

Chapter 1: Self-Direction: An Overview

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Chapter 1

Self-Direction: An Overview¹

This chapter provides an overview of the key features of self-direction as a service delivery model in the provision of long-term services and supports to public program participants living “at home.”² It describes the two major features of self-direction—employer authority and budget authority—and the key program design choices within these two features that account for state program variations.

Self-direction is also referred to as “consumer-direction” and “participant-direction” when referring to specific programs. This Handbook uses the terms self-direction and participant-direction unless referring to programs that use other terms.

This chapter references several Medicaid requirements, which are described in greater detail in Chapter 2.

A. What is Self-Direction?

Self-direction is a service model that empowers public program participants and their families by expanding their degree of choice and control over the long-term services and supports they need to live at home.³ Many self-directing program participants (hereafter participants) share authority with or delegate authority to family members or others close to them. Designation of a representative enables minor children and adults with cognitive impairments to participate in self-direction programs.⁴

Self-direction represents a major paradigm shift in the delivery of publicly funded home and community-based services (HCBS). In the traditional service delivery model, decision making and managerial authority is vested in professionals who may be either state employees/contractors or service providers. Self-direction transfers much (though not all) of this authority to participants and their families (when chosen or required to represent them).

Self-direction has two basic features, each with a number of variations. The more limited form of self-direction—which the Centers for Medicare & Medicaid Services (CMS) refer to as employer authority—enables individuals to hire, dismiss, and supervise individual workers (e.g., personal care attendants and homemakers). The comprehensive model—which CMS refers to as budget authority—provides participants with a flexible budget to purchase a range of goods and services to meet their needs.

For purposes of reviewing states’ programs, CMS defines these authorities as distinct, that is, states may select either employer authority (hiring staff) or budget

authority (managing a budget and purchasing goods and services). However, while some states offer only employer authority, to date, all states that offer the budget authority also offer employer authority. Thus, throughout this Handbook, the term budget authority will refer to both hiring workers (employer authority) and making purchases through an individual budget (budget authority), unless a distinction is being made between the two types of authorities. For example, when participants use their budgets to hire individuals to provide services they are exercising both budget and employer authority. Both authorities allow variations, which are described in detail in the section below on key program design decisions.

Choice is the hallmark of self-direction and this includes the choice not to direct and to direct to the extent desired. Program designs should permit individuals to elect the traditional service model if self-direction does not work for them or to direct some of their services but receive others from agency providers.

Current Availability of Self-Directed Services

As of 2001, 139 self-direction programs were operating in every state except Tennessee and the District of Columbia. They include programs funded by Medicaid, Older Americans Act Title III, the Social Services Block Grant, and state revenues.⁵

Forty percent of these programs were fewer than five years old.⁶ A survey in 2007 found at least one Medicaid-funded self-direction program in all but one state. Forty states have a total of 62 self-direction programs serving elderly persons.⁷ No reliable data exist on the number of Medicaid beneficiaries nationally and by state who receive HCBS (including personal assistance services) under the Medicaid State Plan or waiver programs, and no reliable data are available on the number who direct their services.

However, the USDHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) estimated that, in 2004, approximately 1.2 million Medicaid beneficiaries were receiving HCBS at home, and roughly one third (400,000) directed their services (300,000 in California, 100,000 in the rest of the country).⁸

Most of the states with a long history of providing “employer authority” have not yet chosen to adopt the more comprehensive budget authority or have done so very recently. Most of the states that have adopted the budget authority model had previously offered no or very limited employer authority.⁹

B. Key Program Design Decisions

Within each of the two basic self-direction features—employer authority and budget authority—policymakers and program administrators have to make several important design decisions. Because states make different choices on multiple program dimensions, the result may, at first, appear to be a confusing multitude of self-direction program variations, but many variations are relatively minor.

Medicaid requirements may affect design choices insofar as some choices may be permissible only under specific authorities. For example, the monetary value of a benefit may be deposited directly to participants' bank accounts only under the 1915(j) Medicaid State Plan authority. CMS requirements are discussed in greater detail in Chapter 2.

A frequently asked question is how Cash & Counseling programs differ from the CMS Independence Plus designation for waiver programs. CMS coined the term "Independence Plus" in 2002 as part of an initiative to promote person-centered planning and self-direction options. States could apply for an Independence Plus waiver under either a Section (§) 1115 demonstration waiver or a §1915(c) home and community-based services (HCBS) waiver (hereafter, §1115 and §1915(c) waivers). Independence Plus waivers authorized stand-alone waiver programs in which only self-directed services were offered.

The authorization of the 1915(j) Medicaid State Plan option in the Deficit Reduction Act of 2005 (DRA-2005) eliminated the need for states to obtain a §1115 waiver to offer self-directed services under the State Plan. Indeed, CMS will no longer approve such waivers solely for self-direction programs and CMS informed states that already had them that they cannot be renewed. Instead, states must pursue other alternatives, which may include a §1915(c) waiver program or a §1915(j) Medicaid State Plan amendment.

Similarly, CMS revisions to the §1915(c) waiver application process, which occurred in 2005–2006, eliminated the need for states to apply for §1915(c) Independence Plus waivers. Self-direction programs—with both employer and budget authority features—have now been fully integrated into the §1915(c) waiver application. By completing Appendix E of the application, states can offer waiver participants a choice of traditional and self-directed services within any HCBS waiver program. Waiver participants are increasingly being offered the opportunity to elect to have an individual budget and to direct all of their waiver services or only a portion of them.

States may still request the Independence Plus designation at their option, the requirements for which are described in the §1915(c) waiver application instructions at <https://www.hcbswaivers.net/> (on the left hand side choose 1915(c) Application Download).

Files May also be found by pasting this link into your web browser:

https://www.hcbswaivers.net/CMS/help/version_35_1915c_Waiver_Application_and_Accompanying_Materials.zip

However, few states perceive a need to request the Independence Plus designation because it no longer denotes a unique waiver program. This is a positive sign because it indicates that self-direction is now an integral feature of HCBS waiver programs in many states.

The various terms used to describe self-direction programs can be confusing, particularly when states use neither Independence Plus (IP) or Cash & Counseling (C&C) in programs that meet either IP or C&C criteria. See the Box below for a clarification of terms and program names.

Self-Direction Program Names

Independence Plus, as described above, is the name of a CMS self-direction initiative. However, states with Independence Plus waivers have their own names, for example, Montana’s Independence Plus waiver is called the Big Sky Bonanza program.

Cash and Counseling (C&C) is the project name for the demonstration and replication projects supported by 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), the Retirement Research Foundation (RRF), and the Administration on Aging (AoA).

Although the term is used to describe a specific self-direction model that offers participants maximum flexibility and an individual budget, each C&C state has developed its own program name. Indeed, whereas Cash & Counseling was the name given to the grants sponsored by the RWJF and ASPE, none of the states that received these grants has used “Cash & Counseling” as their program name. For example, Arkansas’ program is called “Independent Choices,” New Jersey’s is called “Personal Preference,” and New Mexico’s is called “Mi Via (My Way).”

States that received C&C grants from the RWJF—and the RRF in the case of Illinois—agreed to make program design choices in accordance with the C&C Vision Statement. However, any program in accord with the C&C Vision Statement can be considered a C&C program, whether or not the state received a C&C grant or wishes to use this name. (See the Vision Statement with its description of key elements of the C&C model at the end of this chapter.)

Cash & Counseling and Independence Plus programs share some similarities; however, many “budget authority” programs do not have all the components that are needed to be considered either a C&C program or an Independence Plus program.

Cash. In most programs to date, the term “cash” is a misnomer, because virtually all self-directing participants with individual budgets do not receive cash or even a check to deposit in a personal checking account. Rather, they have an individual budget, with the funds in that budget generally held by a financial management service (FMS) provider, to be used to pay for goods and services to meet their assessed needs.

The original C&C Demonstration and Evaluation (CCDE) allowed participants to receive a check if they met certain requirements. However, most did not want this option and preferred an individual budget. Many participants in the CCDE, however, received a small portion of their benefit in cash and a few current programs do authorize some portion of participants' budgets to be paid in cash. Sometimes this involves only small cash advances (e.g., for taxi fares) or reimbursements issued by an FMS provider for goods and services—other than attendant care—specifically included in participants' approved spending plans. In these programs, states have oversight over how participants spend the cash—they must say how they are planning to spend it in advance and often have to submit receipts to the FMS provider to document the expenditure.

Only one program—in Oregon—authorizes the entire benefit to be paid in cash without the involvement of an FMS provider. Participants pay their workers and file taxes; some hire private accountants to help with this task. The State retrospectively reviews a random sample of participants to ensure that funds are being spent appropriately.

Under the new §1915(j) self-directed personal assistance services (PAS) Medicaid State Plan option, states may elect to offer a cash option. It is not yet known how frequently the cash option will be offered, and, if offered, how many participants will take advantage of it. Of the four approved state plan amendments under section §1915(j), Alabama, Oregon, and Arkansas have elected to offer a cash option.

Employer Authority and Budget Authority

The core feature of self-direction is the choice and control that participants have in regard to the paid personnel who provide personal assistance services. This is because almost all participants receiving HCBS receive personal assistance services and, for many, this is either the only or the primary service they use.¹⁰

If a state maintains a list of qualified “individual providers” and requires participants to hire individuals only from that list, this practice is not compatible, generally speaking, with self-direction (unless virtually any participant-hired worker can be immediately approved).¹¹ As will be discussed further below, participants do not have to be the legal “employer of record” in order to direct their workers, but they must control the terms of their employment in order to be considered “self-directing.”

At a minimum, self-direction programs must allow participants or their representatives the employer authority to hire, manage, and dismiss their workers. This includes recruiting job candidates; interviewing applicants and checking their references (if applicants are not already well known to the participant); deciding whom to hire; setting or negotiating workers' schedules

and training needs; assigning tasks to workers; supervising and evaluating the quality of workers' job performance; and deciding to dismiss (at will) workers whose performance is unsatisfactory.

In self-direction programs, participants must have a role in paying workers by, at a minimum, approving timesheets. In some programs, participants' role in paying their workers goes further; for example, they may have to co-sign the worker's paycheck before it can be cashed.¹²

In almost all programs that offer only employer authority, participants have little or no authority to determine workers' hourly wages. In contrast, participants in budget authority programs typically negotiate hourly wage rates and additional fringe benefits with their workers. The only requirement is that they abide by applicable federal/state laws regarding minimum wage, overtime pay, workers compensation, disability insurance, and unemployment insurance. See Chapter 7 for a detailed discussion of these laws.

In some states, participants must also abide by collective bargaining agreements with unions representing participant-directed workers. These agreements may establish a minimum wage rate for personal care aides employed by public program participants, which is higher than the statutory federal or state minimum wage rates. This is compatible with self-direction as long as union-negotiated wage rates are reflected in participants' budgets (i.e., the budgets are increased to take account of the higher wages). However, the integrity of the model is compromised if the wage "floor" is also the wage "ceiling" and precludes participants from choosing to offer higher wages and benefits if they wish and can afford to do so within the limits of their budget authority.¹³

Under the budget authority model, participants have additional flexibility to use their allowances not only to hire individual workers but also to purchase other goods and services to meet their disability-related needs. These other goods and services may substitute for human assistance or otherwise enhance their independence; they typically include assistive technologies and home modifications, transportation services, laundry services, meal services, personal care supplies (e.g. incontinence pads), and uncovered prescription and non-prescription drugs.

Participant-directed goods and services typically include items that would not be covered in "traditional" programs and may also be purchased from non-traditional sources. It is up to each program, however, to set the parameters of allowable goods and services. Some states are more flexible than others in what they will allow. In the Cash & Counseling Vision Statement, flexibility to use funds to make purchases other than aide services is a required program element, without which a state could not join or remain a part of the national C&C grant initiative.

Why Offer Budget Authority?

State policymakers and program administrators often ask this question. It is a legitimate question, especially because most participants with budget authority spend 80 to 90 percent of their funds to employ workers. Maximizing individuals' choice and control has intrinsic value but there are also practical reasons for offering the budget authority (in combination with employer authority.)

First, as mentioned above, having budget authority allows participants to negotiate pay and benefits with their workers and, specifically, to offer higher wages to attract better qualified, more productive workers. Participants with high needs who require personal assistance with routine health or nursing tasks may especially benefit from this extra flexibility. High-need participants may also benefit most from having monetary advances paid directly to them because this policy may better enable them to keep reliable, long-term workers by personally guaranteeing that they will be paid the full amount due on time.¹⁴

Second, as already discussed, goods and services such as assistive technologies and home modifications can enhance independence and reduce reliance on human assistance (of which there is seldom enough available, especially for high-need individuals). Assistive technologies can also address health and safety needs and can play an important role in risk management.

Finally, state program administrators and service providers often ask whether having budget authority will be important to participants enrolled in an HCBS waiver program that already covers a wide range of goods and services (including some assistive devices and home modifications). In this case, budget authority for goods and services may not be as attractive an option as for participants in waiver programs without these services.

Nevertheless, research indicates that the types of goods and services purchased with individual budgets often are not otherwise available even in generous HCBS waiver programs because they reflect individualized needs and preferences; for example, the purchase of a microwave oven to reduce reliance on workers to prepare meals.¹⁵

Moreover, many HCBS waiver programs deliberately limit the range of covered services to control costs. "Capital" expenditures such as equipment and home modifications may be covered under traditional waivers, but often, only after onerous and time-consuming prior authorization procedures.

Benefit Determination

States determine the amount of the benefit allocation, which enables them to predict and to control individual and overall program costs. States require participants in self-direction programs to undergo an individualized needs assessment carried out by a professional assessor, who may be a case manager

working for the state or county or a service provider (self- or agency-employed). This is a federal requirement as well.

Individuals—and often family—actively participate in the assessment by expressing their felt needs. They can challenge an assessment they consider inaccurate. A major misconception about participant-directed budgets is that once the budget is determined it is fixed and cannot be changed.¹⁶ In fact, budgets are increased or decreased when needs change, either at regularly scheduled reassessments or when the participant or family request a reassessment.

The amount of resources available to participants to manage their self-directed services is based on the service/supports plan, which, in turn, is based on an individualized assessment of needs, preferences, wants, and abilities. It is a CMS requirement—based on statute—that the methods used to establish individualized budgets must reflect an individualized needs assessment.

In employer authority programs, the benefit is an authorized amount of aide services (hours or visits per week or per month), to be paid at the Medicaid-established rate. In budget authority programs, the benefit allocation is a dollar allowance or budget (per month or per year) and states have a number of options for how to set the budget. A required feature of C&C programs is that participants must be told the amount of their budget before making the choice between self-directed and traditional services. The various options for establishing individual budgets are discussed in Chapter 5.

The Use of Representatives

Most self-direction programs permit participants to use a representative to assist them in managing and directing their services and budgets. Representatives can ensure that participants' preferences are known and respected and can manage tasks that participants would carry out if they were able. Some programs limit options for self-direction to individuals who are fully capable of making decisions and managing their budgets on their own. C&C programs were required to permit representatives to be surrogate decision makers to enable participation by minor children, adults with cognitive impairments, and others who may need some or total assistance to choose and direct their services.

Cognitive impairments can be caused by a wide range of conditions including dementia, stroke, traumatic brain injury, developmental disabilities, and serious mental illness. Individuals with serious illnesses, such as cancer, may also need assistance to participate. All of these individuals are capable of expressing preferences, but may need assistance to manage their services and budget.¹⁷

Some programs allow participants to use representatives without formally designating them as such. Program participants in states that received C&C grants were required to formally designate representatives; that is, individuals had to be

screened to ensure that they demonstrated a strong commitment to the participant's wellbeing and were interested in and able to carry out program responsibilities and to comply with program requirements.

Although formal designation requires individuals to fill out a form acknowledging acceptance of the duties and responsibilities of a representative, there is no legal transfer of authority or responsibility with respect to personal decision making or financial matters from the participant to the representative (as would be the case if an individual were to grant power-of-attorney or a court were to appoint a guardian or conservator).¹⁸ A number of states have developed simple, user-friendly forms and processes for designating representatives.¹⁹

An issue intrinsic to the use of representatives is avoiding a conflict of interest.²⁰ C&C programs generally do not permit representatives to be paid either as workers or for serving as representatives and CMS has adopted this policy as well. There are exceptions, however, such as when parents of young children with developmental disabilities are allowed to both direct their children's budgets and be paid caregivers, as is permitted in Florida's self-direction program.

In some instances, states make exceptions for family caregivers who cannot identify at least one other family member—such as a disabled child's grandparent, aunt, or uncle—or a close family friend or godparent who is willing to take on the role of representative.

New Hampshire does not allow court-appointed guardians or agents designated in an activated power-of-attorney to be either a representative or a worker. If a power-of-attorney has not been activated, a named agent may serve as a representative but not a worker.²¹ While these prohibitions are designed to avoid a conflict of interest, in some cases they may restrict an individual from participating in a self-direction program. For example, if an individual has only one family member who is willing and able to assume multiple roles.

Program requirements for person-centered planning also apply to surrogacy insofar as representatives must represent the best interests of participants, which includes ascertaining and acting in accordance with their preferences—unless they are impractical. If representatives serve their own interests rather than those of participants, the counselor may advise a change of representative. In egregious cases, the state may require a change of representative or, if no other can be identified, require a transfer to traditional services. The CCDE found the need for such interventions to be rare.²²

Employing Family Members

Medicaid and other public programs allow participants to hire friends and relatives as paid caregivers. Paying relatives is no longer as controversial as it once was; most programs permit at least some types of relatives to be hired, although a few

programs continue to prohibit any related individuals from becoming paid workers. Medicaid formerly did not allow the hiring of “legally responsible” relatives (i.e., spouses, and parents and legal guardians of minor children), but now does in §1915(c) waiver programs and section §1915(i) and (j) State Plan option programs. However, CMS still prohibits the hiring of legally responsible relatives in self-direction programs under the Medicaid State Plan Personal Care Services option.

Allowing participants to hire family members is among the key design features in the C&C Vision Statement, and a requirement for C&C grantees, though programs were not required to permit payments to spouses and parents of minor children.²³

Participant’s Status as “Employer” or “Co-Employer”

Participants may be the common law employer of their workers and use a fiscal/ employer agent to issue paychecks and file payroll taxes. Alternatively, an organization—such as a Center for Independent Living, Area Agency on Aging, or even a traditional licensed home care agency—may serve as co-employer. Usually a co-employing organization serves as the “employer of record” only for payroll and tax-filing or other specific, narrowly defined purposes, while participants exercise the traditional employer prerogatives of hiring, training, scheduling, supervising, and dismissing—if necessary—their employees. This latter example is often termed the “agency with choice” model of fiscal support.

In some instances, other entities may assume the role of employer of record only for very narrowly defined purposes, while the participant continues to be the recognized employer for tax and most other purposes. For example, in California, non-profit “public authorities” have been established within counties to serve as the employer of record for participant-employed workers only with respect to collective bargaining with the union representing the workers. Many participants strongly desire the status of legal employer of record and they also want to be sure that their workers perceive them—and not a “co-employer” organization that issues their paychecks—as the “boss.”

In deference to these considerations, states that have received C&C grants have been required to allow participants to be the recognized employer and have a fiscal/employer agent to write checks and file payroll taxes, but they may also offer participants the agency with choice option. See Chapter 7 for a detailed discussion of these options.

Supports for Self-Direction

Many individuals need information and assistance to participate in self-direction programs and almost all programs provide support with financial management tasks. Indeed, almost all programs require the use of a fiscal/employer agent and/or a co-employer (i.e., the agency with choice model) to file applicable payroll taxes when participants employ workers. The major exception is when the total annual

amount of funding available is less than the threshold amount for which payroll taxes are due, which can be the case in small family caregiver support programs.

Most self-direction programs also offer participants the assistance of a counselor (some programs use terms such as “support broker,” “consultant,” “advisor,” or “flexible case manager”). The counselor’s primary function is to help participants develop the skills necessary to self-direct. This typically involves explaining the responsibilities of an employer (tax and labor law requirements) and assisting participants with required paperwork to enable workers to be hired, paid, and to have payroll taxes filed on their behalf.

In budget authority programs, counselors can help participants fill out the forms required to establish a spending plan for their budgets. Counselors often liaison between self-directing participants and the FMS provider. They review initial spending plans and subsequent modifications to let participants know if there are any goods or services in the plan that the state will not authorize or any intended purchases that the state must specifically review and prior authorize.

Counselors may also act as participants’ “go-between” and advocate in seeking state approval, when needed. They counsel participants to evaluate risks and make sure that they develop backup plans to ensure that urgent needs are met, for example, when workers cancel with little notice or fail to show up. They may provide suggestions and advice about service options, and recruiting and managing workers. However, they do not do any recruiting, hiring, supervising, or dismissing themselves. If a participant expresses anxiety or fear about a worker’s reaction to being dismissed, the counselor could agree to be present during the dismissal.

CMS requires the provision of information and assistance to participants exercising budget authority in HCBS waiver programs and under the §1915(j) Personal Assistance Services option. While this requirement typically is met through the provision of counseling (i.e., support brokerage) services, states may propose alternative methods for meeting it. Chapter 6 describes the counselor’s role in detail.

Concerns about whether the counselor role can appropriately serve as an alternative to traditional professional case management has emerged as one of the major sources of resistance to self-direction programs. Ways to address such resistance is discussed in Appendix I.

Ensuring Quality

Critics of self-direction programs may use quality concerns as a rationale for their opposition. Historically, states’ quality management systems have given much of the responsibility for oversight to traditional provider agencies. In self-direction programs, quality management strategies empower participants and/or their representatives to be the primary judges of the quality of the services they direct.

Participants also develop their own individualized backup support and risk management plans with support from counselors and their representatives. Counselors will help identify resources, but a major tenet of the self-direction philosophy is that no one can care more deeply about participants' health and welfare than participants themselves.

Generally speaking, participants decide, as part of the person-centered planning process, what arrangements they prefer to make for emergency assistance, should it be needed. Their plans may include any or all of the following: (1) reliance on identified backup workers who have agreed to be available on short notice either informally or for pay, or (2) an arrangement with a private home health agency or registry—including those that serve a private pay clientele and are not regular Medicaid providers—to furnish occasional assistance. However, self-direction programs can facilitate access to emergency assistance by developing worker registries and making referrals. For example, both the Los Angeles and San Francisco In-Home Supportive Services public authorities run worker registries and offer worker referrals for emergencies.

Many self-direction programs obtain feedback from participants, representatives, and family members (when appropriate) as well as data from support service providers to continuously improve the program. Because Medicaid law requires states to ensure the health and welfare of §1915(c) waiver participants, CMS requires state waiver programs to describe how they will discover, track, and remediate critical incidents at the individual and provider level in a timely fashion. They must demonstrate that their system for doing so also enables them to make systems improvements. Many states meet these requirements using an incident management system. States define critical incidents, which can include abuse, neglect, exploitation, and other harmful incidents or events.

CMS also requires state waiver programs to analyze incident data in order to develop strategies to reduce the risk and likelihood of the occurrence of future incidents. The requirements for critical incident reporting do not assume that participant-directed services are inherently riskier than services delivered under the traditional service system; they apply to both traditional and participant-directed services.

State-specific design choices intended to promote quality may involve requirements that impose certain limits on participants' discretionary employer authority. For example, some states require criminal background checks on all workers; others require them only for non-relatives or only for persons not otherwise living in the home, or only for un-related workers hired through a job bank or registry that is required to screen all workers seeking work through the registry. Some states will not permit participants to hire individuals who fail to pass the check; others require only that the participant be informed of the result.

Many states have laws requiring that criminal background checks be conducted for home care workers, but some analysts believe that relatives should be exempt from these requirements and that participants should determine whether or not a check is needed.²⁴ At the same time, participants need to understand the importance of criminal background checks when hiring individuals that neither they nor their family or friends know.

The main philosophical issue with respect to criminal background checks and other regulations imposed to ensure quality or safety (e.g., mandatory training and credentialing of workers, mandatory employer training for participants and representatives) is that cumulatively they can erode participants' choice and control. Moreover, they add costs, which can add up.

Thus, states are encouraged to think carefully about whether and when such requirements add sufficient value to justify their cost and the circumscribing of participants' responsibility and authority. See Chapter 8 for an in-depth discussion of quality management in self-direction programs.

The Cash & Counseling Vision Statement

Cash & Counseling is a self-direction model that seeks to empower individuals by providing them maximum flexibility to choose and control their services and supports. Its goal is to enhance their ability to live the lives they wish to lead in their communities. The Cash & Counseling Vision Statement evolved from a tested model which yielded very positive results. The following principles are essential to the Cash & Counseling model.

- Cash & Counseling reflects a belief that individuals, when given the opportunity to choose the services they will receive and to direct some (or all) of them, will exercise their choice in ways that maximize their quality of life.
- Cash & Counseling is one option among several service delivery models but it should be available for all participants who want it.
- Because participation in Cash & Counseling is voluntary, there should be a seamless process for moving between this option and the traditional system.
- Cash & Counseling is not used as a vehicle for reducing benefits to participants.
- Cash & Counseling includes participant-centered-planning to ensure that individuals spend their budgets to meet their stated goals.

- Cash & Counseling requires a flexible individualized budget that participants may spend on services and supports that enhance their ability to live in the community.
 - Participants may use their individualized budget to choose and directly hire workers to provide services.
 - Participants may use their individualized budget to purchase goods, supplies, or items to meet their needs.
 - Participants may allocate their funds between hiring workers and purchasing other goods and services.
- Cash & Counseling allows participants to select a representative to help them with making decisions and managing their services.
- Cash & Counseling provides a system of supports to assist participants to develop and manage their spending plan; fulfill the responsibilities of an employer, including managing payroll for directly-hired workers; and obtain and pay for other services and goods.
- Cash & Counseling obtains feedback from participants, representatives, and family members (when appropriate) as well as data from support service providers to continuously improve the program.

Ideally, participants are able to hire legally responsible relatives, purchase goods and services from vendors without Medicaid provider agreements, and receive some part of the budget in cash for expenditures such as taxi fares.

The system of supports in Cash & Counseling programs are designed by the sponsoring governmental entity, with input from participants, families, and other stakeholders. Many functions may be included and these may be performed by a variety of staff, depending on a state's particular program design. The key elements of the Cash & Counseling model are described below.

Key Elements of the Cash & Counseling Model

State Responsibilities and Accountabilities

- Provide information and outreach to ensure that individuals have access to this option.
- Establish the individual budget amount using a transparent, equitable, and consistent methodology.
- Identify and address potential conflicts of interest in the design and operation of the program (for example, representatives hiring themselves as paid workers).
- Establish expectations and standards for the supports system and build sufficient capacity to sustain the system and serve participants in a timely manner.
- Ensure that participants/representatives are involved in the design and operation of the program.
- Establish effective communication paths between support entities, participants, their representatives, and the state program.
- Establish a process for review and approval of spending plans.
- Establish a quality management system, including but not limited to:
 - Ensuring that the program reflects C&C principles and obtains feedback from participants and representatives,
 - Monitoring the supports system performance, and
 - Conducting program reviews that assess program compliance and financial accountability.

System of Supports: Counselor and Fiscal Management Services

- Provide participants/representatives with information about the concepts of self-direction and participants' rights and responsibilities.
- Assist participants in identifying their goals and needs using a participant-centered planning process.
- Assist participants in developing their spending plan.
- Provide clarification and explanation about program-allowable expenditures and documentation/record keeping.

- Assist participants/representatives in developing an individual backup plan.
- Provide training and assistance to participants/representatives on recruiting, hiring, training, managing, evaluating, and dismissing self-directed workers.
- Assist participants/representatives in monitoring expenditures under the spending plan.
- Assist participants/representatives in revising their spending plan.
- Assist participants/representatives in obtaining services included in their spending plan.
- Instruct and assist participants/representatives in problem solving, decision making, and recognizing and reporting incidents.
- Coordinate activity between support entities, participants/representatives, and the state program.
- Process hiring package for participant-hired workers.
- Process payroll for directly hired workers in accordance with federal, state, and local tax, labor, and workers compensation laws for domestic service employees and government or vendor fiscal/employer agents operating under Section 3504 of the IRS code.
- Process and make all payments for goods and services in accordance with participants' approved spending plan.
- Issue easily understood reports of budget balances to participants/representatives and counselors, periodically and upon request.
- Issue programmatic and financial reports to government program agency/Medicaid agency periodically and upon request.

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 a §1915(c) 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>

Crowley, J. (2005). *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid.* Washington, DC: The Kaiser Commission on Medicaid and the Uninsured.

This issue paper explores the difference between Independence Plus (IP) and Cash & Counseling programs, and the §1115 demonstration, IP and §1915(c) waivers.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1195>

Greene, J. (2007). *State Approaches to Consumer Direction in Medicaid.* Hamilton, NJ: Center for Healthcare Strategies, Inc.

This issue brief, developed through a national survey of Medicaid agencies, summarizes how states are incorporating a variety of consumer-directed strategies to help beneficiaries use health care dollars more efficiently.

Available at: http://www.chcs.org/usr_doc/State_Approaches_to_Consumer_Direction.pdf

NASUA (2004). *State’s Experiences Implementing Consumer-directed Home and Community-based Services: Results of the 2004 Survey of the State Administrators, Opinion Survey and Telephone Interviews.* National Association of State Units on Aging & The National Council on the Aging.

This publication presents the results of a survey conducted in 2004 to determine the extent and characteristics of consumer-directed services for older persons in 50 states and 6 US territories.

Available at: http://www.nasua.org/pdf/20027_NASUA.pdf

Phillips, B., Mahoney, K.J., & Foster, L. (2004). *Implementation Lessons on Basic Features of Cash & Counseling Programs.* Boston, MA: Cash & Counseling National Program Office.

Based primarily on interviews with demonstration staff and other stakeholders, this paper draws lessons from their learning process on the design of basic features.

Available at: <http://www.cashandcounseling.org/resources/20070404-152907>

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.

The Cash & Counseling Demonstration was implemented in three states—Arkansas, Florida, and New Jersey. Based on their experiences, this paper draws lessons on designing and implementing a Cash & Counseling program, to provide information useful to states thinking of adopting such a program.

Available at: <http://aspe.hhs.gov/daltcp/reports/cclesson.htm>

Simon-Rusinowitz, L., Mahoney, K.J., Loughlin, D.M., & Sadler, M.D. (2005). Paying family caregivers: An effective policy option in the Arkansas Cash and Counseling demonstration and evaluation. *Marriage and Family Review*, 37 (1/2), 83–105.

In this comparison of consumers who hired family vs. non-family workers, consumers who hired relatives received more service and had equal or superior satisfaction and health outcomes, compared with those who hired non-relatives. Findings are further clarified by drawing from worker focus group reports and program experience, and policy issues are specifically addressed.

Available at: <http://www.cashandcounseling.org/resources/20060222-111538>

Simon-Rusinowitz, L., Martin, D. J., Martinez Garcia, G., Sadler, M.D., Marks, L.N., Loughlin, D. M., Tilly, J., & Mahoney, K.J. (2005). *An Option to Hire Relatives as Caregivers in Two States: Developing an Education and Research Agenda for Policy Decision-Makers*. University of Maryland Center on Aging.

This presentation outlines the debate over hiring family caregivers in the Cash & Counseling program. A two-state case study is discussed and results are presented.

Available at: <http://www.cashandcounseling.org/20061212-155135>

Spillman, B.C., Black, K.J., & Ormond, B.A. (2007). *Beyond Cash and Counseling: The Second Generation of Individual Budget-based Community Long Term Care Programs for the Elderly*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

This report describes 10 individual budget programs serving older persons, identifies four areas of program design that are of particular importance to the success of the individual budget model, and discusses how the states have addressed them.

Available at: <http://www.kff.org/medicaid/upload/7579.pdf>

Spillman, B.C., Black, K.J., & Ormond, B.A. (2006). *Beyond Cash and Counseling: An Inventory of Individual Budget-based Community Long Term Care Programs for the Elderly*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

This issue brief discusses the background for the most flexible service delivery model and examines the extent to which states are adopting it for their older Medicaid long term care beneficiaries.

Available at: <http://www.kff.org/medicaid/upload/7485.pdf>

Tilly, J. (2007). *Consumer-directed Home and Community Services for Adults with Dementia*. Washington, DC: The Alzheimer's Association.

This issue brief discusses practical and policy issues related to consumer-directed services for adults with dementia and their family members. It includes recommendations for program administrators planning these programs.

Available at: http://www.alz.org/documents/advocacy_public_policy_issue_brief_71107.pdf

Tritz, K. (2005). *Long-Term Care: Consumer-directed Services Under Medicaid*. CRS Report for Congress. Washington, DC: Congressional Research Service and The Library of Congress. (Order code: RL32219).

This issue brief provides an overview of consumer-directed services under Medicaid, including Cash & Counseling programs.

Available at: <https://www.policyarchive.org/handle/10207/1930>

Web-Accessible Resources

Assistant Secretary for Planning and Evaluation (ASPE)

Web-address: <http://www.aspe.hhs.gov/>

An entire section of this website is devoted to self-direction and includes several reports concerning Cash & Counseling. http://aspe.hhs.gov/_/topic/topic.cfm?topic=Consumer%20Choice

Cash & Counseling National Program Office

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

This website contains wide-ranging resources concerning self-direction, including state initiatives to incorporate self-direction into the delivery of Medicaid HCBS.

California In-Home Supportive Services Consumer Alliance

Web-address: <http://cicaihss.org/regions.htm>

California's In-Home Supportive Services program is the largest self-direction program in the country and the Alliance is composed primarily of its self-directing program participants. The site has extensive information about the program.

Clearinghouse for Home and Community-Based Services

Web-address: <http://www.hcbs.org/>

This website is the repository for wide-ranging resources concerning state efforts to expand the delivery of HCBS for people with disabilities and older persons. Self-direction is one of many topics for which resource materials are compiled and made accessible online. For example, a number of resources can be found at <http://www.hcbs.org/browse.php/sby/Date/topic/202/Consumer%20Direction>

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty and Janet O’Keeffe co-authored this chapter. Kevin Mahoney and Lori Simon-Rusinowitz are contributing authors.
- 2 “At home” means residing in their own houses or apartments or with relatives and friends, not in residential care, including licensed facilities other than nursing homes, such as assisted living, personal care homes, and small group homes for individuals with intellectual and other developmental disabilities.
- 3 Individuals who pay privately for their long-term services and supports may choose to hire, manage, and dismiss their workers rather than use agency workers, and control how their money will be spent. Self-direction may also be an option in managed care programs—privately or publicly funded.
- 4 Cognitive impairment may be due to a wide range of conditions, including developmental disabilities, brain injury, dementia, or serious mental illness.
- 5 Doty, P. and Flanagan, S. (2002). *HIGHLIGHTS: Inventory of Consumer-directed Support Programs*. Washington, DC: U.S. Department of Health and Human Services.
- 6 NASUA (2004). *State’s experiences implementing consumer-directed home and community-based services: Results of the 2004 survey of the state administrators, opinion survey and telephone interviews*. National Association of State Units on Aging & The National Council on the Aging. Available at: http://www.nasua.org/pdf/20027_NASUA.pdf
- 7 Spillman, B.C., Black, K.J., & Ormond, B.A. (2007). *Beyond Cash and Counseling: The Second Generation of Individual Budget-based Community Long-Term Care Programs for the Elderly*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Available at <http://www.kff.org/medicaid/upload/7579.pdf>

The PAS Center at the University of California/San Francisco maintains a web-based inventory of PAS programs by state. (Users can click on the state on a map of the U.S. to obtain a description of that state’s programs.) If a program includes self-direction options, that information is included in the program description. Web-address: http://www.pascenter.org/state_based_stats/index.php

- 8 The estimate is based on a survey of self-direction programs that ASPE sponsored in 2001, information provided by the Cash & Counseling (C&C) National Program Office about numbers of participants in C&C programs, and information provided by CMS about the numbers of participants in Independence Plus waiver programs.

- 9 In 1999, in California, 96 percent of Medicaid personal care users hired their own workers and in Oregon, 90 percent of “aged/disabled” HCBS waiver users of personal care services did so. In Kansas, the employer authority was available to all HCBS waiver participants, but the exercise of this authority varied from a low of 10 percent among MR/DD waiver participants to 30 percent among elderly persons, and 70 percent among adults under age 65 with physical disabilities. See U.S. General Accounting Office. (May 1999). *Adults with Severe Disabilities: Federal and State Approaches for Personal Care and Other Services*. Washington, DC: GAO/HEHS-99-101.

In Washington State, as of the early 2000s, over half of Medicaid beneficiaries receiving home care (including the great majority of those with heavy care needs) hired their own aides. Wiener, J.M., Gage, B., Brown, D., et al. (2004) *Redirecting Public Long-Term Care Resources*. RTI International report to the Administration on Aging. Washington, DC.

- 10 Depending on the program, the term “personal assistance services” can be broader than “personal care” services, which is often defined narrowly as assistance with activities of daily living. The new §1915(j) Medicaid state plan option defines the term Personal Assistance Services (PAS) to include §1915(c) waiver services in addition to personal care services.
- 11 In some states, independent provider qualifications are very rigid. For example, in Florida, providers of respite services in the traditional MR/DD HCBS waiver need not work for agencies but they must have passed a criminal background check and a special training course. The parent of a Cash & Counseling Demonstration and Evaluation (CCDE) participant stated that prior to joining the C&C program, she had been unable to hire a public school special education teacher who was very familiar with her child to provide weekend respite. Although the teacher had relevant training far beyond the minimum required for a respite aide, the respite aide training requirement could not be waived.

Moreover, even though the special education teacher had already passed a criminal background check required by the school system, she needed to get another one to meet the Medicaid provider requirements simply because Medicaid did not recognize that she had already met this requirement. Because the special education teacher would have had to take time off from her regular job to fulfill these requirements, she was unable to meet them and the parent could not get her on the qualified individual provider list.

- 12 This requirement is uncommon; it was originally adopted by state agencies that processed payroll for participant-employed workers to make it clear to workers that participants, not the state agency, were their employers.

- 13 This does not mean that states cannot set any wage limits at all. For example, some programs do not permit participants to pay hourly wages/benefits greater than the state would pay an agency to provide the same service. However, because the agency rate includes agency overhead, this rule gives participants considerable flexibility to offer higher pay to their workers than agency aides receive.
- 14 This was the original rationale for the California In-Home Supportive Services program’s “advance pay” option. However, fewer than 1,000 of the program’s 400,000 participants receive advance payments for their workers and the fiscal agent always withholds and files the employer share of payroll taxes. Oregon is the only state that advances the entire budget to participants. This program used to be limited to 300 participants, but enrollment will likely increase now that it is operating under the §1915(j) authority.
- 15 See Schore, J., Foster, L., & Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling Program. *Health Services Research*, Volume 42 (1), Part II:446–466. This volume of the journal was a special issue titled: Putting Consumers First in Long-Term Care: Findings from the Cash and Counseling Demonstration and Evaluation, Eds. A.E. Benjamin and Mary L. Fennell. The information on the purchases participants in NJ, AR, and FL made other than aide care is discussed on page 460 and also presented in Table 3 on pp. 458–459.
- 16 Crowley, J. (2005). *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured. Available at: <http://www.hcbs.org/moreInfo.php/doc/1195>
- 17 Friss Feinberg, L. & Newman, S. (2005). *Consumer-direction and Family Caregiving: Results From a National Survey*. New Brunswick, NJ: Rutgers Center for State Health Policy and National Academy for State Health Policy. Available at: www.hcbs.org/moreInfo.php/doc/1409
- 18 There is some debate about the extent of legal formality and regulation that ought to be involved in designating representatives. See Kapp, M. (2007). Consumer-driven long-term care: Shaping the government’s role. *Marquette’s Elder Advisor*, 8, 199–214.
- 19 Link to forms: <http://www.cashandcounseling.org/esources/20070424-164848>
- 20 O’Keeffe, J., Wiener, J., Greene, A. (2005). *Real Choice Systems Change Grant Programs. Consumer Direction Initiatives of the FY 2001 and 2002 Grantees: Progress and Challenges*. Baltimore, MD: USDHHS, Centers for Medicare and Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/1601>

- 21 Jill Burke, Granite State Independent Living Center, New Hampshire. Personal communication, June 10, 2008.
- 22 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>.
- 23 Simon-Rusinowitz, L., Martinez Garcia, G., Martin, D., Sadler, M.D., Tilly, J., Marks, L.N., et al. (in press). Hiring relatives as caregivers in two states: Developing an education and policy agenda. *Journal of Social Work in Public Health*.
- 24 The main argument against mandatory criminal background checks for all participant-hired workers is that, in most programs, a substantial majority of participants hire family members and others with whom they are well acquainted. Thus, participants will likely know whether these individuals have ever been charged or convicted of criminal offenses. Even if they have been, prohibiting their hiring provides no real protective function because many friends and family members are already involved with the participant; indeed, they may already be living with them.