS does not require that states develop processes concerning these generic dimensions of waiver operations that are specifically keyed to self-direction. However, when a state offers a self-directed services option, CMS expects that such processes will take into account any special considerations that might attend self-direction. For example, a state is expected to ensure that service plans provide for backup services when appropriate.

States also have the option to pay relatives, including legally responsible relatives and guardians.

CMS continues to award the Independence Plus designation to §1915(c) waivers that demonstrate an especially strong commitment to self-direction of waiver services, subject to specific criteria.<sup>42</sup> The criteria include: (a) affording participants both the employer and budget authorities, (b) implementing a participant-led service planning process, (c) allowing participants to direct all or most of their waiver services, and, (d) only supporting participants in living arrangements where fewer than four persons share housing that they control.

A state must request that CMS review its waiver application to determine whether it merits the Independence Plus designation.

Some states have elected to deliver §1915(c) waiver services in tandem with the provision of State Plan services by operating a §1915(b)/§1915(c) concurrent waiver program.<sup>43</sup> Such waivers utilize a managed care model to coordinate the provision of services to Medicaid participants. Self-direction may be incorporated into this type of waiver program.

## **5. Section 1115 Research and Demonstration Waivers**

### ***Basic Scope***

Section 1115 of the Act gives the Secretary of Health and Human Services wide-ranging authority to grant states waivers of federal Social Security Act provisions for the purpose of demonstrating alternative approaches to service delivery. When a state is interested in testing such alternative approaches, this waiver authority provides states with a means to obtain relief from statutory requirements that stand in the way of implementing such approaches. A state is required to develop a research strategy to assess the extent to which its alternative approach results in improved or more efficient delivery of services to participants.

In recent years, states principally have employed this authority to restructure the delivery of Medicaid health care services rather than long-term services. The authority also has been employed to expand eligibility for Medicaid services. §1115 waivers operate under “budget neutrality” requirements (i.e., expenditures can be no higher under the waiver than they would otherwise have been).

### ***Application of Authority to Self-Direction***

Before the enactment of the DRA-2005 self-direction authorities, federal law did not easily accommodate the incorporation of self-direction into the delivery of Medicaid HCBS, especially HCBS furnished under the Medicaid State Plan. As a consequence, the §1115 authority had to be invoked when a state was interested in implementing a wide-ranging self-direction option (including budget authority) for State Plan personal care services. For example, it was necessary to use this authority in order to conduct the Cash & Counseling demonstrations, which offered participants a cash option, permitted participants to redirect personal assistance funds to purchase other goods and services, and allowed payment of legally responsible relatives for services.

Federal policy has now evolved to provide states with other vehicles (especially the §1915(j) authority) to implement self-direction options. As a consequence, states now have little or no reason to invoke the §1115 waiver authority solely to initiate a self-directed services option for Medicaid HCBS unless self-direction is a component of a broader Medicaid reform proposal. As a general matter, §1115

waivers may only be used to test service delivery approaches that are not otherwise feasible under Medicaid law. The requirements that attach to operating services under §1115 authority waivers also can be especially burdensome for states.

## **B. Self-Direction in other Federal and State HCBS Programs**

Self-direction is by no means confined to the delivery of Medicaid-funded HCBS. In this section, the application of self-direction in Older Americans Act and Veterans Administration programs is discussed. State-funded HCBS programs that incorporate self-direction are also briefly described.

### ***Older Americans Act Programs***

Enacted in 1965, the federal Older Americans Act (OAA) supports a federal, state, tribal, and local partnership known as the National Aging Services Network.<sup>44</sup> The Network provides a wide range of HCBS to help older people and others to remain in their homes and communities.<sup>45</sup> The Network currently manages over \$5 billion in public and private resources and provides direct services to over 9 million older individuals and 1.5 million family caregivers each year.

The OAA authorizes the Aging Services Network, at all levels, to promote the development of comprehensive and coordinated systems of long-term services that enable seniors to remain in their own homes and communities for as long as possible. Consistent with the flexibility provided under the Act, the Network has carried out this statutory responsibility using strategies and approaches that reflect varying national, state, and local conditions, policies, and practices.

OAA services, from their inception, have been dedicated to the principle of empowering older adults to continue to live in their homes and be engaged in their communities, a goal which can be facilitated through self-directed services. The Aging Services Network has increasingly provided for self-direction of services, including the provision of vouchers to purchase individually selected goods and services. A 2004 survey of non-Medicaid programs found that 22 percent of self-direction programs identified nationwide were funded with OAA funds and that OAA programs were more likely than other programs to use a voucher as the payment method.<sup>46</sup> OAA-funded self-direction programs showed the most substantial growth starting in 2001, at least partly attributable to the launching of the OAA National Family Caregiver Support Program.

Established in the 2000 reauthorization of the OAA, the National Family Caregiver Support Program (NFCSP) enabled each state to develop services for family caregivers. Administration on Aging (AoA) guidance regarding NFCSP encouraged states to include self-direction options in their programs, such as allowing states to make direct payments to family caregivers or provide a voucher or budget for goods and services. A 50 state survey of family caregiver programs conducted in 2003 found that only a small number of NFCS programs

did not include some type of self-direction.<sup>47</sup> Most provide a choice between agency providers or an independent provider hired by the family to furnish respite services.

### **Self-Direction in the 2006 Reauthorization of the Older Americans Act**

The OAA Amendments of 2006 authorize the Assistant Secretary for Aging to “promote the development and implementation of comprehensive, coordinated systems at federal, state, and local levels that enable older individuals to receive long-term services in home and community-based settings, in a manner responsive to the needs and preferences of older individuals and their family caregivers.”<sup>48</sup>

Title II of the OAA also authorizes the Assistant Secretary to: “facilitate, in coordination with the Administrator of the Centers for Medicare & Medicaid Services, and other heads of federal entities as appropriate, the provision of long-term services in home and community-based settings, including the provision of such care through self-directed models...” These models are described as (1) including an assessment based on the needs and preferences of an individual; (2) providing the option for individuals to direct and control their services, with the assistance of a representative if needed; and, (3) enabling individuals to develop and carry out a service plan. In addition, the reauthorization included a definition of self-directed services that clarifies roles and responsibilities with regard to assessment, service planning, and control of an individual budget.<sup>49</sup>

### **Self-Direction in Current AoA Initiatives**

In 2007, AoA launched a Nursing Home Diversion Modernization Grant program to begin implementing the new service provisions in the OAA. The program is designed to assist the Aging Services Network in modernizing its existing efforts to serve individuals who are not eligible for Medicaid so they may avoid nursing home placement for as long as possible. This opportunity is targeted at transforming the use of existing OAA Title III funds, and other non-Medicaid funds, into “flexible, consumer-directed service dollars” to ensure that services are tailored to individuals’ needs rather than being tied to a service or set of services. Twelve states have been awarded grants under this initiative and more states will receive grants in the future.

### ***Veterans Administration Programs***

One of the longest-standing federal programs that provides individuals with funds to purchase HCBS is the Veteran Administration’s Housebound and Aid and Attendance Allowance Program.<sup>50</sup> The program supplements the pensions of veterans and surviving spouses who meet eligibility requirements, including the need for regular assistance to perform activities of daily living. Individuals may use the cash benefit to purchase goods and services to help them remain in their

homes—including personal care furnished by family, friends, and other workers. They may also use the funds to help cover the costs of assisted living and nursing facility care.

### ***State-Funded HCBS***

Historically, state-funded HCBS programs provided the basis for the design of many Medicaid HCBS waiver programs. Many state-funded HCBS programs incorporated self-direction options before Medicaid waiver programs were created and were the source of many of the essential self-direction elements that have been incorporated into Medicaid and other federal HCBS programs such as OAA programs.<sup>51</sup> Several states provide for self-direction options in their state-funded HCBS programs. Examples of such programs include:

- ***Family Support Services.*** Nearly all states operate some form of family support program that provides assistance to the families of individuals with intellectual and other developmental disabilities. These state-funded programs include some that purchase services, such as respite care, on behalf of families; others that allot funds to families out of which they may purchase goods and services; and others—called “cash subsidy” programs—where the family receives a fixed amount each month to help them defray the expenses associated with having a family member with a disability.

In most instances, these state-funded family assistance programs include some self-direction options. For example, Nevada operates a program—State-Funded Self-Directed Autism Services—that provides a monthly payment to families who have a minor child with autism.<sup>52</sup> The payment is deposited in an account held by a financial intermediary, which handles payroll and taxes for workers that the family has hired to provide services to the child. Cash-subsidy programs usually provide families with latitude about how they may use the funds, including meeting the needs of the individual with a disability or helping meet other family expenses.

- ***State-Funded Personal Assistance Programs.*** Many states continue to operate state-funded personal assistance programs. Some of these programs exclusively target working-age adults with disabilities (e.g., the New Jersey Personal Assistance Service Program) while others target older persons. Frequently, programs for working-age adults with disabilities are operated by the State Vocational Rehabilitation agency in conjunction with the delivery of independent living services. For example, North Carolina offers participant-managed personal assistance services through its Independent Living Center network.<sup>53</sup> Under this program, individuals with disabilities have the authority to hire, supervise, and dismiss their personal assistants. Similarly, the Illinois Home Services program affords individuals the opportunity to select, employ, and supervise their personal assistants.<sup>54</sup>

- ***Home Care Cash Assistance.*** A few states provide additional cash assistance payments to individuals who receive income assistance payments. In a few cases, these supplemental payments are expressly aimed to enable individuals to purchase in-home assistance. An example is the Colorado Home Care Allowance provided to older persons and people with disabilities who need hands-on assistance to avoid placement in a nursing facility.<sup>55</sup> Recipients may use the funds to directly purchase in-home services, including hiring workers to provide personal assistance and other services.

Clearly, states have great flexibility in incorporating self-direction into HCBS underwritten solely with state funds, because these programs do not have to navigate some of the complications associated with Medicaid funding. However, state-funded HCBS programs generally operate with relatively limited funding.

## Resources

### ***Publications***

**Centers for Medicare & Medicaid Services (2008).** *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria.* Baltimore, MD: USDHHS.

This publication contains extensive information concerning federal policies that apply to the operation of an HCBS waiver, including incorporating self-direction into the delivery of waiver services.

*Available as “Version 3.5 Instructions Final 2.1.2008”, a part of the 1915(c) Waiver Application and Accompanying Materials under links and downloads at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>*

### ***Web-Accessible Resources***

#### **Centers for Medicare & Medicaid Services**

*Web-address: <http://www.cms.hhs.gov/home/medicaid.asp>*

This website contains federal information concerning the operation of the Medicaid program.

Information about self-directed HCBS is located at: <http://www.cms.hhs.gov/IndependencePlus/>

#### **National Association of State Medicaid Directors**

*Web-address: [http://www.nasmd.org/Home/home\\_news.asp](http://www.nasmd.org/Home/home_news.asp)*

This website contains information about the Medicaid program, including all State Medicaid Directors’ letters issued since 2004, links to State Medicaid websites, information about Medicaid statutory and regulatory issues, and current federal legislative and policy initiatives.

#### **Administration on Aging**

*Web-address: <http://www.aoa.gov/>*

Information about the Choices for Independence Initiative is located at: <http://www.hhs.gov/news/press/2006pres/20061205.html>

#### **Cash & Counseling National Program Office**

*Web-address: <http://www.cashandcounseling.org/>*

This website contains extensive, wide-ranging resources concerning self-direction, including state initiatives to incorporate self-direction into the delivery of Medicaid HCBS. An example is a memo from Medicaid Policy, LLC, Washington, DC that outlines three provisions in the Deficit Reduction Act of

2005 relating to the availability of federal Medicaid funds for the provision of participant-directed and other HCBS to low-income elderly persons and low-income individuals with disabilities. The three provisions are a Cash & Counseling option (section 6087), an HCBS option (section 6086), and a Money Follows the Person demonstration project (section 6071). The memo is located at: <http://www.cashandcounseling.org/resources/20060404-112138>.

## Citations, Additional Information, and Web Addresses

- 1 Gary Smith is the lead author of this chapter. Linda Velgouse is a co-author.
- 2 Kaiser Commission on Medicaid and the Uninsured (2006). *Medicaid and Long-Term Services*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Available at: <http://www.kff.org/medicaid/upload/Medicaid-and-Long-Term-Care-Services-PDF.pdf>. Private payers accounted for 23 percent of total expenditures while the Medicare program accounted for another 20 percent; other sources accounted for 15 percent.
- 3 Burwell, B., Sredl, K., & Eiken, S. (2008). *Medicaid Long-term Care Expenditures in FY 2007*. Cambridge, MA: Thomson Healthcare. Available at: <http://hcbs.org/moreInfo.php/source/150/doc/2374/Medicaid-Long-Term-Care-Expenditures-FY-2007>
- 4 Ibid.
- 5 Ibid.
- 6 Doty, P., Kasper, J. & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *The Milbank Quarterly*, 74(3), 377–409. Available at: <http://aspe.hhs.gov/daltcp/reports/lessons.htm>
- 7 Pamela Doty, Office of the Assistant Secretary for Planning and Evaluation. Personal communication, July 2008.
- 8 Phillips, B. et al. (2003). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey*. Washington, DC: Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. Available at: <http://aspe.hhs.gov/daltcp/reports/cclesson.htm>. Several more reports about the results of the demonstrations are located at: [http://aspe.hhs.gov/\\_/topic/topic.cfm?topic=Consumer%20Choice](http://aspe.hhs.gov/_/topic/topic.cfm?topic=Consumer%20Choice).
- 9 More information about this program is available at: <http://www.rwjf.org/reports/npreports/sdpdd.htm>.
- 10 Mary Sowers, Center for Medicare and Medicaid Services. Personal communication, July 2008.
- 11 P.L. 109–171.
- 12 Section 6071 of DRA-2005 authorized the Secretary of Health and Human Services to make \$1.75 billion in Money Follows the Person (MFP) demonstration grants over a five-year period to states to support the transition of individuals from institutional settings to the community. These grant funds may be used to pay for special transitional services to facilitate community placement. States are also eligible to receive enhanced federal financial

participation (FFP) for a one-year period for the costs of HCBS furnished to persons who move to the community.

After one-year, the state must ensure that individuals will continue to receive HCBS through the Medicaid State Plan and/or a §1915(c) waiver. In order to qualify for the enhanced FFP, individuals must transition to community living arrangements that they own or lease, their family home, or a community-based residential setting where no more than four unrelated people reside. CMS has awarded MFP grants to 31 states to support the transition of individuals from nursing facilities, ICFs/MR, and other institutional settings to the community.

Section 6071(c) of DRA-2005 specifically provides that a state may offer MFP demonstration participants the authority to direct their HCBS. The self-direction elements of the MFP authority closely parallel the self-direction provisions contained in the §1915(i) HCBS State Plan authority. These elements include providing for a person-centered service plan development process and the option for the state to give participants choice and control over an individual budget. More information concerning MFP is located at: [http://www.cms.hhs.gov/DeficitReductionAct/20\\_MFP.asp](http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp).

- 13 As provided in §1902(a)(23) of the Social Security Act, participants may select any qualified and willing provider to furnish services.
- 14 Individuals may establish additional qualifications as long as they do not contradict those that the state has established. For example, a person may require that the worker can communicate in sign language.
- 15 HCBS may be delivered under additional authorities and through various service delivery arrangements. For example, the delivery of Medicaid health and long-term services may be integrated under the §1915(a) authority. HCBS also may be included in managed care programs offered under the provisions of §1932 of the Act. The Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003 created a new type of Medicare coordinated care health plan, the Medicare Special Needs Plan (SNP). SNPs may be created to “wrap-around” the delivery of health and long-term services for Medicare/Medicaid dual eligibles. Section 6044 of DRA-2005 gives states the option to create alternative Medicaid benefit packages, including tailored benefits to meet the special health needs of participants. As a general matter, self-direction options may be employed in conjunction with these other authorities or service delivery arrangements.
- 16 Section 4480 of the *State Medicaid Manual*.
- 17 Centers for Medicare & Medicaid Services (2005). *Medicaid-At-A-Glance: 2005*. Available at: <http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf>

- 18 Ibid.
- 19 Ibid.
- 20 The text of §1915(i) is located at: [http://www.paelderlaw.com/pdf/DRA\\_Provisions.pdf](http://www.paelderlaw.com/pdf/DRA_Provisions.pdf)
- 21 The services authorized under §1915(c) that a state may offer via §1915(i) are: (a) case management; (b) homemaker; (c) home health aide; (d) personal care (including attendant services, adult companion, personal emergency response system, and assistive technology); (e) adult day health; (f) habilitation (including home-based habilitation, day habilitation, behavioral habilitation, educational services, prevocational services, and supported employment); (g) respite care; and (h) services for persons with chronic mental illnesses (including day treatment, psychosocial rehabilitation, and clinic services).
- 22 Federal law does not permit states to claim federal financial participation in the costs of services furnished to adults with mental illnesses between the ages of 22 and 64 in an “Institution for Mental Disease” (IMD). An IMD is a hospital, nursing facility, or other institution of more than 16 beds that primarily engages in the diagnosis and treatment of mental disease. The “IMD exclusion” has proven to be a barrier to states in operating HCBS waivers for these adults. Because adult IMD services are not Medicaid-reimbursable, an HCBS waiver cannot operate to furnish alternatives to such services. Three states (CO, MT, and WI) operate HCBS waivers that specifically target adults with serious mental illnesses. These waivers are structured to furnish HCBS as alternatives to nursing facility rather than IMD services. Many other states operate HCBS waivers for people with disabilities that accommodate adults with serious mental illnesses. More information about this topic is contained in: Smith (et al.) (2005). *Using Medicaid to Support Working Age Adults with Serious Mental Illnesses in the Community: A Handbook*. Washington, DC: U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation (available at: <http://aspe.hhs.gov/daltcp/reports/handbook.htm>).
- 23 Under the §1915(c) waiver authority, a state may offer waiver services to persons with incomes up to 300 percent of the federal Supplemental Security Income (SSI) payment, which is approximately 225 percent of the Federal Poverty Level. While §1915(i) permits states to cover persons with incomes up to 150 percent of the Federal Poverty Level, a state may only offer HCBS to persons who are financially eligible for Medicaid in eligibility groups that the state already has included in its Medicaid State Plan.
- 24 Available on the Internet at: [http://www.nasmd.org/issues/docs/HCBS\\_as\\_a\\_State\\_Plan\\_Option\\_Preprint\\_January\\_2007.doc](http://www.nasmd.org/issues/docs/HCBS_as_a_State_Plan_Option_Preprint_January_2007.doc)
- 25 §1915(i)(1)(G)(iii) of the Act.

- 26 The text of §1915(j) is located at: [http://www.paelderlaw.com/pdf/DRA\\_Provisions.pdf](http://www.paelderlaw.com/pdf/DRA_Provisions.pdf).
- 27 State Medicaid Director Letter #07–013, dated September 13, 2007, provides guidance on the implementation of section 6087, Optional Self-Direction Personal Assistance Services (PAS) Program (Cash and Counseling) of the Deficit Reduction Act of 2005. Section 6087 amends §1915 of the Social Security Act to add §1915(j) as a new subsection. The letter is available at: <http://www.cms.hhs.gov/SMDL/downloads/SMD091307.pdf>.
- 28 Available on the Internet at: <http://www.cms.hhs.gov/SMDL/downloads/SMD091307Encl.pdf>
- 29 The Alabama amendment incorporates self-direction into the delivery of services in two of the state’s HCBS waivers. More information about the Alabama Personal Choices program is available at: [http://www.medicaid.state.al.us/programs/long\\_term\\_care/other\\_personal\\_choices\\_program.aspx?tab=3](http://www.medicaid.state.al.us/programs/long_term_care/other_personal_choices_program.aspx?tab=3).

The Florida amendment, submitted to expand options for consumer direction via their §1115 waiver, includes information on enrollment caps, delivery system, services provided, and budget neutrality, and is available at: <http://www.cashandcounseling.org/resources/20060118-115726>.

Oregon’s request to amend and extend their §1115 demonstration program to promote self-direction for persons receiving community supports is available at: <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/downloads/ORIndependentChoicesAmend&Extend.pdf>.

Arkansas’ request to amend and extend their §1115 demonstration program to promote self-direction for persons receiving community supports is available at: <http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp?filtertype=dual&datefilterinterval=&filtertype=data&datafiltertype=2&datafiltervalue=Arkansas&keyword=&intNumPerPage=10&cmdFilterList=Show%2bItems>.

- 30 §1915(j)(4)(A) of the Act.
- 31 Federal Medicaid law generally requires that a state furnish services on a comparable basis to all eligible Medicaid participants. Under the §1915(c) waiver authority, a state may limit its provision of waiver services to persons with specified diagnoses or conditions, by age, and/or by Medicaid financial eligibility category. A state also may elect to limit waiver services to specified regions by securing a waiver of statewideness.
- 32 Federal limitations restrict the groups of individuals who may be served through a single HCBS waiver. Waivers are structured to serve individuals who meet level-of-care criteria for particular types of institutional services:

hospitals, nursing facilities, and Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). This generally means that a waiver may not serve both individuals with intellectual and other developmental disabilities and older persons. Within a specific waiver, states have considerable latitude in specifying the individuals who may participate in a waiver, including limiting the waiver by age and/or specific condition or diagnosis.

- 33 These states furnish HCBS to Medicaid participants under the Section 1115 Research and Demonstration waiver authority.
- 34 Burwell et al., *op. cit.*
- 35 Information about the Independence Plus initiative is located at: [http://www.cms.hhs.gov/IndependencePlus/01\\_Overview.asp](http://www.cms.hhs.gov/IndependencePlus/01_Overview.asp).
- 36 The National Association of State Directors of Developmental Disabilities Services, the National Association of State Units on Aging, the National Association of State Medicaid Directors, the National Association of State Head Injury Administrators, and the Alliance of Cash and Counseling States.
- 37 The Version 3.3 HCBS waiver application was released in November 2005 but has since been replaced by subsequent versions. Version 3.5 was issued in January 2008. CMS continually updates the waiver application and the current version is also being updated. With respect to self-direction, there are no substantive differences in the treatment of self-direction among the various versions of the application.
- 38 The current HCBS waiver application and the accompanying instructions/technical guidance are located at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>. While the website listed here was current at the time of publication, always check for the latest iteration at the CMS website.
- 39 In the HCBS Waiver Application *Instructions, Technical Guide, and Review Criteria* that accompanies the waiver application, CMS has defined individual-directed goods and services as: “services, equipment or supplies not otherwise provided through this waiver or through the Medicaid State Plan that address an identified need in the service plan (including improving and maintaining the participant’s opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR promote inclusion in the community; AND/OR increase the participant’s safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Individual-Directed Goods and Services are purchased from the participant-directed budget. Experimental or prohibited treatments are excluded. Individual-Directed Goods and Services must be documented in the service plan.”

- 40 A few states extend the coverage of Individual Directed Goods and Services to waiver participants who do not formally self-direct. More commonly, the coverage is confined to individuals who self-direct and exercise budget authority. For example, West Virginia includes this coverage in its Personal Options self-direction program in its Medicaid HCBS waiver for older persons and individuals with disabilities. Waiver participants may save up to \$1,000 from their budget to purchase participant-directed goods and services. For more information, go to: <http://www.cashandcounseling.org/resources/20070611-111748>.
- 41 When financial management services (FMS) are furnished as a Medicaid administrative activity, costs are reimbursable at the standard 50 percent administrative claiming FFP rate. Under this option, a state may limit the number of entities that furnish FMS, for example, by selecting them through a Request for Proposals process. When FMS services are furnished as a waiver service, the costs are reimbursable at the state's services claiming rate, which may be higher than 50 percent. However, any willing and qualified provider must be permitted to furnish FMS. When FMS are covered as a waiver service, a state also may designate the FMS provider as an "organized health care delivery system." Such a designation may simplify compliance with Medicaid provider agreement requirements. There is an extensive discussion of the provision of FMS as an administrative activity or as a covered waiver service in the CMS HCBS Waiver Application *Instructions, Technical Guide, and Review Criteria*, including managing provider agreements.
- 42 These criteria are located in the HCBS Waiver Application *Instructions, Technical Guide, and Review Criteria*.
- 43 The §1915(b) waiver authority permits a state to obtain a freedom of choice waiver in order to limit the providers of Medicaid State Plan services. Several states (e.g., Michigan and Wisconsin) and sometimes jurisdictions within a state operate concurrent §1915(b)/§1915(c) waivers. For example, the North Carolina Piedmont Cardinal Health Plan operates as a concurrent §1915(b)/§1915(c) waiver for the provision of mental health and developmental disabilities services in a five-county area. More information about self-direction under the §1915(b) waiver authority is located at: [http://www.cms.hhs.gov/IndependencePlus/04\\_1915%20\(b\)%20Freedom%20of%20Choice%20Waivers%20and%20Self-Direction.asp](http://www.cms.hhs.gov/IndependencePlus/04_1915%20(b)%20Freedom%20of%20Choice%20Waivers%20and%20Self-Direction.asp).
- 44 The Older Americans Act is located in Chapter 35 of Title 42 of the U.S. Code.
- 45 The Network comprises the federal Administration on Aging (AoA), 56 State Agencies on Aging, 655 Area Agencies on Aging, 237 tribal organizations, approximately 29,000 community-based provider organizations, over 500,000 volunteers, and a wide variety of national and local non-profit organizations.

Over 30 State Agencies on Aging administer Medicaid HCBS waiver and State Health Insurance Assistance Programs. In over 25 states, State Agencies on Aging also serve younger populations with disabilities.

- 46 Program characteristics vary widely. The most prevalent self-directed services offered are personal assistance and homemaker services. Most typically, consumers have the choice of working with an agency or hiring their own worker. For more information see: National Association of State Units on Aging and The National Council on the Aging (2004). *States' Experiences Implementing Consumer-Directed Home and Community Services*. Washington, DC, which is available at: [http://www.nasua.org/pdf/20026\\_text.pdf](http://www.nasua.org/pdf/20026_text.pdf).
- 47 Family Caregivers Alliance and National Conference of State Legislators (2004), *The State of the States in Family Caregiver Support: A 50 State Study*. Available at: [http://www.caregiver.org/caregiver/jsp/content/pdfs/50\\_state\\_report\\_complete.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/50_state_report_complete.pdf)
- 48 Contained in P.L. 109–365. A summary of this legislation is located at: <http://www.ncoa.org/attachments/CRSOAAReport.pdf>.
- 49 The definition of Self-Directed Care contained in Section 102 (46) of the 2006 Reauthorization of the OAA is as follows:
- “The term ‘self-directed care’ means an approach to providing services (including programs, benefits, supports, and technology) under this Act intended to assist an individual with activities of daily living, in which:
- (A) such services (including the amount, duration, scope, provider, and location of such services) are planned, budgeted, and purchased under the direction and control of such individual;
  - (B) such individual is provided with such information and assistance as are necessary and appropriate to enable such individual to make informed decisions about the individual’s care options;
  - (C) the needs, capabilities, and preferences of such individual with respect to such services, and such individual’s ability to direct and control the individual’s receipt of such services, are assessed by the area agency on aging (or other agency designated by the area agency on aging) involved;
  - (D) based on the assessment made under subparagraph (C), the area agency on aging (or other agency designated by the area agency on aging) develops together with such individual and the individual’s family caregiver (as defined in paragraph (18)(B)), or legal representative:
    - (i) a plan of services for such individual that specifies which services

such individual will be responsible for directing;

(ii) a determination of the role of family members (and others whose participation is sought by such individual) in providing services under such plan; and

(iii) a budget for such services; and

(E) The area agency on aging or State agency provides for oversight of such individual's self-directed receipt of services, including steps to ensure the quality of services provided and the appropriate use of funds under this Act.”

- 50 More information is available at: <http://www.vba.va.gov/bln/21/pension/vetpen.htm#7>. Also see: <http://www.veteransaidbenefit.org/>. These allowances are paid in the form of an increase to an eligible veteran's or eligible surviving spouse's pension payment. The amount can be as high as \$1,520 per month for an unmarried veteran.
- 51 For example, the California In-Home Supportive Services (IHSS) program is one of the nation's longest standing personal assistance programs. Since its inception, the program has empowered individuals to directly manage their support workers. Initially funded only with state dollars, the IHSS program now is principally underwritten with Medicaid personal assistance dollars. In 2004, CMS approved a §1115 Independence Plus waiver that permitted the state to cover IHSS self-direction options that were not allowed under the Medicaid State Plan, including cash allotments to directly pay personal assistants and payments for personal assistance provided by spouses and the parents of minor children. More information is available at: <http://www.dss.cahwnet.gov/cdssweb/PG139.htm>. The State is currently seeking to convert the waiver program to a §1915(j) program.
- 52 For more information, go to [http://mhds.nv.gov/index2.php?option=com\\_docman&task=doc\\_view&gid=816&Itemid=230](http://mhds.nv.gov/index2.php?option=com_docman&task=doc_view&gid=816&Itemid=230).
- 53 This program is operated by the North Carolina Department of Health and Human Services, Division of Vocational Rehabilitation.
- 54 More information is available at: <http://www.dhs.state.il.us/page.aspx?item=29738>.
- 55 This program is operated by the Colorado Department of Human Services.