

Developing and Implementing Self-Direction Programs and Policies: A Handbook



Robert Wood Johnson Foundation

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Developing and Implementing Self-Direction Programs and Policies: A Handbook

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Dedication

During development of this Handbook, Gary Smith—one of its principal authors—died.

Gary was a valued colleague and a wonderful friend; a towering figure in the developmental disabilities field and the preeminent expert on Medicaid policy.

He was a resource to hundreds of people around the country and was always generous with his time—never letting a request for help go unanswered.

Although millions of people with disabilities have never heard his name, his work in public policy has made an ongoing positive difference in their lives. We dedicate this Handbook to his memory.

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Reviewers

The Handbook benefited from the comments of multiple reviewers of earlier drafts, including several staff at the Centers for Medicare & Medicaid who were asked to give particular attention to references to federal laws, regulations, and policy guidance in order to ensure factual accuracy.

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Purpose, Audience, and Organization of This Handbook

Increasingly, states are implementing home and community service delivery models that provide options for individuals and their families to direct and manage their own services and supports. These models are called self-direction and are 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.

Over the last decade the amount of information about self-direction has increased enormously. For states that want to start or expand a self-direction program, finding the exact information they need can be a time-consuming, challenging, and not always successful process.

This Handbook was developed to provide state staff, policymakers, service providers, program participants, and other stakeholders with a single comprehensive source of information about self-direction programs and policies. Its primary purpose is to explain how States can increase program participants’ choice of and control over their services and supports. The Handbook will be a useful tool for all those working to expand self-direction options in programs already providing home and community services and supports, and to develop new self-direction programs.

Chapter One—Self-Direction: An Overview—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. 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.

Chapter Two—Legal Authority—describes several 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 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.

Chapter Three—Involving Participants in Program Design, Implementation, and Evaluation—describes several approaches for involving program participants in two areas: program design, implementation, and evaluation; and peer support and mentoring. Program participants are the primary stakeholders and to ensure their buy-in, they need to be involved at every stage of program development—from its initial design to activities for continuously improving services.

Chapter Four—Enrollment—presents enrollment strategies, policies, and procedures and discusses different approaches to designing these elements, including their advantages and disadvantages. The chapter also provides information about how to identify and address issues that may slow enrollment, especially in the early stages of program implementation.

The next three chapters discuss the basic elements of a self-direction program: individual budgets, counseling, and financial management services.

Chapter Five—Individual Budgeting—discusses the essential elements of individual budgets: person-centered planning, budget methodologies, determining needs, and service planning. It also discusses methods for calculating the budget amount; the process for authorizing spending plans; and approaches for monitoring, managing, and modifying individual budgets.

Chapter Six—Counseling—discusses the key components of counseling: providing information and assistance to individuals electing to direct their services—a key supportive service in self-direction programs. It also discusses the differences between counseling and traditional case management and describes various counseling models states use, and how programs can ensure quality counseling services. States use a variety of terms to describe the counseling role, including support broker, service coordinator, flexible case manager, consultant, advisor, and community guide. This Handbook uses the terms *counseling* and *counselors*.

Chapter Seven—Fiscal/Employer Agent Services—describes the key features of five financial management services (FMS) models and focuses on the issues and challenges related to two in particular: the Government and Vendor Fiscal/Employer Agent models. These two FMS models are highlighted because they provide participants with a high degree of choice and control over their services—allowing them to be the common law employer of their workers while providing needed payroll and other fiscal supports.

Chapter Eight—Quality Management in Self-Direction Programs—provides information about quality management elements that are relevant for *all* service delivery models as well as those that are unique to self-direction programs. It also describes the key components and principles of quality management for self-direction programs.

Chapter Nine—Self-Direction and Health Care—discusses ways in which self-direction programs, especially those that provide individual budgets, can facilitate participants' access to health care and maintain and improve their health and functioning. The chapter also discusses how Nurse Practice Acts can hinder or facilitate self-direction, how states can address safety risks when participants have extensive health care needs, and how a few states have incorporated self-direction options into managed care plans.

Chapter Ten—Looking Ahead—discusses emerging issues, including unionization of participant-directed workers and how they might affect self-direction programs as well as new opportunities to offer self-directed services.

Three Appendices discuss specialized topics.

Appendix I discusses the use of strategic communications to ensure the success of a self-direction program.

Appendix II describes an information technology designed to meet certain unique requirements of self-direction programs. This technology—called the Consumer Direction Module (CDM)—is a secure web-based software application specifically designed to support self-direction programs that allow individual budgets.

Appendix III describes the origins, development, and expansion of self-direction programs.

Designed to serve as a reference guide, the Handbook is written in easily understood language, but with sufficient annotation of source material to fulfill its technical support role. The endnotes in each chapter provide not only citations of source material, but also web-links for obtaining the material, when available. The endnotes also provide additional background or technical information about issues discussed in the chapter as well as web-links to other information sources. Each chapter also includes a resource section with relevant publications and web-accessible resources. All publications include links for obtaining them online.

Obtaining the Handbook and Updates

The Handbook was designed as an online document that will be updated to reflect current policy and to provide new resources. The Handbook is available at www.participantdirection.org.

Each Handbook chapter has been designed to be downloaded easily and to fit into a three-hole punch binder. Individuals who download the Handbook will be given the option of being notified of updates. Once available, updates can be downloaded and inserted in the binder, as a substitution or an addition.

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.

Chapter 2: Legal Authority

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Chapter 2

Legal Authority¹

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.² 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.³ 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.⁴ In 2007, Medicaid HCBS spending reached \$42.3 billion.⁵

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]).⁶

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.⁷

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.⁸

On a parallel track, RWJF also launched its Self-Determination for People with Developmental Disabilities Program in 1995.⁹ 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.¹⁰

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.¹¹ 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.¹²

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.¹³

- ***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.¹⁴
- ***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.¹⁵ 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.”¹⁶ 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.¹⁷ 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.¹⁸ 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.”¹⁹

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 2007.²⁰ 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.²¹ 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.²² States are limited to offering services to participants whose income does not exceed 150 percent of the federal poverty level.²³

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.²⁴ 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.²⁵ 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 2007.²⁶ 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.²⁷ The letter is accompanied by a Medicaid State Plan amendment (SPA) pre-print that states may submit in order to invoke this authority.²⁸ 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.²⁹

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.³⁰

The authority has the following major features:

- **Disregard of Statewideness 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;³¹
- 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:³²

- 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.³³ 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.³⁴

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.³⁵ 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.³⁶ 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.³⁷ 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.³⁸

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.³⁹ 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.⁴⁰

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.⁴¹

- ***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.⁴² 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.⁴³ 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.⁴⁴ The Network provides a wide range of HCBS to help older people and others to remain in their homes and communities.⁴⁵ 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.⁴⁶ 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.⁴⁷ 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.”⁴⁸

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.⁴⁹

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.⁵⁰ 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.⁵¹ 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.⁵² 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.⁵³ 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.⁵⁴

- ***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.⁵⁵ 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

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.aoa.gov/about/legbudg/oa/Choices_for_Independence_White_Paper_3_9_2006.doc

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.
- 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.

- 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
- 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
- 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.
- 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.

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.hhs.gov/medicaidStWaivProgDemoPGI/downloads/ARReqtoAmend&Extend.pdf>.

- 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.
- 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.
- 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
- 48 Contained in P.L. 109–365. A summary of this legislation is located at: <http://www.ncoa.org/attachments/CRSOAARepor.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.
- 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.

Chapter 3: Involving Participants in Program Design, Implementation, and Evaluation

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Chapter 3

Involving Participants in Program Design, Implementation, and Evaluation¹

Research on states' efforts to change their long-term services systems—including those to initiate or expand self-direction programs—has found that their success depends to a significant extent on early and sustained stakeholder involvement and buy-in.² Program participants are the primary stakeholders and to ensure their buy-in, they need to be involved in program development, design, implementation, and evaluation.

This chapter describes several approaches for involving participants in two areas: program design, implementation, and evaluation; and peer support and mentoring. In this chapter—as throughout this Handbook—the term participant, when used generally, includes both current and potential participants and—when they are unable to provide input themselves—their formal and informal representatives.

A. Involving Participants

There are many phases during which it is important to involve and seek participants' input and feedback: the program design and pre-testing phase; program implementation; program evaluation; and continuous quality improvement. States should make it a priority from the outset to identify strategies for ensuring participant involvement in each phase and sustaining it for the long term. When a new program will serve a diverse population, states also need to ensure that participants from all target groups are represented. To ensure meaningful involvement, states need to be receptive to participants' input and use it to modify approaches and strategies.

Involving advocates should not be seen as an alternative to involving participants. An advisory group that achieves 51 percent “participant” representation by including a large number of representatives from advocacy groups will not effectively represent participants' views. Participants' experience provides a unique perspective. The opinions of advocates matter but their views may differ from those of participants.

Participants' involvement in design, implementation, and evaluation can contribute to a program's success in multiple ways. Their experience provides essential information about what does and does not work, what types of outreach and enrollment strategies will be most effective, and how best to meet the needs of all participants. For example, Rhode Island's participant advisory group provides input on marketing and other program operations and is currently helping the state to implement its marketing strategy. Members of the group have

been conducting outreach to community health and rehabilitation providers to educate them about the program—both individually and with project staff.

The remainder of this section discusses several methods for involving participants: formal advisory groups as well as focus groups, surveys, and telephone response lines.

Formal Advisory Groups

The most common method states use to involve participants (and other stakeholders) in program design and implementation is through membership in an advisory group or on a task force. States may expand the scope of work of an existing group or create a new group. For example, some states that received Systems Change grants used an existing Olmstead Task Force or Work Group to both develop the grant proposal and to oversee and work on grant activities. Others created a subcommittee of an existing group to serve as an advisory committee for the grant, and others formed a new advisory group when the grant was awarded.

Factors to consider when deciding whether to use an existing group or to create a new group include the scope of work and effectiveness of existing groups, the views of leaders from the disability advocacy community, the advocacy experience of participants and/or their respective advocacy community, and the strength of other stakeholder groups.

If a state's advocacy efforts are well developed and participants are experienced at providing input as part of a larger group, they should be able to effectively articulate their views even when other stakeholders have strong contrary views. However, states should be aware that inexperienced participants may need additional education and training to effectively participate so they are not “intimidated” or “drowned out” by more experienced and vocal stakeholders.

In some cases, participants may be more comfortable providing input as part of a stand-alone participant advisory group—at least initially. Rhode Island created a participant panel to oversee its Cash & Counseling grant; the panel meets monthly but also participates in diverse stakeholder meetings every quarter.

Several organizations provide training for individuals who are interested in developing their advocacy and leadership skills, and such training may assist participants to feel more confident about providing input when serving on Advisory Boards. For example, Partners in Policymaking, one of the best-known training programs, offers training to people with all types of disabilities. Some of their training resources are available free of charge at www.partnersinpolicymaking.com/online.html. Another organization, the Self Advocate Leadership Network, is specifically designed to train individuals with developmental disabilities to become self-advocates. For participants under age 28, the National Youth Leadership Network aims to develop a new generation of disability leaders and provides

opportunities for networking and leadership development (<http://nyln.org>). States can refer interested participants to these organizations.

Another consideration is whether to include participants from different disability groups in the same advisory group. If the program is serving several disability groups, a mixed participant advisory group is needed. However, if one disability group has a longer history of advocacy and there is a risk that others will be “drowned out,” it may be necessary to have separate groups initially. Over time, the groups can be merged.

Consumer Advisory Committees in virtually all of the states receiving Systems Change grants included a wide range of stakeholders, including providers and state staff, but by design and intent, participants, family members, and advocates constituted a majority of the members. Many Systems Change grantees reported that while including diverse stakeholders in the same group could be very challenging, it was essential because they all needed to understand differing needs and opposing views and to learn to compromise.³

To ensure that all relevant stakeholders are involved, advisory groups often have large memberships—30 or more individuals. A large group can make it very difficult to work on some program and policy issues that require focused work by individuals with specific knowledge and experience. To address this potential problem, states often establish subcommittees or smaller work groups to deal with specific tasks, such as developing outreach and educational materials. States need to ensure that participants are also included in these smaller groups.

Recruiting Participants

Recruiting participants to serve on an advisory group can seem daunting to state staff. One starting point is to identify and tap into existing networks such as Independent Living Centers, People First, and other advocacy groups. The overriding consideration when recruiting participants is their current use of services and their willingness and ability to fully participate.⁴

States with existing advisory groups can recruit from these groups but should also attempt to recruit new participants who have specific interests and/or new perspectives. Frequently, the same participants are recruited to serve on many different committees. But participants who are new to the process can often shed new light on problems, offer new ideas to solve those problems, and identify new problems.⁵

Many assume that elderly persons are too frail, impaired, or ill to serve on an advisory group or do not have the same interest as younger individuals in developing and improving programs. This view may be valid at times for individuals of all ages, not just elderly participants. However, lack of participation may also reflect significant barriers to participation. When it is difficult to recruit

participants with severe impairments and acute illnesses—as well as those in remote areas—to serve on an advisory group, states can secure their participation in other ways, such as through focus groups, as described below. See also a recent report prepared by the National Association of State Units on Aging at <http://www.cashandcounseling.org/resources/20080303-111313/>.

Another effective approach is to form a nominating committee of participants and advocates to recruit and select other participants to serve on an advisory group. The Massachusetts Real Choice grant project used this approach. (More information is available at <http://www.umassmed.edu/uploadedFiles/CPIGS.pdf>.)

Importantly, states should explore funding options to sustain advisory group activities in advance. States with grants may be able to use grant funds to support activities. If not, consulting with other state agencies with experience involving participants, such as vocational rehabilitation, can help to identify other potential funding sources.

New Mexico's waiver program—Mi Via (My Way)—has a large stakeholder advisory group called the Self-Directed Waiver Subcommittee, which includes participants and their families, service providers, advocacy organizations, and state officials.⁶

Each of the constituencies served by Mi Via is represented: elderly persons; medically fragile children; and individuals with physical disabilities, developmental disabilities, AIDS, and brain injuries. Unlike other constituencies, few elderly persons attend meetings, so their family members, providers, and sometimes advocacy organizations, such as AARP, represent their interests. Not all members attend each meeting but they are kept up to date through a listserv.

The Subcommittee has been meeting monthly since 2004 and the State uses an independent facilitator to help members reach consensus on issues. The State has also established a smaller group comprising one participant from each of Mi Via's constituencies to conduct more focused work on policies and materials, such as the Mi Via Participant Guidebook and the Mi Via participant satisfaction survey.

The Subcommittee has contributed to the design of Mi Via and to the development of program materials. For example, feedback from Subcommittee members led the state to change its budget methodology. Initially, participants' budgets were based on their previous year's service use but, because some geographic areas lack sufficient providers for certain services, some participants were unable to obtain all the services authorized and so their utilization was low. Members of the Subcommittee felt that this was unfair and the State revised its methodology to address their concerns.

Ensuring Participant Involvement in Advisory Groups

Many practical barriers can prevent participants from coming together to form an effective advisory group and sustaining the group over time, such as lack of transportation and accommodations to meet needs at meetings. Some of the solutions that states and other organizations have developed to address these barriers are presented below.

Accessibility

- Ensure that the meeting venue is entirely accessible—both inside (e.g. restrooms) and outside (reachable by public transportation and with accessible parking.)
- Determine prior to the first meeting what specific accommodations individuals need to participate effectively. If resource constraints limit the type of accommodations that can be made available, states need to choose participants to match those that are available. Accommodations that may be needed are accessible formats, such as Braille, audio tape, large print, and electronic files on disks; and meeting accommodations, such as Communication Access Real-time Translation (CART), microphones, and interpreters.
- It is not necessary to conduct all meetings in person. Telephone, video, and web-based conferencing can be used to involve participants who have difficulty traveling as well as to avoid some of the expenses of in-person meetings. However, these alternative approaches generally work better with smaller work groups or subcommittees than with larger groups.

Ensuring and Sustaining Regular Attendance and Participation

- Lack of transportation can prevent regular meeting attendance, particularly for participants with mobility impairments. Some states pay for participants' travel expenses when this is a more practical approach than directly arranging transportation for them. If resources are not available, states can work with participants to identify potential sources of transportation in their social networks or through community resources, such as paratransit services and Independent Living Centers.
- Use a skilled, independent facilitator. If resources will not permit hiring one, identify a community leader who is willing to assume this responsibility.
- Allow time for participants to coalesce as a group by learning about each other's interests and issues. This may include allowing the group to meet without staff present. Appointing a participant as a co-chair can also create a climate of collaboration and help build trust.

- Ensure that the views of the advisory group are recorded, synthesized, and used to inform program and policy development. It is also important that group members receive feedback about how their input has been used.

Focus Groups, Surveys, and Telephone Response Lines

Focus groups, surveys, and telephone response lines—as well as informal consultation—provide an opportunity for states to obtain input from a greater number of participants than those who can serve on advisory groups. These additional methods of involving participants can complement, but should not replace, the input provided by a formal advisory group.

Several states have used focus groups and surveys to obtain participants' input. For example, a major goal of Colorado's Systems Change Independence Plus grant was to establish a statewide backup and critical incident management system for all of the State's self-direction programs. In addition to analyzing the State's current system, grant staff conducted focus groups with participants and other stakeholders to obtain their views on whether a new system was needed. Responses indicated a consensus that the existing system was the most appropriate for self-direction programs and that a statewide backup system was not needed.

An advantage of focus groups is that they can be conducted on a relatively small budget if states partner with Centers for Independent Living, Area Agencies on Aging, the Arc, and other state advocacy networks to gain access to participants.⁷

As well as keeping costs down, involving participants in focus groups and surveys can elicit better responses than if professionals conduct them alone. *Ask Me!* is a Participant Quality of Life Survey administered by the Arc of Maryland for the Maryland Developmental Disabilities Administration (DDA). All community programs licensed by the state DDA participate and about 1,300 service users are surveyed each year by peer surveyors.

This approach is based on the belief that, as a result of their first hand understanding of disability and their receipt of services, people with developmental disabilities are able to elicit more meaningful responses from service users than traditional surveyors. Interviewers receive four to five hours of initial training as well as several training sessions throughout the year and are organized regionally to minimize transportation costs. The 35 interviewers work in pairs and receive assistance with setting up interviews, transportation, and answering questions. They are paid \$11 per interview. For more information, go to www.thearcmd.org/programs/ask_me.html.

Response lines are another method for obtaining participants' input, particularly during a pilot or initial program implementation when the “kinks” are being worked out. For example, Arkansas set up a participant complaint “hotline” for

its new self-direction program and program managers reported that the feedback received through the hotline was helpful in identifying and troubleshooting problems. When Arkansas' toll free self-direction information line receives many requests for information from the same geographic area, a state official goes out to meet with participants and providers in the area.

If participants have easy access to the Internet, states may be able to use listservs and other online forums to seek their views on specific issues. Oklahoma has made extensive use of information technology to involve participants in program design as part of their Systems Change grant work. In New Jersey, the Cash & Counseling grant's project director established a toll-free number and set aside a regular time each week during which participants could call in to exchange ideas and get questions answered by program staff.

All of these methods for ensuring accurate and timely feedback from participants and caregivers can also be key components of quality assurance and improvement activities. (See Chapter 8 for a discussion of quality management systems.)

B. Peer Support and Mentoring

In programs serving individuals with disabilities, peer support is generally defined as a structured relationship in which participants facing similar challenges interact to provide or exchange information and emotional support. Peer mentoring is a more formal type of peer support in which individuals with disabilities who have more knowledge and/or experience assist less-knowledgeable and less-experienced persons.

Peer support and mentoring can enhance participants' ability to direct their services. This section discusses several types of peer support and mentoring that states have used when designing and implementing self-direction programs.

Peer Support Groups

Support groups that bring together individuals with similar experiences provide a forum in which people can share the problems they are confronting and identify potential solutions to those problems. Independent Living Centers commonly offer peer support groups that bring together individuals with disabilities on a periodic basis to exchange experiences, brainstorm solutions to problems, learn about disability issues and advocacy opportunities, and provide a sense of community.

Similarly, local chapters of the Alzheimer's Association, the National Multiple Sclerosis Society, and other organizations concerned with chronic conditions host support groups for individuals with the condition or for their family caregivers. The local chapters of People First and other similarly organized self-advocacy networks serve as de-facto peer support groups and also offer an excellent opportunity to help educate individuals about self-direction.

Online support groups

Support groups are increasingly moving online (e.g., healthboards.com and caregiving.com). Online groups have several advantages over face-to-face groups. They can provide support to people who cannot leave their homes due to illness, disability, or caregiving responsibilities, and they allow individuals with rare needs to connect with people who share their needs and concerns, irrespective of where they live. Some people also prefer the anonymity of an online group as this may allow them to be more candid about their problems. Online groups can be less expensive to facilitate than face-to-face groups, although a moderator is often required to monitor conversations and ensure that the forum is not being misused.

At a minimum, states can inform participants about existing support groups in the community or online but they can also create opportunities for group support. Alternatively, the state can simply provide financial support and leave the organization to peers. For example, the Family Directed Support Network for Families of People with Disabilities in Utah consists of 35 local councils across the entire State that are run by volunteers with financial support and some technical assistance from the Governor's Council for People with Disabilities. Network members help each other identify available services and funds, decipher technical language, complete paperwork, locate employment and equipment, and support each other with advocacy efforts. More information is available at <http://www.cms.hhs.gov/PromisingPractices/Downloads/utfds.pdf>.

States can make use of existing networks to encourage peer support among participants who direct their own services, or set up a similar network solely for participants in self-direction programs.

National Participant Network

The 15 states that received Cash & Counseling grants are currently developing a National Participant Network to strengthen participant involvement in self-direction programs. The Network—comprising participants, caregivers, and advocates—shares ideas about how to improve self-direction programs, develops ways to advocate for self-direction at the state and national level, and partners with states to strengthen participant involvement in self-direction programs.

Peer Mentoring

Advisory groups and focus groups that include both participants new to the process and those with experience create opportunities for peer mentoring. However, peer mentoring opportunities and relationships can also be created intentionally and individuals can be trained to mentor their peers.

Independent Living Centers typically offer peer mentoring services. They recruit individuals who have learned to live independently and are willing to assist others to reach the same goal. States can both link participants to existing mentoring programs and establish peer mentoring opportunities for participants. For example, one of the more successful enrollment approaches in Arkansas' Independent Choices program came about when a woman in her late eighties who was homebound offered to speak on the phone with other elderly persons who were trying to decide whether they could really manage their own services. Her advice and mentoring gave many of her peers the confidence to enroll in the program.

As part of Virginia's Systems Change grant initiative, the Partnership for People with Disabilities at Virginia Commonwealth University established the Consumer-Directed Services Resource Network, a volunteer technical assistance network of participants, families, facilitators, and providers to assist people interested in trying out a self-direction option. This unique approach enables individuals who might have concerns about their ability to use the option to do so with additional support.⁸

In some programs, peers may be paid to provide specific services. However, to be reimbursed by Medicaid, the services must be listed as a waiver service and peers must meet specified provider qualifications. They may also be reimbursed through state general revenues or grant funds. In the mental health system, some peer support services, when provided by trained and certified peers, have recently been approved by CMS as a directly billable Medicaid service, and some Developmental Disabilities waiver programs offer peer services. Information and assistance services, which CMS requires to be provided in self-direction programs, may also be provided by peers who meet a state's qualifications.

Resources

Publications

Bergman, A., Ludlum, C., O'Connor, D., Starr, J., & Ficker Terrill, C. (2002). *Stakeholder Involvement in Home and Community-Based Services: Roles in State Planning, Program Development, and Quality Improvement.* Home and Community-Based Services Resource Network.

This brief paper offers tips to states for involving stakeholders in their decision-making process for planning, program development, and quality improvement. It also offers summaries of successful collaboration efforts in three states.

Available at: www.hcbs.org/moreInfo.php/doc/150

CMS State Medicaid Director letter regarding peer support services under the Medicaid program (2007).

This letter provides guidance to states interested in furnishing peer support services in mental health that can be billed under the Medicaid program. It covers supervision, care coordination, and training and credentialing.

Available at: <http://www.cms.hhs.gov/SMDL/downloads/SMD081707.pdf>

Holt, J., Jones, D., Petty, R., Crisp, S., Roth, H., & Galantowicz, S. (2007). *Facilitating Consumer Partnerships in State Policy and Program Design.* Houston, TX: Independent Living Research Utilization.

This 35-page publication provides a comprehensive discussion of methods states can use to develop and sustain consumer partnerships. It includes several checklists and practical information for ensuring consumers' involvement in state program and policy development.

Available at: <http://www.hcbs.org/moreInfo.php/doc/2071>

Lomerson, N., McGaffigan, E., O'Connor, D., & Wamback, K. (2007). *When CPIGs Fly: Meaningful Consumer Involvement in Systems Change.* Shrewsbury, MA: Center for Health Policy and Research, University of Massachusetts Medical School.

This brief publication describes Massachusetts' experience creating a participant advisory group as part of its Real Choice Systems Grant beginning in 2003. It includes 10 important lessons learned about meaningful participant involvement.

Available at: <http://www.umassmed.edu/uploadedFiles/CPIGS.pdf>

***Making Accessibility Real: A Guide for Planning Meetings, Conferences and Events* (2003).** Home and Community-Based Services Resource Network.

This guide is intended to help readers think broadly about the concept of accessibility in the context of planning meetings and conferences. It provides

strategies for identifying and meeting the accessibility needs of participants, including those with specific functional challenges, and provides references to accessibility standards.

Available at: www.hcbs.org/moreInfo.php/doc/52

Moseley, C. (2006). *The Guide: National Association of State Directors of Developmental Disabilities Handbook on Inclusive Meetings*. Alexandria, VA: National Association of State Directors of Developmental Disabilities.

This guide provides a framework for involving participants in state-sponsored activities where issues affecting their interests are being discussed.

Available at: <http://www.nasdds.org/pdf/TheGuide.pdf>

National Association of State Units on Aging (2008). *More Can Be Done: Involvement of Older Consumers in the Design, Implementation, and Oversight of Home and Community-based Services*. Prepared for the National Program Office for the Cash & Counseling Demonstration at Boston College.

This paper helps State Units on Aging and others in the aging network identify concrete steps they can take to support the role of older individuals as public policy advocates. It addresses the extent to which older HCBS participants are involved in public policy advocacy, the barriers to their successful involvement, and the strategies that are being used to attract, retain, and support older persons as participants in HCBS policy-setting activities. It is based on a survey of State Units on Aging with Cash & Counseling programs.

Available at: <http://www.cashandcounseling.org/resources/20080303-111313>

Sander, M., and Cheek, M. (2004). *Facilitating A Productive Advisory Committee*. Aging and Disability Resource Center Technical Assistance Exchange.

This publication provides practical tips on how to design and implement a successful advisory group.

Available at: <http://www.adrc-tae.org/tiki-page.php?pageName=Advisory+Committee+Brief>

Weaver, P. (2002). *Involving Consumers on Boards*. Washington, DC: Center For Medicare Education.

This publication includes practical tips for successfully involving participants on governing boards.

Available at: http://www.adrc-tae.org/tiki-download_file.php?fileId=26756

Web-Accessible Resources

Advocating Change Together

Web-address: <http://www.selfadvocacy.com/>

Advocating Change Together is a grassroots disability organization based in Minnesota run by and for people with developmental and other disabilities. The website has a useful online catalog of free educational materials to promote self-advocacy and disability rights.

Georgia Certified Peer Specialists Project

Web-address: <http://www.gacps.org/Home.html>

The project's website has extensive information about the role of peer specialists, relevant Medicaid regulation, a discussion of relevant ethics, and links to other resources.

Partners in Policymaking

Web-address: <http://www.partnersinpolicymaking.com/online.html>

This website has free online training courses for individuals and families who want to become active partners in the policymaking process.

Self-Advocate Leadership Network

Web-address: <http://www.hsri.org/leaders/>

This website has training tools for self-advocates and organizations interested in supporting program participants to become advocates. The website includes a training tool specifically related to self-direction, entitled Self Determination and You.

Citations, Additional Information, and Web Addresses

- 1 Vidhya Alakeson is the lead author of this chapter. Lee Bezanson and Janet O’Keeffe are co-authors.
- 2 O’Keeffe, J., O’Keeffe, C., Coleman, B., Greene, A.M., Brown, D., Anderson, W., & Osber, D. (2007). *Real Choice Systems Change Grant Program - FY 2001 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/1891>; and O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). *Real Choice Systems Change Grant Program - FY 2002 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2172>
- 3 Ibid.
- 4 Holt, J., Jones, D. L., Petty, R. E., Crisp, S., Roth, H., and Galantowicz, S. (2007) *Facilitating Consumer Partnerships in State Policy and Program Design*. Houston, TX: ILRU Community Living Partnership. Available at: <http://www.hcbs.org/moreInfo.php/doc/2071>
- 5 Ibid.
- 6 The Subcommittee is part of a Policy Advisory Committee for the New Mexico Aging and Long-Term Services Department.
- 7 The Arc is the world’s largest community-based organization of and for people with intellectual and other developmental disabilities.
- 8 O’Keeffe, J., et.al. (2007). op. cit.

Chapter 4: Enrollment

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Chapter 4

Enrollment¹

Enrollment strategies, policies, and procedures are important elements of a new self-direction program. This chapter discusses different approaches to designing these elements, including their advantages and disadvantages. The chapter also provides information about how to identify and address issues that may slow enrollment, especially in the early stages of program implementation.

A. Choosing an Overall Enrollment Strategy

Prior to offering self-directed services in a new program or as a new option in an existing program, states need to develop an enrollment strategy to achieve a sufficient number of participants to sustain the infrastructure that supports self-direction.

States may want to start slowly—even limit initial enrollment—in order to have time to gather feedback, make needed changes to program features and procedures, and then focus on increasing enrollment. While doing so provides time to fine-tune the program, this approach can present problems because counselors and financial management services (FMS) entities need to serve a minimum number of participants relatively quickly in order to cover their fixed costs.

Many states have chosen to implement a new program in a few counties to gain experience and fine-tune it before expanding statewide, an approach that is compatible with strong enrollment in the selected counties.² Others have used grants to pilot a new program on a very small scale, in one or two areas with a small number of participants, in order to “work out the kinks.”

Iowa used a planned phase-in process for its new program, beginning in one region of the State and adding new regions every few weeks. This approach enabled program staff to ensure that enrollment procedures were working well before having to operate statewide. Alabama, however, experienced the less positive side of gradual phase-in: because the program was implemented in a less populated area of the State, enrollment was much slower than anticipated during the first six months.

New Mexico implemented its new self-direction waiver, *Mi Via*, statewide and began enrolling individuals from several waiver programs from the outset. In retrospect, program staff felt that it would have been better to bring in one or two waiver populations to *Mi Via* at a time and to have piloted the waiver initially in one or a few areas rather than starting statewide.³

States also need to determine whether they will initially limit enrollment to individuals already receiving home and community-based services (HCBS). If so, they can focus outreach on a defined target population. Doing so can decrease the number of individuals applying who are subsequently found ineligible (e.g., those who do not meet Medicaid’s eligibility criteria). However, the efficiency of outreach when limited to current HCBS program participants has to be weighed against the need for a sufficient number of participants to justify the fixed costs of the support services that must be on hand right from the start.

If states do not limit enrollment to current HCBS participants, then individuals who have been under-served or un-served by the traditional service system may sign up for the new self-direction program. In this case, program staff can counter criticism that the program has induced demand and increased costs by citing research findings that the potential of a self-direction program to deter nursing home use is greater in Medicaid programs where a significant minority of participants entitled to home care have been under-served in the traditional service system.⁴

As no strategy is ideal in all cases—each has pros and cons—states need to carefully consider which strategy will work best given their particular circumstances. Regardless of the strategy chosen, program staff should establish methods for obtaining feedback from early enrollees—as well as those who chose not to enroll—to gain insights into the education approaches and enrollment processes that may need improvement. See the discussion on tracking enrollment later in this chapter.

B. Outreach

Outreach—providing information about the new program—is needed to ensure that all eligible and potentially eligible individuals know about the new self-direction program and have the information they need to decide if it is right for them. Individuals may learn about the new program through formal channels determined by the state, but they may also hear about it from agency case managers, current workers, consumer advocacy organizations, friends and family, and other sources.

In addition to planning and carrying out outreach, states must be prepared to both counter misinformation from other sources and to take advantage of opportunities for “free” marketing (e.g., through the media). Developing a strategic communications plan is discussed in Appendix I. The information provided here focuses on a few key areas that states need to address when developing their communications plans.

Planned Outreach

States must first decide how much information they will provide directly and how much will be provided by other sources it enlists. It is essential that states identify sources that can provide accurate information about the new self-direction program. Most states have information about their new programs on websites, from which individuals can obtain accurate information. However, many potential participants may not have easy access to a computer or may not know how to find information on the Internet.

To determine which sources to enlist, states must first determine which sources potential applicants trust and tend to rely upon most when seeking information about long-term services and supports. In many instances, the messenger is as important as the message. Arkansas and Florida found that a letter from their respective Governors explaining the new program to current waiver participants was a very effective mechanism for disseminating information about the program.

To obtain information about authoritative sources of information for potential participants, Arkansas conducted focus groups and found that, in addition to family members, potential participants sought the advice of physicians and pharmacists. Acting on this information, Arkansas developed an outreach campaign to these professionals.

Participants in HCBS waiver programs generally have case managers (or support coordinators), who can provide information about the new program. However, several of the Cash & Counseling (C&C) replication states found that some case managers did not provide accurate information about the program because of their own skepticism and/or negative judgments about whether self-direction would be appropriate for their clients.⁵

Given limited resources, states must decide how much time and funding should be invested in outreach to individuals, family members, and in training others (e.g., case managers) to provide outreach. They need to determine where to target their efforts to achieve the greatest return. This decision will be based on the unique circumstances in a given state; for example, whether the new program is the only self-direction option offered or is building on or expanding other self-direction programs; and whether there is strong resistance to the program from service providers.

Experience in the Cash & Counseling Demonstration and Evaluation (CCDE) states has shown that individuals like to learn from their peers. For example, about half of the outreach workers that Florida hired to make in-home presentations to families of children and adults with mental retardation and other development disabilities (MR/DD) were themselves parents of children with MR/DD. Many had been active in local Developmental Disability Councils and knew other parents whose children were in HCBS waiver programs.

States might therefore consider having participants serve as peer mentors or informal advisors for others trying to determine if self-direction is right for them. They may not be able to travel to make in-home presentations, but they could be available for phone or e-mail consultations. See Chapter 3 for additional information on involving peers.

In the CCDE states, about half of the participants designated a representative, suggesting that states need to market programs not only to potential participants but to their families as well.⁶ Family members exert a great deal of influence over individuals' enrollment decisions and, for minor children or individuals with moderate and severe cognitive impairment, they are the decision makers.

To ensure that all potential participants have information about the program, several states have translated outreach and enrollment materials into commonly spoken foreign languages, such as Spanish in Florida and Spanish and Russian in New Jersey. Other states have made videos about the program and distributed them. See the Resources section at the end of this chapter for information to obtain examples of outreach and education materials from several states.

Unplanned Outreach

It is important to recognize that much of what people hear about a new program will not come directly, or even indirectly, from the state. Some of what they hear will be favorable and some unfavorable; some will be accurate and some will be inaccurate. Stories abound on how some local home care providers and/or workers have spread negative information about a new self-direction program.

States need to have a plan to augment accurate and favorable information and correct misinformation. The C&C National Program Office (NPO) has created a tool kit for involving traditional home care providers in program development, addressing their concerns, answering their questions, allaying their fears, and dealing with overt hostility.⁷ See Appendix I for a discussion of methods to involve stakeholders, address negative messages, and counter resistance.

As news of the new program spreads and enrollment increases, states may be able to reduce outreach activities. However, states need to recognize that due to participant and staff turnover, some level of outreach needs to be ongoing. Experience with outreach and the enrollment process can provide valuable information for fine-tuning activities in these areas to be both effective and efficient.

C. Establishing Enrollment Policies and Procedures

The enrollment process—comprising multiple policies and procedures—can facilitate or slow enrollment. A complex enrollment process with multiple steps and required approvals will present a disincentive to enroll for some individuals,

particularly if the state does not have sufficient staff and the process takes several weeks or even months to complete. A waiting list and long delays in completing the enrollment process do not convey a positive message about the program. During delays, individuals' initial enthusiasm may diminish and, if they are without services for any significant amount of time as a result, they may decide to return to the traditional service system.

The joint goals for the enrollment process are effectiveness and efficiency. When designing the enrollment process, states should simplify it to the extent possible and ensure efficient processing of required documentation. Additionally, staff responsible for implementing the process need to be thoroughly trained to do so.

Staffing

It should be obvious that states need to have sufficient staff to enroll interested individuals in a timely manner and sufficient counselors and FMS providers so that newly enrolled participants do not subsequently encounter significant delays in making the transition to self-direction. Nonetheless, inadequate staffing is one of the factors responsible for slow enrollment in some states.

The reasons for inadequate staffing vary. If outreach and enrollment workers are state employees then it may be that the state's hiring process is cumbersome and it has taken a very long time to get all the required bureaucratic approvals. Or the Governor may suddenly institute an across-the-board hiring freeze, unanticipated and ill-timed for the launching of a new self-direction program. On the other hand, it may be difficult to find service providers in the community who are interested in carrying out outreach, enrollment, or post-enrollment counseling activities. Sometimes, a bottleneck occurs when outreach, enrollment, and counseling staff have to be trained and only one state-employed trainer is available.

Having dedicated workers when launching a program can help ensure a smooth, efficient, and timely implementation. Although Minnesota requires case managers and care coordinators in managed care organizations to inform participants about all service options for which they are eligible, enrollment in its new self-direction program was slow initially. To boost enrollment, the State contracted with three Centers for Independent Living (CILs) to provide enrollment assistance services, including outreach, initial education about the new program, and technical assistance to case management agencies.

If states lack resources to fund dedicated staff, grant funding can be sought for this purpose. Minnesota used funds from a Robert Wood Johnson Foundation (RWJF) C&C grant and several states have used Centers for Medicare & Medicaid Services (CMS)-funded Systems Change grants to help implement new self-direction programs. Several Systems Change Grantees reported that they could not have conducted comprehensive education activities without grant funding.⁸

Grant funding can be very useful in enabling states to hire sufficient staff, especially when program officials believe they can exercise greater control by treating many if not all aspects of outreach and enrollment as Medicaid administrative functions best performed by state employees or contract workers. Ultimately, however, grant funding ends and states must be able to sustain the level of staffing necessary. Whether sustainability is best served by having state employees, administrative contractors, or Medicaid service providers carry out some or all outreach and education tasks is a judgment call that each state must make based on considerations unique to the state.

Timeliness of the Enrollment Process

States need to closely monitor the time it takes from enrollment in the new program to the receipt of services and to ensure that it is not so long that it leads new enrollees to drop out. If it takes longer than anticipated, on average, for new enrollees to receive services, the state needs to investigate the reasons why.

Perhaps new enrollees are not receiving as much support as they need to complete the required paperwork. They may be making mistakes or failing to provide all required information, causing their paperwork to be repeatedly rejected—a sign that forms need to be reviewed and made more “user friendly.” When program staff complete as much of the information on the forms as possible before mailing them to participants, it reduces potential mistakes and increases the likelihood that accurate and complete forms will be returned.

Certain processes that may be required in some states but not others (e.g. mandatory criminal background checks before participant-employed workers can begin work) may be taking much longer than expected and this may be a serious problem; for example, if workers cannot afford to wait to be cleared and take other jobs instead.

Inefficient communication across state agencies or between regional offices and the central office can cause delays, as can a requirement that multiple agencies be involved to fulfill program requirements. For example, one agency may be responsible for enrolling participants but they may not authorize service provision until a different agency has reclassified the participants as “self-directing” in the Medicaid Management Information System (required to ensure that traditional providers will not file new claims for self-directing participants’ services.)

To ensure efficient communications, New Mexico found it very helpful to use a contracts manager who makes sure that all the details necessary for implementing a new delivery program with varying populations are coordinated in a timely manner by the designated individuals and/or teams.⁹ See the Resources section at the end of this chapter for information on obtaining an online tool kit of materials that other states have developed.

Policies Regarding Representatives

Virtually anyone, no matter how physically or mentally impaired, can participate in a self-direction program as long as they have a family member or close friend to be their representative.¹⁰ To ensure that anyone who wants to enroll in a self-direction program is able to, states must develop strong criteria, job descriptions, and training for representatives. See Chapter 1 for additional information about representatives.

It is also advisable to have some criteria to determine when an individual needs a representative to participate. Some individuals may not realize that they need assistance to direct their services and counselors have to identify this need as soon as possible in the enrollment process and assist the individuals to identify an appropriate representative.

At the same time, states must recognize that not everyone will be suitable for the program and must have provisions to require participants who repeatedly show they cannot handle self-direction or those who present a danger to themselves or others, to return to the traditional service delivery system.

Assigning Responsibility for Conducting Enrollment

States have several options for assigning responsibility for enrollment. Programs can train all traditional case managers to assume this role, designate or select some traditional case managers, hire new dedicated staff for the initial enrollment period, or have counselors conduct enrollment.

Using traditional case managers may not always be the best approach for several reasons. First, they may be resistant or actively opposed to the new program. Even if supportive, they may be overburdened with current responsibilities. Unless they are assigned to enrollment activities as a full time endeavor, competing demands may prevent them from performing enrollment tasks often and regularly enough to become efficient. The state also needs to determine if those conducting enrollment will also be performing level-of-care assessments or assessments of need and if not, how the individuals performing these activities will work together.

Florida's initial enrollment efforts yielded very few participants, which did not increase until the State (1) sent out a letter from the Governor informing waiver participants of the new self-direction option, (2) established dedicated enrollment teams—utilizing care managers who supported the program, and (3) conducted focus groups to understand what issues and problems traditional care managers were having so the State could develop ongoing training programs to address them. The State also established hotlines to answer questions from potential participants.

Whoever conducts enrollment must believe in the benefits of the new program and be unbiased. Case managers who work for the state or an independent case

management agency may be more open to the program than those who are employed by provider agencies.

Arkansas and New Jersey decided they could not rely on service providers who felt they would lose business and so set up a separate system to handle outreach, education, and enrollment. Florida continued to use existing care managers and independent support brokers because they concluded that it would be impractical not to. But Florida's experience made it clear that traditional case managers/support coordinators often had to learn a new paradigm to be able to effectively educate individuals about self-direction and facilitate their enrollment.

To help states educate case managers about self-direction, CMS funded the development of a training program. Information for obtaining the program is available in the Resource section at the end of this chapter.

Providing Program Information to Interested Individuals

In addition to basic information provided as part of outreach activities, states have to develop materials that provide more detailed information to applicants and those who need more information to make a decision. Applicants and any family or friends they want to involve need to have a clear understanding of their rights and responsibilities under the new program as well as how it compares to the traditional system.

They need to know exactly how the program will work—the amount of their budget, allowable purchases, potential problems and how they can be addressed, and available supports (e.g., financial management services (FMS) and counseling). It is important to achieve a balance between providing too much or too little information. At a minimum, individuals need sufficient information to make an informed decision about whether self-direction is right for them.

Many states implementing self-direction programs have found it very useful to involve individuals who might be interested in the program in designing and pre-testing program materials and forms. New Mexico found that outreach and educational materials about self-direction are much more effective when they contain photographs and personal quotes to illustrate the diversity of individuals using the option.

When to Provide Information.

States also need to decide whether information about the new program will be provided during (re)assessment or as a stand-alone process. Each approach has merit. Telling individuals about the program during the (re)assessment home visit/process may be efficient and it may allow states to space outreach somewhat evenly throughout the year.

On the other hand, providing information to help individuals decide whether or not they want to enroll in the program can become just one more item that has to be fit into a very busy session and those conducting the (re)assessment may also view it as a burden and not give it their full attention.

Conducting Home Visits

Virtually all of the 15 states that have received C&C grants have found that home visits are essential for conducting enrollment. New Jersey tested enrollment over the phone, but abandoned that practice after a brief trial. However, telephone contacts prior to a home visit can assess the level of an individual's interest. Doing so can help to ensure that those with a high level of interest get priority for a home visit.

Although home visits are expensive, they can help ensure that individuals do not enroll and then drop-out of the program because it was not what they expected. Some states, especially those with large rural areas, have stationed enrollment staff around the state to cut down on travel time and costs associated with home visits. It also makes it easier to schedule a visit without a long wait that may occur if the enrollment specialist has to cover a large territory.

States also need to determine how many home visits enrollment staff should make and set up a system to answer follow-up questions. Home visits are expensive and time-consuming. Thus, providing information by phone, mail, or e-mail prior to the visit can shorten the time needed for the home visit and lessen the likelihood of having to make multiple visits.

Clearly, family and friends play a key part in the enrollment decision and every opportunity should be taken to make enrollment visits convenient (e.g., by conducting some visits on evenings or weekends so family can attend). Some individuals want to have individuals they plan to hire present so they too will understand the option.¹¹

Finally, states need to set up a process for moving from enrollment to developing a spending plan. Some states, for example New Jersey, encouraged counselors to provide consumers with materials they could look over prior to the home visit so if the individual decided during the visit to enroll, the enroller could begin developing the spending plan during the same visit and provide IRS and immigration forms for workers to complete prior to starting work.

Some states have dedicated outreach and enrollment workers, but do not assign or allow participants to choose a counselor (support broker or consultant) until after they are enrolled. However, an advantage of having counselors enroll participants is that, once enrolled, the counselor can begin working with them during the initial home visit on a spending plan and the paperwork needed to hire workers.

D. Tracking Enrollment

States should consider their information needs for managing outreach and enrollment and improving these processes. The CCDE states tracked enrollment by month and compared the numbers with outreach activities performed during the same time period in order to determine which outreach activities were more effective. A number of states have kept track of reasons for not enrolling after initial interest was expressed and used this data for continuous quality improvement.

Not all states collect data about individuals who apply for or enroll in their programs. Both self-direction and agency-based home care programs consistently report not having core management data such as: (1) the length of time it takes for a potential participant to receive information, (2) the number of individuals who make an initial contact who actually apply to the program, or even (3) how long it takes a person once enrolled to receive services or supports.

Because a series of detailed steps are needed to enroll in public programs, and these may be even more complicated in a self-direction program, it is critical to track applicants' and participants' experiences. Program managers are often surprised to learn how long some of their processes take or how cumbersome the process is to complete.

To identify important types of tracking information, it is useful to begin by documenting the program's processes for outreach, enrollment, service plan development, and ongoing support. For example, what steps do applicants have to take to obtain information, to find out if they are eligible, to enroll, to develop a spending plan, and to receive services and supports? Once a program has documented these processes, it is then possible to make decisions about which aspects should be tracked.

While states will want to tailor data collection to their specific program, it is common to track the length of time from initial call to eligibility determination, enrollment, and receipt of first service. It is also typical to record disenrollment rates and reasons for leaving the program.

Information from tracking systems can inform continuous quality improvement. For example, one program had lower participation than expected despite a high volume of referrals. After examining enrollment procedures and developing a tracking system, program staff found that a large proportion of enrollees left the program before receiving services because the process to develop and implement the individual budget was so long and cumbersome. To avoid such problems, some programs have set up methods to identify and intervene in processes where the lag time is greater than a specified number of days—usually 60 or 90.

Despite agreement that such tracking information is an important component of both the enrollment process and quality management, many programs still lack systems to collect such information for two reasons. First, programs do not typically take the time to document their processes, so it is difficult to know which information is most important to track. Second, most programs do not have adequate management information systems in place to record, process, and report tracking data. Home care programs have well-developed systems for financial accountability, but participant process and outcome data are much less likely to be collected or retrievable.

An investment in information systems to track key data can yield major benefits by providing information to improve program efficiency. The systems should be designed to ensure that the data collected can be integrated with other data the state collects. For example, linking feedback from participants on the program with data on dis-enrollment can provide an opportunity to better understand how to improve participants' experiences.

E. Factors That Influence Enrollment

The enrollment process itself influences the number of individuals who sign up for a new program, but other factors do as well. Some are internal to the program and others external, and they all interact. States should have an understanding of these factors both when designing the enrollment process and when tracking it, to enable them to identify issues and problems that need to be addressed.

The three factors that influence enrollment are: (1) the program's key features—particularly relative to other self-direction programs available, (2) the characteristics of potential participants, and (3) stakeholders' views.

States typically have less control over participants' characteristics and stakeholders' views, except insofar as these factors can be affected by program design features as well as the enrollment process and other administrative features. These latter factors are largely under state control. Because all of the factors that influence enrollment are inter-related, the discussion of each one below will overlap somewhat.

Program Design Features

Design features are the specific program components that make it more or less appealing to potential participants. Restrictions on who may be hired as a personal care aide (specifically, prohibiting the hiring of family members or family members who live in the same household) will limit enrollment. Permitting participants to hire spouses and parents for their minor children as paid providers will expand enrollment.

Restricting participants to use their individual budgets only for personal aide services will limit enrollment, particularly if a state already has an agency with choice self-direction option that allows participant to hire their own workers. On the other hand, allowing participants to spend their individual budgets on a wide range of disability-related goods and services in addition to aide services will make self-direction more attractive to more individuals.

Requiring participants to manage an individual budget and perform all financial management tasks, including filing of employment taxes, without assistance, will greatly limit enrollment. (This is an option under state-funded programs but not Medicaid-funded programs.)¹²

Perceived Fairness of the Individual Budget Amount

Perhaps the single most important program design feature that has emerged as having a major impact on enrollment in programs offering budget authority is the perceived relationship between the dollar amount of the individual budget and the dollar value of the services that would otherwise have been authorized under the traditional service.

In the past, several states operated programs under Section (§) 1115 waivers. To ensure the budget neutrality these waivers require, states had to “discount” individual budgets so they would not be higher than the cost of traditional service usage, even though that usage was less than what was authorized due to a shortage of service providers.

Even though CMS no longer approves §1115 waivers for self-direction programs, and self-direction programs offered under §1915(c) waivers do not have to be cost neutral *relative to traditional HCBS waiver services*, some states discount budgets based on concerns that the new program will increase Medicaid expenditures because previously under-served participants will now receive all of their authorized services.¹³ Discounting is not permitted under the §1915(j) self-direction Personal Assistance Services State Plan option.

The issue of discounting budgets can pose problems for state administrators because participants’ perceptions of what discounting means for them can have a negative impact on enrollment. Potential participants may perceive this discounting to be unfair and it may make some suspect that the state is offering the self-direction option as a means—and a “cover”—for cutting benefits. If they think this, they will be less likely to enroll.

Such concerns are not restricted to participants. Discounting can be used by traditional providers to argue against the program, which can seriously undercut support from advocacy groups. In Minnesota, some case managers do not support the new program because they feel that discounted budgets will not meet their clients’ needs.

It is difficult to explain to participants why the dollar amount of their budget should not be based entirely on their assessed need and why they should have their budgets reduced because some of them might not have received all of their authorized services from traditional providers. The difficulty of explaining how this could possibly be fair is compounded by the fact that “average” rates of under-service do not accurately describe individuals’ experience.

“Averages” mask considerable variation: some persons do get everything they are entitled to in the traditional system, whereas a minority may get little or even no services due to worker shortages and other factors that prevent traditional providers from delivering services in some areas of a state.

If, however, the real issue is that traditional service plans are routinely inflated because case managers authorize more services than are really necessary and almost no participants actually receive anything close to the services authorized, then state administrators may need to address this problem first. Arguing that service plans are not really meant to be taken seriously because nobody is really expected to receive all of the services authorized seems a dubious explanation for budget “discounting.”

Thus, states must ensure that the needs assessment and benefit determination processes can be justified as fair and equitable to both self-directing and non-self-directing participants. Likewise, it is important that those performing the needs assessment and developing either the traditional care plan or setting the individual budget for self-directing participants not have any conflict of interest.¹⁴

Because discounting is generally viewed negatively, states need to determine when their traditional programs are not providing authorized services and take action to correct this situation.

Characteristics of Potential Participants

Several characteristics can determine whether individuals will find self-direction appealing and, most importantly, whether, given their particular circumstances, they will be able to self-direct and benefit from self-direction.

Research and program experience have definitively disproved some misconceptions about who is and is not strongly attracted to self-direction. One such discredited stereotype is that self-direction only or primarily appeals to cognitively intact, younger adults with physical disabilities. If this had been true, none of the three CCDE states could have met the enrollment targets needed for the controlled experimental evaluation.

Individuals’ (and families’) interest in enrolling will be based on their understanding of the new program and an assessment of its pros and cons. This assessment in turn will be based on their needs and their experiences with the

current service system, including their current service arrangements. While states cannot change individuals' experiences, they can ensure that they have accurate and unbiased information about the new program. Including potential participants on advisory groups and workgroups to develop educational materials can help to ensure that these materials answer their questions and address their concerns.

Satisfaction with the Current System

Perhaps the most important factor that will affect individuals' interest is their satisfaction or dissatisfaction with the service options currently available in the state. Individuals in the traditional system—and those who are exercising employer authority in existing self-direction programs—who are satisfied with these arrangements will likely have little incentive to enroll in a new program that entails the assumption of additional responsibilities. Conversely, those who are dissatisfied with current service options will likely be very interested in enrolling.

Pennsylvania and Washington had two different self-direction programs established prior to introducing a new budget authority program and had a difficult time explaining the new program and its benefits to potential participants, case managers, and providers.

Past experience suggests that self-direction will be especially attractive to individuals who find the traditional services system inflexible and unreliable, as well as those who have been unable to receive all the services they were assessed to need. Usually, such problems reflect a lack of sufficient providers, especially aide shortages, in the traditional service system. Self-direction can provide a way to overcome shortages of traditional providers by tapping into a different labor pool, such as family, friends, and neighbors, especially if such persons are not looking for full-time work.

Scheduling is another source of dissatisfaction with traditional services that self-direction can remedy. Agencies are often unable to find aides willing to work on weekends or early enough in the morning or late enough at night to accommodate participants' needs or preferences for assistance getting into and out of bed. Additionally, many agencies will only send workers in two- to four-hour blocks of time, whereas participants need workers to work a more intermittent schedule throughout the day and can find family or friends willing to do so. For example, a neighbor may be willing to assist a participant for an hour each morning and evening.

Perceived Difficulty of Recruiting Workers

Individuals' willingness to enroll in self-direction programs will be greatly influenced by how difficult they think it will be to recruit workers they will want to hire. This in turn will be highly influenced by whether or not they have family members, friends, or neighbors whom they know and trust and think they might employ.

Being allowed to hire family members—and having a family member who is interested in being hired—appears to be somewhat more important to older people.¹⁵ Because many potential participants require or prefer to have the assistance of a representative and the representative cannot be a paid worker, willingness to enroll may also be contingent on having one relative available to serve as an unpaid representative and another relative or a close friend available to work for pay.

Interest level may also be influenced by whether or not the program allows participants the flexibility to offer higher hourly wages and better benefits than agencies typically offer. Many individuals interviewed in focus groups have indicated that they know how much agencies pay workers and believe they can attract better qualified and more productive workers if they have the flexibility to pay higher wages.

Analyses of worker data from the CCDE found that in two of the three participating states—New Jersey and Florida—participants did pay their workers more, on average, than agency workers were paid.

Some long-established self-direction programs such as California’s In-Home Supportive Services (IHSS)—which has about 416,000 participants—have overcome the barrier to self-direction that is posed when individuals do not have family, friends, and neighbors available to hire. The IHSS public authorities, at least those in large metropolitan areas, all operate registries where participants can obtain referrals to workers not previously known to them who are looking for employment as IHSS aides. The registries screen workers by performing criminal background checks, at a minimum, and they try to refer workers to participants who live nearby.

The extent of an individual’s need for assistance may also play a role in determining interest level. Again, the experience in California’s IHSS program is that individuals at the lower end of the need spectrum, especially those who mainly need assistance with house-keeping and meal preparation, are often satisfied with agency workers. Individuals with greater needs for hands-on personal care and especially persons with quadriplegia and others who have very intensive and intimate personal care needs typically have the strongest desire to hire and supervise workers whom they have personally selected.

Stakeholders’ Views

Stakeholders’ views about a new self-direction program can vary considerably, from enthusiastic support to vigorous opposition. Resistance to the new program from stakeholders who may be skeptical about self-direction or perceive it as a threat to their financial interests can have a particularly negative effect on enrollment. Many of the 15 states that received C&C grants report resistance from case managers in the traditional system, which has been more of a problem

than resistance from traditional home care agencies that view self-direction as economic competition.

Resistance from traditional agency providers will likely lessen if they recognize that worker shortages do not allow them to fully meet the demand for services. States should communicate with providers (as discussed earlier) and help them to understand that if there is a shortage of workers, it is in their interest to encourage individuals who have family, friends, and neighbors they can hire directly to do so. Doing so makes it possible for the agencies to focus their services on those who most need their help to obtain aide services. Their resistance may also decrease when they understand that they can refer clients whom they have had difficulty satisfying—or who have not treated their agency workers well—to a self-direction program.

If the state is depending on traditional case managers to educate and enroll potential participants, their lack of enthusiasm and sometimes active discouragement can severely dampen enrollment. As discussed earlier, states often do best when they develop a cadre of dedicated staff who are committed to the program and will market it. This can be done by retraining case managers and then selecting only those who respond with enthusiasm and also by recruiting individuals who have never worked as traditional case managers. States can also have counselors conduct enrollment. Specific approaches to deal with resistance are discussed in detail in Appendix I.

On the other hand, consumer advocacy groups and “satisfied customers” can boost enrollment. Consumer advocacy groups can be very helpful in overcoming resistance to self-direction from skeptics and critics. State officials should involve groups such as state and local AARP and Alzheimer’s Association chapters, Development Disabilities Councils, and Independent Living Centers in the planning of the program. When enrollment begins, these groups can then assist in outreach efforts and in countering negative views.

Once the new program is underway, individual participants may be willing to use their networks to share their positive experiences and to help potential enrollees decide and new enrollees get started. (See discussion of peer involvement in Chapter Three.) Several states have made videos about their programs featuring satisfied participants and have distributed DVDs to potential participants and stakeholders.

States experiencing slow enrollment should analyze all of the factors to determine how the enrollment process is working. Factors that are presenting barriers to or slowing enrollment need to be analyzed to determine if they are amenable to change.

Resources

Publications

McInnis-Dittrich, K., Simone, K., & Mahoney, K. (2006). *Consultant Training Program*. Baltimore, MD: Centers for Medicare and Medicaid Services, Disabled & Elderly Health Programs Group.

This manual is intended to address two identified training needs for consultants/support brokers working with participants in self-directed care. MODULE ONE: Facilitating the Paradigm Shift for Consultants, and MODULE TWO: The Dynamics of Choice and Decision-Making for Participants.

Available at: <http://www.cashandcounseling.org/resources/20060602-113610>

Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. (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.

This report documents the issues raised and opportunities uncovered during the design and implementation of Cash & Counseling programs in the original three demonstration states. The report discusses aspects of the program including counseling and spending plans, outreach and enrollment, the role of representatives, uses for the cash allowance, preventing exploitation and abuse, and financial management services.

Available at: <http://www.cashandcounseling.org/resources/20051202-163649>

Web-Accessible Resources

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. In particular, on the interactive map site, each state has provided a wealth of materials, including enrollment forms and other marketing materials. For example, <http://www.cashandcounseling.org/resources/browse?SourceIndex=Arkansas>

Also, the following toolkits are available:

Burness Communications (2006). Cash & Counseling Communications Toolkit. Available at <http://www.cashandcounseling.org/resources/20060519-134758/>

Burness Communications (2008). Working with Providers: A Toolkit for States Implementing Cash & Counseling Programs and Consumer-Directed Services.

Available at <http://www.cashandcounseling.org/resources/20080415-145147/>

Lastly, numerous examples of materials developed by states that received C&C grants can be found in the resource and publication section, using the search engine <http://www.cashandcounseling.org/resources>.

Choose Type of Resource: Marketing Materials. The results will list communication plans, branding materials, and marketing tools.

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty and Janet O’Keeffe co-authored this chapter. Kevin Mahoney is a contributing author.
- 2 While some new self-direction options are not separate programs (i.e., they are an addition to an existing program), for ease of reference, this Handbook will use the term program, unless a distinction between an option and a program is needed.
- 3 In addition to the waiver populations, Mi Via also serves a population not covered by a waiver program—people with acquired brain injuries. O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). *Real Choice Systems Change Grant Program - FY 2002 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2172>
- 4 Dale, S.B. & Brown, R. (2006). Reducing nursing home use through consumer-directed personal care services. *Medical Care*. 44(8):760–767.
- 5 Focus group research in Florida indicated that the opinions of case managers about the new self-direction program carried a lot of weight with their clients. However, clients and case managers both reported that participants and family members were less trusting of and reliant on their case managers’ advice when they had experienced significant case manager turnover and believed they knew more than recently hired case managers.
- 6 The percentage of participants who designated a representative varied by state and target population—from 40 to 60 percent. Schore, J., Foster, L. & Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research*, 42(1p2):446–466. Available at: <http://dx.doi.org/10.1111/j.1475-6773.2006.00679.x>
- 7 McInnis-Dittrich, K., Simone, K., Mahoney, K. (2006). *Consultant Training Program*. Baltimore, MD: Centers for Medicare & Medicaid Services, Disabled & Elderly Health Programs Group. Available at: <http://www.cashandcounseling.org/resources/20060602-113610/>
- 8 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 & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/1601>.
- 9 O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). Op.cit.

- 10 Research has shown that self-direction programs work well for individuals with developmental disabilities and mental health diagnoses. Shen, C., Smyer, M.A., Mahoney, K.J., Loughlin, D.M., Simon-Rusinowitz, L., & Mahoney, E.K. (2008) Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling program. *The Gerontologist* 48:93–104. Schore, J., Foster, L., and Phillips B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research: Putting Consumers First in Long-Term Care: Findings from the Cash & Counseling Demonstration and Evaluation*. 42(1) Part III, 446–466.

One study found that people with dementia were more interested in directing their services than was the general home care population, perhaps because of their particularly high need for consistent caregivers. Kunkel, S. R. & Nelson, I.M. (2005). *Profiles of Choices Consumers*. Scripps Gerontology Center. Miami University of Ohio. (This paper is only available on the website). http://www.scripps.muohio.edu/research/publications/documents/Final_Choices_Report.pdf

- 11 When Arkansas began enrollment, program staff were initially wary about having current agency-workers present during the home visit because they wanted potential participants to have the opportunity to hear about the new program without being influenced by individuals with potentially negative views about the program. Over time they became more comfortable with doing so because some current workers are nervous about losing their jobs and may have inaccurate information about the new program. Having current workers present—if the applicant prefers—can help to ensure that they have accurate information.
- 12 Oregon used to have a Medicaid State Plan program under the §1115 authority that required participants to deposit a check from the state into a dedicated bank account and to manage their funds without the assistance of a fiscal/employer agent, though some participants hired book keepers to assist them. Mueller, E. Becker, K. & Rider, S. (2006). *Evaluation of the Independent Choices Program Final Report*. Portland, OR: Pacific Research and Evaluation, for the Oregon Department of Human Services, Seniors and People with Disabilities.
- 13 §1915(c) waiver programs must be cost-neutral relative to *institutional expenditures* (i.e., they must not cost more than institutional services).
- 14 CMS requirements for waivers and State Plan amendments for both participant-directed and traditional HCBS coverage under §1915 (i) and §1915(j) reflect these concerns about a conflict of interest; e.g., when a case manager, employed by an agency that will provide services, develops the service plan.

- 15 Schore, J., Foster, L. & Phillips, B. (2007). Op. cit.; Benjamin, A.E. & Matthias, R.E. (2001). Age, consumer direction, and outcomes of supportive services at home. *The Gerontologist* 41:632–642.

Chapter 5: Individual Budgeting

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Chapter 5

Individual Budgeting¹

Individual budgets are a key element in a self-direction program that seeks to increase participant choice and control. Control of the budget enables participants to select and manage the services and items they need to live independently and to more fully participate in their communities. Management of an individual budget affords participants in self-direction programs (hereafter, participants) both the greatest flexibility and the greatest responsibility.

Individual budgeting may mean different things to different disability population groups (hereafter, populations.) For many years, state developmental disability services have used the term to apply to the total resource allocation assigned to each participant, whether or not a self-direction option was available. This Handbook discusses individual budgeting in the context of self direction.

Broadly, the Handbook defines individual budgets as the funds or resources available to participants to meet their needs.² Participants may directly manage their services and expenditures or assign responsibility for this task to a representative. Throughout this chapter, use of the term participant categorically includes representatives, relatives, and support groups when designated by the participant, unless a distinction is being made among them.

A. Essential Elements of Individual Budgeting

An individual budget, expressed in a dollar amount, represents the anticipated cost of services and supports determined to be necessary and sufficient to meet a participant's needs, and over which a participant exercises decision-making authority. A consensus has emerged regarding the essential design elements of individual budgeting.³ In addition to using a process that is straightforward, reasonable, and easily understood, states need to ensure that the process is:

- **Accurate.** The methodology should reflect a valid assessment and provide amounts sufficient to meet participants' needs.
- **Consistent.** The methodology should be consistently applied across the program, state, and eligible population.
- **Reliable.** The methodology should produce consistent results over time with repeated application.
- **Equitable.** The process should ensure that participants with the same or similar needs and circumstances receive comparable budgets. Not only should participants who direct their services receive budgets comparable to

those in the traditional service system (assuming comparable needs), but a rational and fair relationship between the cost of traditional services and the participant-directed budget should exist.

- **Flexible.** The process should allow changes to the budget to be made easily and in a timely fashion to accommodate changes in participants' circumstances and choices.
- **Transparent.** The process should be open to public inspection.

Key components of individual budgeting are: assessing need, developing a service plan, calculating a budget amount, and determining a spending plan. The order in which these activities may be performed can vary depending on the program design. For example, some methodologies calculate the budget amount first, then assess needs and develop a plan to meet those needs. Other methodologies assess needs, develop a plan to meet those needs (typically expressed in service hours), and then assign a dollar value to the plan using a specific formula (i.e., determine the budget amount). Regardless of the methodology, the practice of person-centered planning is the foundation for individual budgeting.

Key Terms

Assessment. Determines what the individual needs.

Service Plan. Develops the plan to meet identified needs.

Individual Budget. Determines the dollar amount to be available for participant-directed services, supports, or items.

Budget Setting. Determines how the dollar amount of the individual budget is determined.

Spending Plan. Determines how the individual budget will be spent—on what, how much to reimburse, who will provide service, etc.

Prospective Budgeting. Calculates the individual budget amount using empirical methods prior to the person-centered planning process.

Retrospective Budgeting. Calculates the individual budget amount through an individualized assessment process using the person-centered planning process.

Practicing Person-Centered Planning

Person-centered planning (PCP) is an overarching philosophy applied to the development, management and evaluation of the individual budget to enable participants to identify their needs and to exercise choice and control in developing a plan to meet these needs and achieve their life goals.⁴

Key principles of person-centered planning are:

- Participants lead all planning activity and decision making and are the primary source of information.
- Participants are furnished with sufficient relevant information and support to facilitate informed decisions.⁵
- Participants direct and manage the planning process in accordance with their identified strengths, capacities, preferences, desires, goals, and support needs.

The PCP approach to service planning does not include a series of strict requirements. Rather, it comprises a body of values, principles, and processes used to tailor planning activities around the individual receiving services and supports.⁶ While the essential elements of person-centered planning apply to all populations, the process varies in how it is applied with specific populations.

Typically, the developmental disability (DD) population focuses on major life goals and decisions regarding living arrangements and locations, companions, education, and employment. The PCP process for the DD population is typically manifested as a structured system and may use a series of tools, checklists, or protocols to guide and document the planning process. For example, “Essential Lifestyle Planning” is a protocol for formally guiding participants in identifying life goals and planning to meet those goals.⁷

In contrast, the system that serves elderly persons and younger adults with primarily physical disabilities uses a less structured approach. Rather than focusing on broadly defined long-term life goals, participants focus on their more immediate goals for daily living; that is, identifying the services and supports they need to perform daily activities (e.g., bathing and meal preparation). Several of the states that received Cash & Counseling (C&C) grants are using a tool specifically designed for elderly persons called Participant Goal Setting. See the Resources section at the end of this chapter for a web address to obtain this tool.

The Michigan Department of Community Health (one of the C&C replication grantees) has made considerable advances in promoting person-centered planning in their Medicaid waiver programs. Through a legislative mandate in early 2000, Michigan established the right of all individuals to have their services developed through a PCP process, regardless of their age, disability, or type of residence. The State is disseminating draft practice guidelines on the PCP process to stakeholders

to obtain their input, is conducting training for providers, and is developing an organizational readiness review tool to assess the extent to which providers are using person-centered planning.

Individual Budget Methodologies

Individual budgets may be used to manage participant-directed services and supports under a variety of funding sources, most commonly, Medicaid. Budgets can be used in the Medicaid State Plan through the §1915(j) authority and in §1915(c) waiver programs. The §1915 (j) authority defines a budget as “an amount of funds that is under the control and direction of a participant when the State has selected the State Plan option for (the) provision of self-directed personal assistance services. It is developed using a person-centered process and is individually tailored in accordance with the participant’s needs and personal preferences as established in the service plan.”⁸

Similarly, the §1915(c) waiver authority defines a participant-directed budget as “an amount of funds that is under the control and direction of the waiver participant when a waiver makes available the Budget Authority participant direction opportunity.”⁹ CMS does not prescribe a methodology for states to use to determine the budget amount. States vary considerably in the methods they use—both in their Medicaid and non-Medicaid self-direction programs.

The Administration on Aging Nursing Home Diversion Grants Program (in 2007 and 2008) encourages grantees to use individual budgets that are: (1) flexible to respond to changing needs; (2) responsive to individualized needs and preferences; and (3) not tied to a particular service, package of services, or types of providers.

While methodologies vary from program to program, during the past decade two basic approaches to determine the individual budget have emerged, the prospective approach and the retrospective approach.¹⁰

In the *prospective approach*, the individual benefit amount is determined prior to the participant-directed planning process. The benefit amount is usually based upon an objective assessment of the participant’s needs often using a statistical model or mathematical calculation to arrive at a total dollar amount or the upper limit for the individual budget amount. Once the total budget amount is determined, a spending plan is developed that identifies the participant’s needed services and supports. This approach allows programs to control costs and project expenditures while allowing participants full control of the budgeted amount.

In the *retrospective approach*, the benefit amount is determined by assessing a participant’s needs and represents a more open-ended process. It is more subjective in nature and is based on individual need rather than empirical data or a mathematical calculation. Once needs are determined, the costs to meet the needs are identified based either on the traditional fee-for-services reimbursement

schedule or other mechanisms. Once participants know the budget amount, they determine their personalized spending plan and implementation strategy. Under this approach, benefit limits may be used to control expenditures.

Regardless of which budget methodology a state chooses, the core components of the individual budgeting process are: (1) determining needs, (2) planning to meet determined needs, (3) setting the budgeted amount, and (4) determining the spending plan. Note that determining needs and planning to meet the determined needs may be components of the same process in both the traditional service systems and in self-direction programs.

Determining Needs

Determining needs is typically based on an assessment of the types of assistance individuals require based on their needs, preferences, abilities, and desired outcomes (i.e., goals). The assessment process takes into account: (1) medical condition(s); (2) functional capacity and limitations, specifically the ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs);¹¹ (3) living arrangements; (4) availability of unpaid supports; (5) social environment; (6) geographic isolation; and (7) behavioral complexities. *The needs assessment determines the need—not how to meet the need.*

The methods states use to perform the assessment vary greatly and often differ within a state according to the population being served. In programs serving persons with developmental disabilities, many states use standardized assessment processes and instruments that are nationally tested and accredited (e.g., the Individual Client Assessment Profile [ICAP] or Developmental Disability Profile [DDP] instruments).¹² In other programs, including those serving elderly persons and younger adults with physical disabilities, instruments may be less standardized but typically assess ADLs and IADLs, as well as medical conditions, behavioral issues, and social and environmental factors.

For example, in Washington, case managers assess participants using the Comprehensive, Assessment, Reporting, and Evaluation (CARE) tool. The CARE tool uses an automated assessment procedure to classify participants into one of 14 levels of acuity to determine the amount of funding available for the service plan. Factors assessed and considered include: clinical complexity, behavior/mood, cognitive ability, ability to perform activities of daily living, and availability of informal supports.

A few states use the Minimum Data Set–Home Care (MDS-HC) assessment tool. The MDS-HC is a comprehensive assessment tool; it assesses multiple factors that determine the need for services, including: cognition, vision, hearing and communication, mood/behavior, social functioning, informal support services, physical functioning (including IADLs and ADLs), continence, medical conditions and medications, and the living environment.

Uniform use of a standardized assessment method is critical to ensure equitable funding of individual budgets. It also helps the state to determine whether budgets are being calculated accurately, consistently, and reliably. Variability in assessment methods can make it difficult for states to estimate and control program costs.

Ensuring consistency can be quite challenging in county-based HCBS programs where the state does not require the uniform application of standardized assessment methods. Successful interventions to ensure equity in such programs include the adoption of a standardized assessment instrument in conjunction with training on the consistent conduct of the assessment process.

Service Planning¹³

Once needs are identified, a plan is developed to address these needs. The culmination of this process is a document referred to in Medicaid statute as the service plan. The service plan may be specific to participant-directed services, such as for State Plan Personal Care, or may be a combination of traditional and participant-directed services, as in many §1915(c) waiver programs.

For the purposes of §1915(c) waivers, the service planning process includes the following components:

- Selection of services that best meet participants' needs, goals, preferences, and abilities;
- Development of a plan to maximize resources and supports available in participants' lives or their communities;
- Determination of the amount, frequency, and duration of services and supports to be authorized;
- Creation of strategies to identify, assess, and manage potential risks;
- Development of a monitoring strategy to ensure health and welfare and oversee the implementation and execution of the plan;
- Identification of the roles and responsibilities of those involved in the implementation of the plan; and
- Creation of individual backup plans for situations that might jeopardize participants' health and welfare.¹⁴

While the above components are required only for §1915(c) waiver programs, it is helpful for all funding sources to identify in the service planning process the key services and supports that must be addressed to safeguard health and welfare and to provide an overall picture of the services and supports available to the individual.

Budget Setting (Calculating the Budget Amount)

States have considerable flexibility in determining individual budget amounts; however, the methods for doing so should be accurate, consistent, reliable, and equitable. It is always recommended that participants be told their budget amounts prior to making a decision about self direction.

States use several methods for calculating the amount of individual budgets, described below. These methodologies (which use historical costs, formulas, and individual assessments) may be used in the prospective or retrospective approach or may be combined. What is important is that states ensure that the methods they use result in budgets that meet participants' needs within program parameters and fiscal constraints.

Historical Costs

Many states derive the individual budget amount from historical Medicaid cost and utilization data, typically retrieved from their Medicaid billing system, the Medicaid Management Information System (MMIS). Historical data are analyzed to make assumptions about a participant's future service use and costs. States may express the resulting individual budget in monthly, quarterly, or annual figures.

States have found this method useful in meeting their financial commitment for budget neutrality (§1115) or cost neutrality, since future costs are based in part on previously incurred costs.¹⁵ However, disadvantages of this method include: (1) lack of historical data for newly-enrolled participants; (2) past utilization may not reflect current needs due to changes in condition; (3) some data may be inaccurate or unavailable and data retrieval may be time-consuming; (4) data may be difficult to analyze due to reimbursement rate increases or policy changes that affected utilization; and (5) claims history provides a view of delivered services that does not reflect under-utilization of authorized services due to access issues, such as labor shortages.

Formulas

Some states employ sophisticated data analyses using mathematical formulas or algorithms to develop individual budgets. Typically, states with these methods have a significant amount of historical data and have devised techniques to identify individual participant characteristics or combinations of characteristics that are likely to influence utilization. An example of such a technique is identifying participant characteristics using the MDS-HC tool described previously.

Such characteristics or variables include medical condition(s), age, mobility impairment, cognitive impairment, behaviors, and many other factors. The formal assessment instrument assigns a weighted score for specific variables, which are then added to reach a total score. The total score is calculated in the context

of other factors such as regional economic conditions—including labor costs—historical expenditures, and funding limitations. The product of these steps is an empirically derived individual budget.¹⁶

Minnesota's formula considers 28 characteristics/variables that have been demonstrated to most influence or predict costs. An annual spending limit or set dollar amount is established based on the scores for the variables, as well as historical costs.¹⁷ The method assumes that the set dollar amount will cover all of a participant's identified needs, but if it does not, the state conducts a reassessment to determine changes in medical and functional needs and makes necessary changes.

Programs in Nebraska, Montana, South Dakota, and Wyoming have been using formula-driven methods for several years. While this approach is statistically complex, states agree that individual budgets calculated in this way reflect the individualized assessment process, historical utilization, and unique state situations, and they agree that this approach can contain costs.¹⁸

Individual Assessment

Basing the budget amount on an individual assessment of needs, goals, preferences, abilities, and desired outcomes has been, in the past, a common approach, particularly in programs serving elderly persons and younger adults with physical disabilities. This approach uses the information provided in an assessment to determine the number of service hours required to adequately meet participants' needs. Once the total number of hours is calculated, this figure is multiplied by the traditional state reimbursement rate(s) or the current fee-for-service rate(s) to obtain the amount of the individual budget.

A major advantage of the individual assessment method is that the individual budget amount matches participants' current needs and is straightforward and easily understood by participants. For this method to meet the consistency, equity, and comparability requirements, however, a standardized assessment process must be used uniformly to determine participants' needs. Otherwise, budget amounts might vary by locality and among individuals performing the assessment. Ideally, two participants with comparable needs and environments should have similar individual budget amounts. Additionally, this outcome should occur whether they are assessed by the same person or different people.

A disadvantage is that unless the individual assessment is standardized and used uniformly across the state, this approach can make it difficult to achieve budget neutrality, cost neutrality, and other state-specific financial constraints. For example, in some states, budgetary constraints require that expenditures for a new self-direction option can not exceed the amount that would otherwise have been spent on services provided by agencies. To ensure this, some states apply a discount or deduction to individual budgets.¹⁹

Alabama and New Mexico apply an automatic discount to the authorized hours in the service plan. Some analysts argue that applying such a discount based solely on historical utilization and the inability of traditional providers to meet demand leaves the state in a questionable position to meet CMS health and welfare assurances by failing to provide adequate services based on current and actual need. Vermont initially discounted individual budgets, but stopped doing so due to complaints from participants and the negative effect it had on program enrollment.

While the amount of a participant-directed budget should not be greater than the cost of traditional services that would have been authorized, it could be less as long as the deduction is reasonable and justifiable (e.g., deductions for the cost of counseling and financial management services). States have the option to cover counseling and financial management as waiver services and to have the costs of these services deducted from participants' budgets. See Chapter 6 for more information about methods to pay for counseling and Chapter 7 for more information about methods to pay for financial management services.

The Spending Plan

Once the budget amount is determined through the program's selected methodology, participants and their informal supports (and counselors as needed and desired) develop a plan to spend the resources allotted. This plan provides a detailed outline of how the funds will be distributed throughout the month or other designated period. Generally, participants elect to hire a personal care worker to assist them to meet their needs and spend a nominal amount on the purchase of goods and services related to their personal care needs.

States vary with regard to the items that participants may purchase with funds from their individual budget. Some allow participants to purchase only personal assistance services and supports, some allow the purchase of any service the program offers, and others allow the purchase of a wide range of services, goods, equipment, and supplies that promote participants' independence or decrease their reliance on human assistance. The §1915(j) authority specifically permits participants, at the state's option, to use their budgets to pay for items that increase their independence or substitute for human assistance, to the extent that expenditures would otherwise be made for human assistance. This is referred to as "permissible purchases" and states may make their own decisions about which items to include.

States have found it helpful to develop individual budgets using generic terms; doing so promotes flexibility. For example, rather than listing the number of personal assistance hours that are authorized, the plan specifies that the individual will receive up to a certain number of service hours or a specific dollar amount. Combining like services (e.g., respite, companion, and personal care) with a single hour or dollar maximum amount enables participants to substitute these

services for one another to meet changing needs, without having to formally change their spending plan.

Most participants use their budgets to hire an individual or individuals to assist with ADLs and IADLs. The Cash & Counseling Demonstration and Evaluation (CCDE) found considerable variation in the types of goods and services participants purchased, with specific items influenced by individual circumstances and preferences. The most frequently purchased goods and services were transportation, laundry service, homeowner's or renter's insurance, small kitchen appliances, small appliances in general, pharmaceutical supplies, durable medical equipment, and furniture.²⁰

The most frequently purchased “assistive technologies” were not medical devices that only people with disabilities might need or use, but rather household appliances, such as microwave ovens and washing machines. These items were especially useful to people with disabilities insofar as they enabled independent performance of certain tasks (e.g. cooking and doing laundry) that otherwise would have to be performed by an assistant.

CMS offers guidance on what it considers allowable goods and services under a §1915(c) waiver in Version 3.5 of the waiver application:

Individual Directed Goods and Services are 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.²¹

Most states implementing self-direction options using Medicaid funding have adopted the CMS definition but provide more specific information and guidance to counselors and staff about allowable goods and services in their operational manuals. Some states develop and distribute pre-approved lists of items from which participants may choose. If participants select an item not identified on the approved list, states may require prior authorization for the purchase. Many states find it helpful to define goods and services using broad, generic language. For example, rather than list appliances as a covered service, the allowable list might read “devices that promote mobility and independence in the home”. Other states

have adopted a flexible approach that allows counselors to simply approve goods and services that “promote the independence of the individual.”

Some states cover services needed to prepare for and seek employment, as well as job coaching, under the budget. Idaho amended its existing §1915(c) waiver for persons with developmental disabilities to include services that assist individuals in securing and maintaining employment. Under this Idaho waiver, participants may also choose their providers of skilled services (i.e., those performed by licensed professionals, such as RNs and LPNs).

States are free to offer budgets that give participants the option to: (1) set the reimbursement rate of pay for their workers within applicable labor law and Medicaid parameters, (2) accrue savings from unspent budget amounts, and (3) participate in community activities by paying for items such as camp fees or fitness club memberships. Montana’s Big Sky Bonanza HCBS program covers culturally based services such as Native American healing rites.

States may also allow participants to pay higher rates for workers willing to work weekends and evenings. While this reduces the number of hours that can be covered, participants might, for the first time, receive needed services during these times. If programs give participants cash, policies that allow participants to accrue savings must ensure that these savings do not cause participants to lose eligibility for public benefits, including SSI or Medicaid, by exceeding asset limits.

B. Authorizing and Modifying Individual Budgets

States may grant the authority to approve purchases identified in the individual budget to one or more of the following: individual counselor, counseling supervisor, regional office staff, or central office staff. States should carefully consider which process will be the simplest and most efficient and prevent delays in commencing services. In states that require central office approval, participants have experienced delays in the commencement of services due to this centralization.

To prevent unnecessary administrative delays, many states allow that if the cost of the individual budget is equal to or less than the cost of the same services provided through the traditional service system, the counselor who has helped the participant to develop the service plan can authorize it. If the cost of the service plan exceeds the cost of the traditional service plan (or exceeds it by a specified percentage), then a supervisor or a state official must approve the budget.

States need to have a process for modifying individuals’ budgets to meet their changing needs immediately and efficiently. One strategy to ensure that this happens is to allow revisions by telephone followed by paper copy. As noted above, grouping like services or goods into categories and permitting substitutions within the subset allows a certain degree of flexibility that may preclude the need

for a formal budget modification. As noted in the discussion on spending plans, rather than list appliances as a covered item, allowable items can be defined as “devices that promote mobility and independence in the home.”

Monitoring and Managing Individual Budgets

While state agencies or offices typically have the ultimate responsibility for program oversight, most states assign responsibilities for the day-to-day management and monitoring of the individual budget to selected financial management services (FMS) entities in collaboration with counseling activities. Once the service plan has been developed and the individual budget amount determined, this information is forwarded to the FMS entity. States may employ a single FMS entity, provide FMS themselves, or give participants a choice of entities.

Basic FMS responsibilities related to managing and monitoring the individual budget include:

- Tracking the individual budget balance and associated expenditures;
- Tracking over-expenditures or under-expenditures;
- Preparing monthly budget reports for participants, listing expenditures and balances;
- Accepting invoices from providers and processing payments based on the individual budget; and
- Conducting quality assurance and consumer satisfaction surveys.

See Chapter 7 for an in-depth discussion of financial management services.

FMS entities use a variety of tracking methods to manage and monitor individual budgets. Many programs, particularly small ones, track individual budget expenditures through an off-the-shelf accounting software package. Some states, for example South Carolina, use an internal database to track expenditures. More sophisticated consulting vendors have developed their own tracking systems which include electronic versions of the individual budget. Having electronic versions makes it easier to retrieve and revise information and speeds the transfer of information between the FMS entity, counselors, and program staff. Also, see Appendix II for detailed information about the Consumer Direction Module, a computerized system for managing and monitoring individual budgets.

Resources

Publications

Agosta, J. (Spring 2004). Pointers for families and individuals who want to manage their own services. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota.

This article discusses the supports individuals and families need to successfully manage their own services. Person-centered planning, individualized budgets, creative use of supports, and honoring individual wishes are discussed in detail.

Available at: <http://ici.umn.edu/products/impact/171/over4a.html>

Moseley, C.R. (Spring 2004). Individual budgeting, control and support: What systems need to tell people. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota.

This article provides comprehensive information about individual budgeting, including assessing the need for support; determining an allocation amount; setting spending limits; responding to changes in support needs; and responding to appeals and requests for re-determination.

Available at: <http://ici.umn.edu/products/impact/171/over3a.html>

Moseley, C.R., Gettings, R., and Cooper, R. (2003). *Having it your Way: Understanding State Individual Budgeting Strategies*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

This report summarizes the results of a study of methods for developing individual budgets. The study describes nine states' individual budget activities and identifies factors that are instrumental in implementing effective individual budgeting methodologies. It also provides information about approaches for transitioning from traditional program funding to individual budgeting.

An executive summary of the report is available at: <http://nasddds.org/pdf/IBExecutiveSummary.pdf>.

The full report may be purchased from NASDDDS at http://www.nasddds.org/Publications/special_pubs.shtml#understanding

Moseley, C.R. (2002). *Individual Budgeting Study: Progress Report*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

This paper summarizes the results of a study of states' individual budgeting

strategies and includes data from additional states and an analysis of several key findings.

Available from the author at: cmoseley@nasddd.org

O'Brien, J. (2001). *Paying Customers are not Enough—The Dynamics of Individualized Funding*. Lithonia, GA: Responsive Systems Associates

This publication discusses the dynamics of individualized funding for the provision of services to people with developmental disabilities. It focuses on how individualized funding may drive the changes necessary to develop services that offer highly customized assistance.

Available offline from the Research and Training Center on Community Living at: <http://rtc.umn.edu/publications/offline.asp>. A scanned copy is available at: http://eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/1a/04/50.pdf

Reinhard, S., Crisp, S., and Bemis, A. (2005). *State Policy in Practice: Participant-Centered Planning and Individual Budgeting*. New Brunswick, New Jersey: Rutgers Center for State Health Policy.

This publication describes the use of person-centered planning in the development of an individual budget. The report highlights Minnesota's and New Hampshire's experience using individual budgets.

Available at: <http://www.cshp.rutgers.edu/Downloads/6810.pdf>

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>

Walker, P. (Spring 2004). *The Vermont way: Evolution of consumer-controlled budgets in Vermont*. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota

Vermont's Division of Developmental Services has used individualized budgets for over 20 years. This article discusses Vermont's experiences and includes a discussion of challenges and major lessons learned.

Available at: <http://ici.umn.edu/products/impact/171/prof8a.html>

Web-Accessible Resources

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; for example, the Scripps Gerontology Center Participant Goal Setting Tool. This tool was developed to help participants in Cash & Counseling programs set personal goals. Available at: <http://www.cashandcounseling.org/resources/20080303-130304>

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. A number of resources about individual budgeting can be found at: <http://www.hcbs.org/advancedSearch.php> (keyword: individual budgeting)

Citations, Additional Information, and Web Addresses

- 1 Suzanne Crisp is the lead author of this chapter. Janet O’Keeffe is the co-author.
- 2 Different programs (e.g., Medicaid and those funded solely by the states) and even different benefits within programs (e.g., Medicaid State Plan or waiver benefits) vary in how they define the types of needs that participants may use their funds to meet. Some focus narrowly on “medical” needs; others encompass a broader range of disability support needs, including, for example, needs related to employment.
- 3 The consensus has been largely derived from the research and experiences of the National Association of State Directors of Developmental Disabilities Services, the Cash & Counseling Demonstration and Evaluation (CCDE), and the Centers for Medicare & Medicaid Services (CMS).
- 4 Agosta, J. (Spring 2004). Pointers for families and individuals who want to manage their own services. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. See Resources section for a link to this article.
- 5 Moseley, C. (Spring 2004). Individual budgeting, control and support: What systems need to tell people. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. See Resources section for a link to this article.
- 6 Moseley, C., Gettings, R.M., and Cooper, R. (2003). *Having It Your Way, Understanding State Individual Budget Strategies*. National Association of State Directors of Developmental Disabilities Services, Inc. <http://tcds.edb.utexas.edu/TSDPT/IndividBudgets.htm>
- 7 Smull, M., *An Overview of Essential Lifestyle Planning*. (1996). <http://www.allenshea.com/brochure.pdf>
- 8 CMS State Medicaid Director Letters: Optional Self-Direction Personal Assistance Services Program, 09/13/2007. Available at www.hcbs.org/moreInfo.php/doc/2038
 Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling); Proposed Rule January 18, 2008. Available at <http://edocket.access.gpo.gov/2008/pdf/08-115.pdf>
- 9 Application for a §1915(c) Home and Community-Based Waiver, Version 3.5, Instructions, Technical Guide, January, 2008. Page 305. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>

- 10 Reinhard, S., Crisp, S., and Bemis, A. (2005). *Participant-Centered Planning and Individual Budgeting*. New Brunswick, New Jersey: Rutgers Center for State Health Policy. See Resource Section for a link to this article.
- 11 Activities of daily living (ADLs) include eating, bathing, dressing, toileting, transferring, grooming, and maintaining continence; instrumental activities of daily living (IADLs) include medication management, light housework, laundry, meal preparation, transportation, and grocery shopping.
- 12 Moseley, C., Gettings, R.M., and Cooper, R. (2003). Op. cit.
- 13 This Handbook uses the term service plan. States vary in their use of terms for this activity, for example, care planning, support planning, or recovery planning (for individuals with serious mental illness).
- 14 Application for a §1915(c) Home and Community-Based Waiver, Version 3.5, Instructions, Technical Guide, January, 2008. Page 178. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>
- 15 §1915(c) waivers must be cost neutral (i.e., the cost of waiver services can not exceed the cost of institutional services). While there is no federal requirement that self-direction programs be cost-neutral relative to traditional service delivery program, when introducing a new self-direction program, state legislatures and budget offices often want assurances that the new self-direction program will be cost-neutral (i.e., not cost more than the state is currently paying for the traditional service delivery system).
- 16 Campbell, E.M., Fortune, J., Frisch, J.K., Heal, L.W., Heinlein, K.B., Lynch, R.M., Severance, D.D. (2004). Predictors of expenditures in Western states. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*. Baltimore: Paul H. Brookes Publishing.
- 17 MN Department of Human Services, Disability Services Division, MR/RC Waiver, Consumer-Directed Services Budget Formula. Available at http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_029336.pdf
- 18 B Campbell, E.M., Fortune, J., Frisch, J.K., Heal, L.W., Heinlein, K.B., Lynch, R.M., & Severance, D.D. (2004). Op. cit.
- 19 In 2003, the majority of the C&C Replication states selected Section (§) 1915(c) HCBS waivers as the Medicaid authority for developing their self-direction programs. Federal Medicaid rules require HCBS waiver programs to be cost-neutral (i.e., the cost of waiver services can not exceed the cost of institutionalization). States have the option of meeting this requirement using per capita costs or aggregate waiver costs, the latter approach providing more

flexibility. The C&C Demonstration and Evaluation (CCDE) states had to meet the budget neutrality requirement of §1115 research and demonstration waivers, which require that federal expenditures for the demonstration cannot exceed federal expenditures without the demonstration.

An early analysis of service plans compared to services delivered revealed that participants in Arkansas and New Jersey were not receiving their authorized hours under the traditional agency-delivered service model due to limited provider capacity. For example, in Arkansas, in the first year of the demonstration program, more than one-quarter of those authorized to receive agency services failed to receive *any* paid personal assistance services, and those who did, as a group, received only 68 percent of authorized hours. In contrast, virtually all CCDE participants (97 percent) reported receiving paid services. Similarly, in New Jersey, approximately 11 percent of participants served in the traditional systems did not receive any paid services compared to only 4 percent of CCDE participants.

The provision of authorized personal assistance increased under the demonstration program because participants were able to select their own workers. As a result, costs for the demonstration program were higher than under the traditional program that used agency workers. To maintain budget neutrality, states began to quantify the shortfall in the delivery of authorized services and to discount individual budgets to reflect this difference. For example, Arkansas reduced all individual budgets by 10 percent.

- 20 Renter's and homeowner's insurance can provide some financial protection in the event a worker not covered by workers compensation insurance is injured while in the home. However, filing a claim can lead to loss of coverage, which could be a major problem if an individual has a mortgage that requires insurance coverage. See Chapter 7 for a discussion of workers compensation insurance.
- 21 The Centers for Medicare & Medicaid Services, §1915(c) Home and Community-Based Waiver Application Version 3.5. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>

Chapter 6: Counseling

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Chapter 6

Counseling¹

Counseling—providing information and assistance to individuals electing to direct their services—is a key supportive service in self-direction programs. States use a variety of terms to describe the counselor’s role, including support broker, service coordinator, flexible case manager, consultant, advisor, and community guide. This Handbook uses the terms counseling and counselors. Regardless of the name used, the goal of counseling is the same: to offer flexible and personalized support to ensure that self-direction works for the participants who choose it.

To be effective, counselors must be able to work with a wide range of participant skill sets, practice person-centered planning, and assist individuals to make informed choices that are consistent with their needs and will help them achieve their goals.

This chapter discusses the key components of counseling and how programs can ensure quality counseling services. It also discusses the differences between counseling and traditional case management and describes various counseling models states use, including those that have combined the case manager and counselor roles.

A. Key Components of Counseling

Counseling comprises two broad activities—providing information about self-direction and providing assistance and training as needed with self-directed tasks. These activities are accomplished within a person-centered framework.

Counselors can provide individuals with detailed information to enable them to make informed decisions about whether self-direction is right for them, and if it is, about how to obtain and manage their services. Because self-direction is a relatively new service delivery option in most states, many individuals will need information about a wide range of topics, including:

- the person-centered planning process
- participants’ rights in the program
- resources, choices, and options
- risks and responsibilities associated with self-direction and decision making
- program limitations or restrictions
- reporting changes in condition and needs

- recognizing and reporting critical events, abuse, or neglect
- requesting a review of decisions, reporting grievances, and dispute resolution
- the availability of criminal background checks and processes for conducting them (depending on the program design)

Person-Centered Planning

Person-centered planning (PCP), a critical component of self-direction, assists individuals to exercise autonomy, choice, and control over the services they need. Individuals may assume very different levels of responsibility, from taking complete charge of their planning, service arrangements, and budgets to relying on a representative or family member to assist them with most or all tasks. Given the wide ranges in both abilities and individual preferences, states need to design flexible counseling services to accommodate participants' needs and wishes and to provide the level of support, assistance, and training needed.

The C&C grant states formalized *participant goal setting* as a method to help promote person-centered planning, particularly with elderly persons and working-age adults with disabilities. Counselors assist participants to set goals and develop a services and support plan to achieve them through the use of an individual budget and spending plan. (See Web-Accessible Resources at the end of this chapter for more information.)

In addition to providing information, counselors also encourage participants to seek information on their own. As program staff in one state noted, if counselors are doing more work than participants, something is wrong.²

Counselors assist individuals with a wide range of self-directed activities. The extent and type of assistance provided to participants varies depending on their needs and preferences. Specific types of assistance include:

- defining needs, preferences, and goals
- developing the individual budget
- managing the individual budget
- developing a backup plan if a scheduled worker fails to show
- developing a backup plan for emergency situations
- identifying and obtaining services, supports, and resources
- recruiting, hiring, and managing workers

- obtaining training in practical skills related to personnel management or problem solving, including; (1) recruitment strategies; (2) how to interview, select workers, and check references; (3) how to negotiate rates and arrange schedules; (4) how to train workers; and (5) how to manage workers and dismiss/replace them if necessary
- making decisions about the purchase of goods and services
- assessing the quality of services received

Traditional Case Management

Self-direction programs vary in their use of traditional case management. In many programs, both case managers and counselors assist participants, but their roles differ markedly. In others, case managers assume the counseling role in addition to continuing some of their traditional responsibilities. While traditional case managers' responsibilities vary, typical duties include:

- explaining the program, process, and eligibility criteria
- presenting setting (institutional, home, or community-based) and service options (traditional agency or self-direction)
- conducting an assessment to determine eligibility (based on medical, functional, social, and behavioral factors)³ and to develop a service plan and match needs with resources
- implementing the service plan
- monitoring the provision of services
- assessing the quality of services
- ensuring cost/budget neutrality, if required
- revising the service plan when changes occur
- performing periodic assessments and eligibility determinations

The case managers' role to oversee and monitor service delivery is often required to ensure that Medicaid or other public programs meet state and federal health and welfare requirements. Often, the case management system is a key component of states' quality management systems.

In many self-direction programs, traditional case managers carry out some or all of their responsibilities. If they are not involved at all, then their responsibilities must be carried out by someone else in the program.

Self-direction programs shift some of the case manager's responsibilities to participants and offer a different set of supports through counseling to identify and enhance participants' skills. Counseling links participants not only to traditional services but also to non-traditional goods and services. For example, purchasing a microwave oven can allow participants to prepare their own meals rather than allocating their budget to pay someone to perform this task.

In self-direction programs that provide participants with both a traditional case manager and a counselor, it is important that case managers and counselors understand their respective roles and responsibilities and work collaboratively.

Federal Requirements

The Center for Medicare & Medicaid Services (CMS) has specified that information and assistance must be available to assist participants to manage their self-directed waiver services.⁴ Both the §1915(c) and §1915(j) authorities view the roles and responsibilities of the counselor as fundamentally different from those of a case manager.

Prior to approval of a self-direction waiver program, federal reviewers will ask, at a minimum, the following questions:

- Does the waiver program furnish to participants: information about the program's benefits, their responsibilities, and their potential liabilities?
- Who provides the above information and what is the process for providing it?
- Is the above information provided in a timely manner to permit informed decision making?
- If both counselors and traditional case managers are involved in the program, how will they work together, particularly to prevent duplication of services.⁵

While information and support may be furnished by one or more entities, states must ensure that there is no duplication of activities. States must also specify the payment authority (or authorities) under which information and support will be furnished, which will be discussed later in this chapter.

States offering a self-direction option under the new §1915(j) authority will be required to furnish assurance that all individuals are given a support system that provides information, assistance, counseling, and training to ensure that participants are able to manage their services and budgets.⁶

B. Developing a Counseling System

Transferring authority and control over services from professional case managers to participants aided by a counselor requires states to develop a new system, which can be challenging. States have two basic options for providing counseling

services: (1) create a new and separate system or service that provides trained counselors, or (2) modify an existing case management system to include the counseling service. If a state chooses the latter option, case managers will have to undergo counselor-specific training and have a manageable caseload.

Within those two broad options, states have developed a variety of counseling models.

Counseling Service Models

To date, programs have developed several models for providing counseling services. These include:

1. The program develops a new service to fulfill the responsibilities of providing information and assistance. (Model used by Minnesota—see box below). The duties of a traditional case manager may be included in the new counseling service or case management and counselor duties may be provided as distinctly different services to participants.
2. Using a Request for Proposal (RFP) procurement process, the program contracts with a new provider entity to furnish counseling services. (Model used by New Mexico’s Mi Via). The new entity may also provide traditional case management services or the program may keep case management functions totally separate.
3. Existing case managers assume additional counseling responsibilities. (Model planned for Pennsylvania’s Services My Way). A single provider agency or individual furnishes traditional case management. This same entity or person is trained on person-centered planning and the new self-direction option. Typically, the caseload of the individual is reduced to compensate for the additional duties to support self-direction. The case manager/counselor continues to perform traditional duties as well as new counseling duties.

Most states use some variation of these models in their self-direction programs. Whichever model states choose, time and resources will be required to: (1) create job descriptions; (2) recruit, hire, and train or re-train staff; (3) develop operating protocols, including communication linkages; (4) develop standards and oversight mechanisms; and (5) fund new positions and related administrative and operating costs.

Minnesota’s Approach to Providing Information and Assistance

Minnesota’s Consumer Directed Community Supports (CDCS) service option uses both traditional case managers and counselors. The counselors—called flexible case managers (FCMs)—provide education about the CDCS enrollment process and forms, assist with developing an individualized budget and spending plan, and assist participants to employ and manage workers and purchase goods. The cost of the FCM service is paid from participants’ CDCS budget.

Traditional case managers perform “required case management.” Their core functions include: (1) assessing functional eligibility for the program at least annually or when there is a significant change in participants’ condition; (2) approving CDCS community support plans (i.e., the service plan) according to established state policy; (3) monitoring participant’s spending; (4) providing information and assistance to participants about CDCS; (5) linking participants to a fiscal support entity and flexible case management services; and (6) ensuring health and welfare.

Minnesota does not require participants to use a flexible case manager to prepare their community support plans (i.e., the service plan). They can receive assistance with writing their plan from family or friends and the lead agency case manager who is their required case manager.

Considerations When Selecting a Model

Adding counseling responsibilities to existing case management programs has been one successful approach, particularly in the developmental disabilities service system because the case management system typically is familiar with the principles and practice of person-centered planning and the philosophy of self-determination.⁸ However, in the aging service system, case managers may find the philosophy of person-centered planning and/or self-direction new and may be hesitant to assume the counseling role. Because self-direction shifts control and responsibility to participants, counselors cannot operate with the traditional case management mind-set of being responsible for participant decision making or outcomes.⁹

It may be difficult for many traditional case managers to feel comfortable with participants, particularly older participants, taking an active role in managing their own services. Some case managers may doubt that older persons have the interest or capability to do so. When Minnesota first implemented its program, some case managers actively discouraged participants from considering self-direction, and others failed to present it as an option based on their own perceptions of participants’ interest and abilities.

The Cash & Counseling Demonstration and Evaluation (CCDE) states have found that delegating counseling tasks to traditional provider agencies was sometimes problematic, particularly if staff lacked sufficient training in program requirements, person-centered planning, and self-direction.¹⁰ Additionally, if caseloads are not adjusted for the increased time needed to learn about and implement a new self-direction option, work overload can interfere with case managers' effectiveness in presenting information about the new option and in assisting those interested in enrolling.

Case managers must have adequate training to fully understand self-direction and to become committed to its philosophy. Otherwise, they may find it very difficult to function as both a traditional case manager and a counselor. However, when traditional provider agencies are fully engaged, success can be achieved. Pennsylvania's Services My Way program plans to use case managers from local Area Agencies on Aging (AAAs) to provide counseling services once they complete training on person-centered planning, the new option, and additional program requirements.

In Kentucky, case managers from local Area Agencies on Aging are also providing counseling. Although these case managers had not previously been associated with the Medicaid waiver programs, they had prior experience working with self-directing individuals in a state-funded program, so were already comfortable with self-direction. See box for a description of Florida's experience.

Florida's Experience Using Traditional Case Managers

In Florida, counseling activities were added to existing case management responsibilities and individuals who enrolled in the C&C Demonstration were assigned to traditional case management agencies. However, many of these agencies and their staff did not initially support the program and as a result, many case managers failed to provide timely assistance to participants.

Florida devoted considerable effort to gain the support of traditional case management agencies. Among other activities, the State published a newsletter to keep these agencies informed about the program's progress, and included "success stories" of participants who had benefited from the program. Support for the program grew gradually among case management agencies and staff, as their skepticism about consumers' ability to direct their own services proved unfounded.¹¹

The Arkansas Independent Choices Program enrolled individuals by using counselors who specialize in the program. Research on the program found that full-time counselors appear to be more efficient, more committed to the

philosophy of self-direction, and more knowledgeable about program rules than part-time counselors.¹²

Counseling and Financial Management Services

When counselors and financial management services (FMS) staff are employed by different organizations, questions are sometimes addressed to the “wrong” organization, and there may be a tendency to “pass the buck” between organizations. Combining counseling and FMS in the same entity can enhance efficiency by facilitating the exchange of critical information, establishing clear accountability, and ensuring that newly enrolled participants receive services in a timely fashion.¹³

Before combining counseling and FMS into a single entity, however, states should consider both the efficacy and practicality of this approach. Combining the two functions may be impractical if a state does not have an entity with the expertise needed to provide all of the services itself or to supervise a fiscal subcontractor. This was the case in Florida, where many case management agencies were reluctant to participate in the CCDE, and few, if any, had the necessary expertise to provide or subcontract for fiscal services.

Combining counseling and FMS may be impractical for other reasons as well. In Florida, over 100 entities provided case management or support coordination; if each also provided FMS, the number of participants served would be too small to support the FMS infrastructure. Arkansas initially combined counseling and FMS in a single organization but has since separated them, largely due to other programmatic changes on the state level.

In contrast, some states—New Jersey and West Virginia—have found it practical to have a single entity provide both counseling and FMS. New Jersey initially began with many counseling agencies and a single FMS entity. After a few years, recognizing the inefficiency of having numerous agencies providing consulting services, the State reduced the number of counseling agencies and later combined counseling and FMS in a single entity that serves the entire state.

Determining the Payment Source for Counseling

Medicaid funds the provision of information and assistance—that is, counseling in self-direction programs—either as a service or as an administrative expense. As discussed above, states may add counseling to an existing service (case management) or create a new service by specifying a new service definition and qualifications for those providing the service. Programs designed in this manner are eligible for federal financial participation (FFP) at the enhanced service rate and must provide participants with free choice of providers.

If states fund counseling as an administrative expense they receive the standard match rate of 50 percent. An advantage of this approach from the state's perspective is that the program can limit the number of providers and may issue RFPs to select one or more vendors to provide counseling services. New Mexico's self-direction program—Mi Via—elected this model and issued an RFP to select a vendor to supply counseling services. While the state has only one vendor, participants may select their own counselor, who is hired by the vendor as a part-time employee. Participant-recruited counselors in New Mexico must complete a prescribed training course and be certified before beginning work with the participant.

If states pay for counseling as a waiver service, they must decide whether or not to deduct the cost of the service from the individual budget. If the cost of counseling is deducted from the individual budget, it is likely that participants will choose to increase workers' wages or purchase additional hours or goods and services rather than purchase additional counseling over and above the initial amount required. This has been demonstrated in Minnesota, where the cost of counseling is paid out of participants' budgets. Consequently, many participants have elected not to purchase this service and have looked to their traditional case manager to furnish the assistance that counselors provide, which has not always been effective because case managers are not trained to provide all counseling services.

Rhode Island requires participants to pay a prescribed fee from their budget for counseling (called advisement services). The State's rationale was that participants who have to pay for counseling services from their budgets will be more likely to fully utilize counselors' services.

Allowing Sufficient Time for Counseling

The CCDE states found that counselors introducing the program to participants and family members took a considerable amount of time. Initial conversations involve discussions about person-centered planning, employer responsibilities, and program features and requirements. Helping participants develop the individual budget was the most time-consuming task. More than one visit was often required to describe, enroll, and prepare an individual to self-direct. However, advance preparation by sending informative materials to the home can minimize the number of home visits needed to develop, implement, and revise the service plan.

Self-direction may be a new concept for many individuals and their families. Counselors should be prepared to provide information and training at a pace that matches participants' ability to understand and retain the information. If participants feel overwhelmed with information, they may become discouraged and elect traditional services even though they want to direct their services. Counselors need sufficient time to work with participants to ensure that they

understand how the program works. Caseload sizes should be adjusted, if necessary, to ensure that counselors have the time they need to fully explain the program, answer participants' and family members' questions, and complete enrollment forms.

Timing of Counseling

Educating and training participants is most effective when done shortly before or after they enroll. Encouraging family members or an informal support person to be present during education and training sessions also appears to improve their effectiveness. Education and training can be facilitated by various tools, including orientation videos and interactive websites.

One example is the Personal Choice Quick Start manual developed for Rhode Island's program. This manual briefly describes the roles and responsibilities of participants, provides tips on communicating with workers and counselors, and discusses successful strategies to manage a budget.¹⁴

Setting Rates for Counseling Activities

Just as counseling activities vary among states, so do rates and rate setting methodologies. A few states pay counselors a flat rate to assist with spending plan development. Limiting payment in this way can prevent excessive costs for counseling services if the completion of a spending plan is prolonged. New Jersey pays a flat rate for the initial development of the spending plan (with an hourly rate and a cap on the number of hours thereafter). Arkansas effectively lowered its counseling costs by changing its payment methodology from a set monthly fee (per member per month) beginning at enrollment to a flat rate for the development of the spending plan and a monthly capped rate for counseling services thereafter.

However, states may need to consider an exceptions policy for individuals with very large budgets. New Mexico, for example, found that participants in the Developmental Disability and Medically Fragile waivers with annual budgets of \$100,000 or higher needed more time than originally allocated to develop individual budgets.¹⁵ Additionally, states should have criteria to determine if a participant's counseling needs are excessive and a representative should be appointed.

Authorizing Counselors to Approve Most Budgets

Establishing policies, processes, and procedures to ensure efficient counseling services can reduce unnecessary paperwork and streamline approvals. States have found two approaches, in particular, to be both effective and efficient: (1) authorizing counselors to approve service plans and individual budgets; and (2) developing a pre-approved list of allowable goods and services and requiring the counselor to seek approval only for items not on the list.

Use of a pre-approved list is an efficient procedure for reviewing spending plans. It can be coupled with audits to ensure that counselors are abiding by the requirement to seek further approval for plans that include goods or services not on the list. The pre-approved list can be modified over time, as permissible uses of the allowance change or if it becomes clear that counselors are not able to make appropriate judgments about some items.

New Jersey and Florida initially had all spending plans reviewed by a state or district level office. When they found that this costly procedure sometimes delayed plan approval due to the time it took to review each document, they changed this requirement. Arkansas, on the other hand, did not require program approval for plans containing only goods and services on a pre-approved list and did not experience a problem with delays in plan approval.

Controlling Costs

States should ensure that individual budgets will not be higher than the costs of serving participants in the traditional system. While self-directing participants should receive the services they need, it is financially, and often politically, problematic for them to receive more state resources for their care than do individuals with comparable needs in the traditional program. Moreover, the program's ability to control costs may be compromised if resources are increased in participants' service plans without regard to costs in traditional programs serving participants with similar needs.

In Florida, counselors, perhaps acting more as advocates and less constrained by the supply of workers than traditional agencies, authorized more hours of care for some participants than would have been authorized in traditional care plans, resulting in higher costs. To prevent a similar problem, New Jersey assigned responsibility for assessment and service planning to Medicaid nurses who were not otherwise involved in the CCDE.

Florida found it impractical to re-assign responsibility for assessment to an external party, but eventually found ways to limit the likelihood that counselors would increase services in care plans beyond what they would have been under the traditional program.

Florida developed standardized care plan protocols for all its waiver programs and compared care plans for participants in the CCDE with those for participants in the traditional program with similar levels of impairment. The State also reviewed plans with high costs relative to participants' level of impairment. In addition, when training counselors, Florida emphasized that participants are responsible only for decisions on how to *spend* resources, not for determining the *amount* of resources available.

States can use these and other procedures to help keep self-direction program expenditures equal to those in traditional programs. Regardless of which system a participant is in—traditional, self-direction, or managed care—the cost of services should be the same. What differs under self-direction is the method(s) through which assessed needs are met.

Providing a Choice of Counselors

Deciding whether to offer participants a choice of counselors is another program design question states must consider. States can allow participants to choose someone from a pool of state-designated counselors, or allow them to hire someone of their own choosing who will then need to complete required training. If States choose the first option only, they must ensure that a sufficient number of counselors are available to permit choice. Whichever option is chosen, states need to guarantee that a sufficient number of counselors are available to meet demand. Doing so helps to ensure a good fit between participants and their counselors.

The availability of a sufficient number of counselors with diverse backgrounds can enable participants to select a counselor with a similar cultural background, one who speaks their language, or one who has experience working with their specific disability (e.g., traumatic brain injury or spinal cord injury). States may address the need for varied backgrounds and skill sets by training a cadre of individuals interested in serving as counselors; participants may then select one who offers a good fit with their needs and interests.

New Jersey initially offered participants the option to locate and hire their own counselor, but discontinued the practice after finding that few participants exercised the option and—for those who did—the process delayed enrollment. The State now offers counseling services through a single entity that provides both counseling and financial management services. Participants may choose among all available counselors and if their initial selection is not a good fit, they may request a replacement.

In Iowa, participants may choose a counselor—called an independent support broker (ISB)—from individuals working for specific agencies, or they may recruit and hire an ISB, who may be a family member. Once selected, the state provides training and certification, but this process can slow the time it takes to receive services.

Setting Caseloads

Counselors need to have a sufficient caseload to be financially viable, to successfully carry out their responsibilities, and to be well versed in the program. One way to achieve this is to limit the number of organizations from which the state draws counselors.

Both New Jersey and Florida initially used a large number of entities for counseling services. As a result, many individual counselors had small caseloads and their many other responsibilities often took priority over their counseling responsibilities. In contrast, Arkansas hired state staff to perform counseling duties and these individuals worked full-time solely with self-directing participants.

After several months' experience with the new program, both New Jersey and Florida decreased the number of counselors. Florida did so by assigning the entire program caseload at a given agency to one or two counselors. New Jersey began to assign newly enrolled participants to the best performing counseling agencies and gradually transferred other participants to these agencies. After several years, New Jersey opted to have a single agency provide counseling services with many fewer counselors.

C. Ensuring the Quality of Counseling Services

Quality management strategies to ensure effective counseling services are discussed below.

Setting Qualifications

Qualifications for counselors will depend on the range of duties they perform. If traditional case managers assume additional counseling functions, states may require additional education and training to understand self-direction, the person-centered planning process, and the range of counseling tasks. The requirements for counselors would be added to existing requirements for case managers (e.g., licensed social workers and nurses, as well as specific educational and experience levels).

The qualifications for counselors, who do not have case management duties, typically focus on the knowledge and skills needed to provide information and assistance with self-direction tasks. Because these activities are more supportive and facilitative and less prescriptive than traditional case management, the skill set might require less attention to education or experience and more to communication skills and knowledge of community resources. Requisite skills for counselors include the ability to:

- communicate with participants, their families, and other support system staff
- understand, accept, and apply the person-centered process and self-direction principles
- understand how an individual's disability might affect communication or behavior
- learn about community resources and how to obtain them

- perform basic math skills to develop an individual budget
- understand and follow program policies

Skills to navigate the human services system may not depend as much on training or certification as on a person's background, history with and knowledge of the community, or relationships with particular individuals, organizations, or groups.

States should identify the responsibilities that require particular expertise or specialized training, those that logically fit together into a reasonable set of tasks and duties, and those that can be performed by individuals with little direct experience. Whatever the duties and related qualifications, developing functional job descriptions that cover all of the counselor's responsibilities is essential.

Once qualifications are articulated, a procedure to verify individuals' qualifications must be developed. Typically, state program staff verify counselors' qualifications; other states assign this responsibility to the FMS entity. Some states require certification for counselors based on mandatory training sessions and the successful completion of skills testing.

Training

Counselors play a critical role in helping participants develop the skills they need to direct and manage their services. To perform this role effectively, they must have adequate training. A counselor training curriculum should include at a minimum: the principles of person-centered planning and self-direction; program policies and procedures; understanding and communicating with particular disability groups, (e.g., working with individuals who have cognitive or speech impairments); and training in specific tasks, such as assessing risks and developing service plans.

Participants may be very interested in self-direction but have concerns about specific responsibilities. For example, if they lack relatives or friends to hire, they may feel that recruiting workers will be too difficult. Counselors can play a critical role in such situations, helping participants develop the skills they need, such as teaching them to find non-traditional workers through creative recruitment strategies.

Developing specific training for counselors on recruiting, hiring, and management techniques is extremely helpful. Having access to worker registries or informal lists of potential workers is also beneficial and can be of great value when workers fail to arrive at their scheduled time. Specific training on how to help participants dismiss workers—particularly family and friends—can also be very helpful as this is an area with which participants have difficulty.

The need for ongoing training to enhance skills and to deal with counselor turnover is critical for an effective counseling system. Several states offer

Internet-based training, which can reduce the cost of the ongoing training needed to deal with staff turnover. For example, Kansas offers training through a six-month, web-based training course that includes person-centered planning, risk management, care plan development, and service coordination.

Computer-based training, DVDs, and videotapes can be very cost-effective methods for providing training for new hires and for continuing education. Manuals also serve as an effective training format and are critical as ongoing reference documents.

Either a website or toll-free telephone number should be available to promptly answer counselors' questions. Pennsylvania uses a web-based system for support coordinators to e-mail questions to a central location and state staff post the answers on the site so that others can benefit from the information. (Support coordinators are AAA care managers who take on the counseling role to provide information and assistance to self-directing participants.)

States should evaluate the adequacy and quality of counselor training, including the content of policy manuals and the effectiveness of specific training programs or presentations. States also need to have a process to identify issues or problems that may indicate that the minimum qualifications they have set are not adequate to provide the assistance needed for self-direction to succeed. This process can consist of a mechanism to obtain feedback about counseling services from participants, workers, state staff, and FMS providers. Participant feedback is probably the single most important source of feedback.

Monitoring and Oversight of Program Design Elements

The creation of policies and procedures to ensure the quality of counseling services is essential. The type and level of oversight applied to the counseling system will depend on the specific program model used. If traditional case managers are providing counseling services, existing oversight procedures must be modified to include the counseling components. If counseling is an additional service, then new oversight procedures will be required. Counselor oversight must be part of the overall strategy to assess the quality of the entire program. See Box below for a description of Minnesota's approach to ensure the quality of counseling services.

Minnesota’s Approach to Ensuring the Quality of Counseling Services

Minnesota requires its counselors—called flexible case managers (FCMs)—to pass a certification test. FCMs must be at least 18 years of age, cannot be the parent of a minor child who is the participant or the spouse of the participant, cannot be the paid worker for any participant to whom they are delivering FCM services, and cannot have any direct or indirect financial interest in the delivery of the services in the plan.

Recent measures to strengthen quality assurance for FCMs include:

New FCM Service Standards in 2008. The State developed additional FCM standards to ensure service quality. The standards address: (1) the functions and limitations of FCM services, (2) ethics and values, (3) service and support planning and implementation, (4) support of self-advocacy, (5) fostering self-determination, (6) the right to privacy, and (7) diversity and inclusion.

Due to widespread confusion about the difference between “required” and “flexible” case management services, the State is planning to substitute the term Counselor and/or Support Planner for FCM. The State uses these new terms in self-direction programs funded under Title III E of the Older Americans Act, but their use in waiver programs requires CMS approval.

Recertification. FCMs must be recertified every two years, effective 2008.¹⁶

New FCM Training Curriculum. The new curriculum is based on the new service standards in order to ensure competence and improve service quality. The three-day FCM skills-building course covers: (1) the FCM service standards, (2) expectations and practice of FCM, (3) person-centered planning skills, and (4) partnering with financial management services entities. The course includes exercises to understand the State’s three payroll models and exercises for effective service planning and budgeting.

New FCM Networks. A few counties and FCMs themselves have initiated several networking groups around the State. One group is coordinated by a county staff person and state staff occasionally attend the meetings. These groups discuss operational and practice issues and work to improve the quality of FCM services statewide. The State obtains input from these groups on a wide range of FCM service issues. Various FCMs communicate routinely with state staff through the CDCS policy mailbox, various workgroups, trainings, or other correspondence.

Readiness Reviews

Prior to implementation, it is advisable to conduct a review of the counseling process. New Mexico—prior to implementation of its Mi Via program—asked the C&C National Program Office to perform a review of the agency selected to provide counseling. The review included interviews with counseling staff, the FMS entity, and state personnel, as well as a document review to ensure that:

- the entities are operating as specified by the program’s policies and procedures
- counselors are able and prepared to perform stated duties
- operating protocols and communication procedures are understood by the counseling agency, the financial management services entity, the participants, and the state office
- quality management measures are in place
- administrative procedures are in place
- participant services are operational
- sufficient numbers of counselors are available to meet anticipated demand

Ideally, the review will be conducted by individuals or entities independent of the program’s operational structure, which will help to ensure objectivity.

Resources

Publications

Foster, L., Phillips, B., & Schore, J. (2005). *Consumer and Consultant Experiences in the New Jersey Personal Preference Program.* Washington, DC: U.S. Department of Health and Human Services.

This publication describes the implementation of New Jersey’s self-direction program, implemented as part of the CCDE. The study obtained information from in-person discussions with program staff, a mail survey of program consultants, telephone interviews with participants, and program records.

Available at: <http://www.cashandcounseling.org/resources/20060607-151609>

Foster, L., Phillips, B., & Schore, J. (2005). *Consumer and Consultant Experiences in the Florida Consumer-Directed Care Program.* University of Maryland Center on Aging, College Park, MD.

This publication describes the implementation of Florida’s self-direction program implemented as part of the CCDE. The study obtained information from in-person discussions with program staff, a mail survey of program consultants, telephone interviews with participants, and program records. The report discusses lessons learned, including those related to “support coordination services.”

Available at: <http://www.cashandcounseling.org/resources/20061107-162153>

McInnis-Dittrich, K., Simone, K., & Mahoney, K. (2006). *Consultant Training Program.* Boston, MA: Boston College.

This manual addresses two identified training needs for consultants working with participants who direct their services and supports: facilitating the paradigm shift for consultants and understanding the dynamics of choice and decision-making for participants. The manual discusses the philosophical framework necessary for successful implementation of participant-directed services and is designed to be delivered in two half-day sessions.

Available at: <http://www.cashandcounseling.org/resources/20060602-113610>

Phillips, B. & Schneider, B. (2005). *Moving to Independent Choices: The Implementation of the Cash and Counseling Demonstration in Arkansas.* College Park, MD: University of Maryland Center on Aging

This report describes the design and implementation of Independent Choices, Arkansas’ model of Cash & Counseling. Lessons learned in Arkansas are discussed, and cover topics including outreach and enrollment, program features, counseling and fiscal services and program structure.

Available at: <http://www.cashandcounseling.org/resources/20051202-173537>

Web-Accessible Resources

Cash & Counseling National Program Office

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

This website contains extensive information about counseling services. Specific resources with links are listed below.

Information concerning participant goal setting and the development and articulation of individual goals is available at: <http://www.cashandcounseling.org/resources/20080303-130304>.

Examples of job descriptions for counselors from New Mexico, Vermont, Washington, and West Virginia are available at: <http://www.cashandcounseling.org/search?TextIndex=job+descriptions>.

Information about Michigan's person-centered planning (PCP) practices, as well as guidance and technical assistance to develop PCP policies and procedures is available at: <http://www.cashandcounseling.org/resources/20080616-162651>.

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 about counseling can be found at <http://www.hcbs.org/advancedSearch.php>. (Keyword: counseling) Users can also add additional topics, keywords, or type/tools to further narrow results.

Citations, Additional Information, and Web Addresses

- 1 Suzanne Crisp is the lead author of this chapter. Janet O’Keeffe is the co-author.
- 2 Suzanne Crisp and Mary Sowers (CMS), (Spring, 2007). Personal communication.
- 3 In waiver programs, this information is used to make the level-of-care determination.
- 4 Application for a §1915(c) Home and Community-Based Waiver, Version 3.5, Instructions, Technical Guide, January, 2008. Page 193. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>
- 5 Ibid. Page 40–41.
- 6 1915(j) *Self-Directed Personal Assistance Services State Plan Amendment Pre-Print*. Page 7. Available at: <http://www.hcbs.org/moreInfo.php/nb/doc/2038/>
- 7 The authors know of one state that has allowed case managers to provide both services to the same participant, but only until the state has sufficient counselors to handle counseling tasks for all participants.
- 8 Self-determination is a grass roots movement for individuals with disabilities, which promotes independence in the community, authority over public resources, supports that are life-enhancing and meaningful, responsibility to ensure resources are expended wisely, and confirmation of participants’ role as self-advocates. The use of the term is much broader than self-direction and refers to an approach to manage all aspects of their lives, not just their services. Additional information is available at www.self-determination.com
- 9 McInnis-Dittrich, K., Simone, K., Mahoney, K. (2006). *Consultant Training Program*. Baltimore, MD: Centers for Medicare & Medicaid Services, Disabled & Elderly Health Programs Group. Available at: <http://www.cashandcounseling.org/resources/20060602-113610>
- 10 McInnis-Dittrich, K., et al. Op.Cit.
- 11 Phillips, B., Mahoney, K., & Foster, L. (2006). *Implementation Lessons on Basic Features of Cash & Counseling Programs*. Boston, MA: Cash & Counseling National Program Office. Available at: <http://www.cashandcounseling.org/resources/20070404-152907>
- 12 Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S. Ditto, W. et al. (June 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/cclession.htm>

- 13 The Consumer Direction Module (CDM)—a web-based software application specifically designed to support self-direction programs—can also help to ensure timely communication. See Appendix II for detailed information about the CDM.
- 14 Available at: <http://www.cashandcounseling.org/resources/20060519-093748>
- 15 O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). *Real Choice Systems Change Grant Program - FY 2002 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2172>
- 16 The waiver renewal and amendments necessary to require recertification of flexible case managers have been submitted to CMS for approval.

Chapter 7: Fiscal/Employer Agent Services

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Chapter 7

Fiscal/Employer Agent Services¹

Self-direction programs offer participants choice of and control over their long-term services and supports. However, with choice and control come responsibilities, including those associated with being an employer, such as management of payroll and employment-related taxes. (In this chapter and throughout the Handbook, the term “participant” categorically includes their representatives.)

Various models of Financial Management Services (FMS) can reduce the employer-related burden for participants and program staff, but they often are the most complex component of self-direction programs to implement. Thus, in order to successfully implement self-direction programs using FMS, it is essential that states have designated program staff with the necessary knowledge who will make the commitment to stay up-to-date with Medicaid rules and regulations related to these programs; applicable FMS models; and federal/state/local tax, labor, and workers’ compensation insurance requirements as they relate to household employers and domestic service workers.

This chapter describes the key features of five FMS models but focuses on the issues and challenges related to two in particular: the Government and Vendor Fiscal/Employer Agent (F/EA) models. These two FMS models are highlighted because they provide participants with a high degree of choice and control over their services—allowing them to be the common law employer of their workers while providing needed payroll and other fiscal supports.

A. Overview of Financial Management Services

What Are Financial Management Services?

The Centers for Medicare and Medicaid Services (CMS) defines Financial Management Services as: *A service/function that assists the family or participant to: (a) manage and direct the distribution of funds contained in the participant-directed budget; (b) facilitate the employment of staff by the family or participant by performing as the participant’s agent such employer responsibilities as processing payroll, withholding and filing federal, state, and local taxes, and making tax payments to appropriate tax authorities; and (c) performing fiscal accounting and making expenditure reports to the participant and/or family and state authorities.*²

The provision of FMS is essential when implementing self-direction programs for several reasons.

- The Medicaid §1915(c) waiver authority does not permit payments for

services to be made directly to participants, either to reimburse them for expenses incurred or to enable them to directly pay a service provider. Rather, payments on the participant's behalf must be made by an intermediary organization (i.e., either a qualified Medicaid provider or an entity under administrative contract with the state). This restriction also applies to the provision of Medicaid State Plan services.³

- Medicaid funds are permitted to be disbursed directly to participants under §1115 self-direction programs and the decision whether to require participants to use FMS is determined by the state based on its program design.⁴ In addition, under §1915(j) of the Social Security Act, CMS does not require states to mandate the use of FMS for participants who elect the “cash” option. Instead, these participants may choose to retain responsibility for some or all of their fiscal and employer-related responsibilities. Even if participants choose to receive some benefits in cash and distribute workers' payroll checks directly, they may choose to have an FMS organization manage the federal and state tax filings and deposits and generate payroll checks for their workers.
- Some FMS organizations may act as a neutral bank for receiving and disbursing public funds (i.e., Fiscal/Employer Agents).⁵ These entities do not provide direct care services, but rather, make payments to service providers and vendors per the direction of participant. This allows the participant to change service providers and vendors as they see fit, based on their level of satisfaction, helping to ensure the quality of their home and community-based services (HCBS).
- FMS provide fiscal accountability for state and local government agencies and safeguards for individuals enrolled in self-direction programs and their workers by ensuring that payroll,⁶ workers' compensation insurance policy management, and vendor payment tasks are performed accurately and in accordance with federal, state, and local rules and regulations, and in a timely manner.
- Some FMS organizations (i.e., Fiscal/Employer Agents) can perform as a “mini management information system” for programs and participants providing a variety of financial reports related to the receipt of public funds, service use, and payments. These reports inform participants about their service use and related expenditures and also act as a fiscal and/or fraud monitoring tool for them and the program's staff.
- When an FMS organization provides services under a co-employment arrangement⁷ with participants (e.g., an Agency with Choice or Public Authority/Workforce Council model), it can provide services directly for workers, (i.e., recruitment, training and supervision of workers, and provision of emergency backup staff), ideally, only at the request of participants who are acting as their worker's managing employer.⁸

Currently, states use one or more of five FMS models to implement Medicaid and state-funded self-direction programs: (1) Fiscal Conduit, (2) Government F/EA, (3) Vendor F/EA, (4) Agency with Choice, and the (5) Public Authority/Workforce Council model. These models are described briefly in Table 1 below.

Table 1. Financial Management Services Models and Key Characteristics

FMS Model	Operating Entity⁹	Worker's Employer	Responsibilities
Fiscal Conduit	State or County (government agency) or Vendor	Participants, unless agency services are used	Disburses public funds via cash or voucher payments to participants and performs other related duties as defined by the program. Some may also provide training and testing for participants on payroll and funds management before allowing them to manage all employer tasks including payroll.
Government Fiscal/Employer Agent	State or County government agency (In accordance with §3504 of the IRS Code and IRS Rev. Proc. 80-4, 1980-1 C.B. 581 and as modified by IRS Proposed Notice 2003-70)	Participants, unless agency services are used	<p>Under IRS rules, a state or local government entity acts as an “employer agent” for participants—performing all that is required of an employer for wages paid on the employer’s behalf and all that is required of the payer for requirements of backup withholding, as applicable.¹⁰</p> <p>It receives, disburses, and tracks public funds based on participants’ approved service plans and budgets; assists participants with completing participant enrollment and worker employment forms; conducts criminal background checks of prospective workers; and verifies workers’ information (i.e., social security numbers, citizenship or legal alien verification documentation).</p> <p>It also prepares and distributes payroll including the withholding, filing, and depositing of federal and state income tax withholding and employment taxes and locality taxes;¹¹ processes and pays vendor invoices for approved goods and services, as applicable; generates reports for state program agencies, counselors (also called support brokers, support coordinators, and other names), and participants; and may arrange and process payment for workers’ compensation and health insurance, when appropriate.</p> <p>The Government F/EA may choose to delegate employer agent tasks to a reporting or subagent per <i>IRS Proposed Notice 2003-70</i>.</p>

(continued)

Table 1. Financial Management Services Models and Key Characteristics

FMS Model	Operating Entity⁹	Worker's Employer	Responsibilities
Vendor Fiscal/ Employer Agent	Vendor (§3504 of the IRS Code and IRS Rev. Proc. 70–6, 1970–1 C.B. 420 and as modified by IRS Proposed Notice 2003–70)	Participants, unless agency services are used	Performs similar tasks to Government F/EA described above except as a vendor in accordance with IRS Rev. Proc. 70–6, 1970–1 C.B. 420 as modified by IRS Proposed Notice 2003–70. The Vendor F/EA may delegate agent tasks to a reporting agent per IRS Forms 2678 instructions.
Agency with Choice	Agency (e.g., Center for Independent Living [CIL], Home Health, Area Agency on Aging [AAA] or Social Service)	Co-employer (also referred to as joint-employer) arrangement with participants and an agency or its subcontracting agency (e.g., CIL, Home Health, AAA, or Social Service)	<p>The agency and participants are co-employers of the workers whom participants recruit and refer to the agency for hire and assignment back to them.¹² The agency is the primary employer of the worker, for the purpose of human resources and payroll management and Medicaid provider requirements. Participants are the secondary employer of their workers and perform or actively participate in the recruitment, training, supervision, and discharge of their workers.</p> <p>The agency also may provide a variety of supportive services to assist participants in recruiting workers and being a managing employer (if requested by participants), i.e., establish and maintain a worker registry, provide referrals and emergency backup staff, or provide training and supervision directly to participants' workers.</p>
Public Authority/ Workforce Council¹³	Independent or quasi–governmental entity	Multiple-employer arrangement with participants and independent or quasi–governmental entity, state or local community-based service program, or human service department	<p>Participants serve as the employer of their workers for recruitment, training, supervision, and discharge purposes. State or county program agencies may serve as the employer of participants' workers for the purpose of managing payroll including withholding, filing and depositing federal and state income tax withholding and employment taxes and locality taxes.</p> <p>The Public Authority (PA) or Workforce Council (WC) serves as the employer of participants' workers for collective bargaining purposes with the union that represents the workers and, in some cases, performs the payroll task. The PA/WC also may maintain a worker registry, and offer voluntary training for workers and participants and emergency backup services to participants.¹⁴</p>

In general, the Vendor F/EA and Agency with Choice FMS models appear to be more popular than other models with states implementing self-direction programs.¹⁵ While many participants only want to hire and manage their workers and therefore prefer the agency with choice model, the Vendor F/EA model (as does the Government F/EA model) affords participants a greater degree of choice and control over their services and workers than other FMS models because it allows participants to be the common law employer of their workers. This level of choice and control is the hallmark of self-direction.

Although a smaller percentage of self-direction programs use the Government F/EA model, the number has increased since October 2003 when the Internal Revenue Service (IRS) first allowed state and local Government F/EAs to contract with and delegate employer agent tasks to a subagent or reporting agent.¹⁶ In addition, the number of states using some form of the Public Authority model (currently referred to in some state legislation as Workforce Councils) has grown from one to five over the past five years: California, Massachusetts, Michigan, Oregon, Washington.

Historically, states that use the Fiscal Conduit model have implemented it in conjunction with state-funded or Medicaid §1115 self-direction demonstration programs to provide participants with the option of receiving and managing all or part of their public benefit funds directly in cash or voucher payments. However, with the passage of §6087 of the Deficit Reduction Act of 2005, codified as §1915(j) of the Social Security Act, which permits states to pay cash to Medicaid participants who direct their services, more states may choose to use the Fiscal Conduit model in the future, possibly in conjunction with the Government or Vendor F/EA model.¹⁷

Employment Status of Workers in Self-Direction Programs

Prior to the early 1990s, most publicly funded self-direction programs considered workers hired directly by participants as “self-employed independent contractors,” and—incorrectly—made no provision for the filing and depositing of federal, state, and local income tax withholding and employment taxes. Although this strategy reduced program costs and the employer burden for state program administrators and participants, it presented states and participants with significant potential liability for unpaid taxes because workers often did not pay their self-employment taxes. Over the past 25 years, the IRS and a number of state unemployment insurance agencies have taken enforcement action against states who classified these workers as independent contractors.

The 2001 IRS Tax Payer Advocate Report stated that directly hired home-based service workers are “employees” and typically they do not meet the IRS’ independent contractor criteria. In addition, under IRS common law rules, workers who provide services to individuals (i.e., participants) are their

employees if the individuals control what will be done and how it will be done, even when freedom of action is afforded to workers.¹⁸ Control refers not only to the results to be accomplished by the work but also the means and details by which that result is accomplished.¹⁹ In order to classify workers correctly as employees; address potential federal, state, and local tax liability for states and individuals; and respond to recent IRS guidance, states have implemented various FMS models, in particular, the two Fiscal/Employer Agent models.

B. Fiscal/Employer Agents: Key Characteristics

Two models of Fiscal/Employer Agents (F/EAs) operate under §3504 of the IRS code: Government and Vendor.²⁰ F/EAs are most effective for implementing self-direction programs, particularly those that allow participants to have individual budgets, for several reasons. First, using an F/EA provides participants a high degree of control over their workers as their common law employers, while reducing their employer-related burden by managing the payroll and bill payment tasks. Second, using an F/EA provides safeguards for participants by ensuring that all required taxes are paid and all Department of Labor and workers' compensation insurance requirements are met. Third, using an F/EA can provide fiscal accountability for states.

The following sections will further describe the key characteristics of these two FMS models, highlighting the tasks performed under each model, and the advantages and challenges of using the models from a state's and an F/EA provider's perspective.

Government Fiscal/Employer Agents

Under the Government Fiscal/Employer Agent ("Government F/EA") model, a state or local government entity applies for and receives authorization from the IRS to act as the employer agent for participants enrolled in its self-direction program in accordance with §3504 of the IRS code, Revenue Procedure 80-4, 1980-1 C.B. 581 (and modified by IRS Proposed Notice 2003-70.) This authority allows the Government F/EA to perform all that is required of an employer for wages paid on the employer's behalf and all that is required of the payer for requirements of backup withholding, as applicable.²¹ Government F/EAs act as a "neutral bank" for the receipt, disbursement, and tracking of participants' public benefits funds, and perform payroll, vendor payment, administrative, and reporting tasks described in Table 1. A Government F/EA may perform these tasks without being considered the common law employer of workers directly hired by participants.

A Government F/EA must file for and obtain a separate, "special" Federal Employer Identification Number (FEIN) for the limited purpose of filing and depositing federal income tax withholding and employment tax forms and depositing federal taxes for the participant-employers it represents.²² Then it must

prepare and submit an application to and receive authorization from the IRS to be authorized as the employer agent for all participants-employers enrolled in its self-direction program.²³

The Government F/EA also must obtain authorization from the IRS to communicate with the IRS regarding employer-related federal tax filings and payments.²⁴ Until the Government F/EA receives the employer agent authorization from the IRS, the participant-employer is liable for any unfulfilled federal income tax withholding and employment tax obligations, including penalties and interest. Once employer agent authorization is received, the Government F/EA is equally liable with participant-employers for any unfulfilled federal income tax withholding and employment tax obligations, including penalties and interest.²⁵

Some state revenue and unemployment tax agencies also require participant-employers to execute limited powers-of-attorney granting Government F/EAs the authority to withhold, file, and deposit state income tax withholding and/or unemployment insurance taxes, and to communicate with state tax agencies regarding these filings and deposits. It is important that program staff know their state and local tax and state labor requirements and how they relate to their self-direction program and the F/EA model used prior to implementing F/EA services.

Delegation of Employer Agent Tasks

IRS Proposed Notice 2003–70 allows a Government F/EA to delegate employer agent tasks to a subagent²⁶ or reporting agent²⁷ to ease its administrative burden. The Notice also provides Government F/EAs with a number of paperwork reduction opportunities.²⁸

When a Government F/EA decides to contract with and delegate F/EA tasks to a reporting agent, it must execute an IRS Form 8655, Reporting Agent Authorization, between itself and the reporting agent. The reporting agent is not liable for any unfulfilled federal income tax withholding and/or employment tax obligations, including penalties and interest.²⁹ Rather, the Government F/EA and the participant-employer are equally liable.³⁰ State and local tax agencies may have similar rules regarding reporting agent liability, which can differ by state.

When a Government F/EA uses a subagent, the IRS requires that it obtain a statement from all participant-employers authorizing the Government F/EA to appoint a subagent to assist in meeting its responsibilities as their employer agent. The IRS also requires the Government F/EA to execute a second IRS Form 2678, Agent/Payer Authorization, between itself and its subagent making the subagent the Government F/EA's employer agent.³¹ The subagent is not liable for any unfulfilled federal income tax withholding and employment tax obligations, including penalties and interest, until authorization is received from the IRS. Once authorization is received, the Government F/EA, the subagent, and the participant-employers are all equally liable for any unfulfilled tax obligations,

including penalties and interest.³² State and local tax agencies may have similar rules regarding subagent liability, which can differ by state.

To reduce the likelihood of any unfulfilled federal, state, and local tax obligations, including penalties and interest, due to reporting agent or subagent errors or omissions, it is important that a Government F/EA be able to determine that the reporting agent or subagent has the knowledge and experience necessary to provide the required services. In addition, the Government F/EA should develop and execute a performance-based contract with the reporting agent or subagent that holds these entities accountable for any federal, state, or local taxes not filed and/or paid—including penalties and interest—that may result from errors or omissions made by the entity in the performance of its duties.

Advantages to States in Implementing a Government F/EA

Implementing a Government F/EA provides several advantages for state and local government program staff.

- Current IRS policies and procedures for Government F/EAs are better documented and have fewer ambiguities than those for Vendor F/EAs. In addition, the IRS employer agent authorization process for Government F/EAs need not delay the enrollment of individuals in self-direction programs if the initial implementation date of F/EA services coincides with the receipt of IRS Government F/EA authorization.
- The IRS has afforded Government F/EAs and their reporting agent or subagent paperwork economies as described in Internal Revenue Service Proposed Notice 2003–70.³³ These paperwork economies can reduce costs related to the provision of F/EA services for states and participants.
- States can furnish F/EA services “in-house,” providing a state with full control over the provision of F/EA services while avoiding the need to manage vendor selection and monitor vendor performance with its associated expenses.
- States can target scarce resources for F/EA implementation and quality monitoring activities on two or fewer entities (i.e., itself as Government F/EA and one subagent or reporting agent, if the state program agency chooses to use one) in a cost effective manner. However, states still need to develop and implement a Government F/EA manual that describes the policies, procedures, and internal controls for all F/EA tasks, any tasks delegated to a reporting agent or subagent, and tasks associated with communicating with and monitoring the performance of these entities in order to ensure effective provision of F/EA services. This manual should be updated at least annually and be the basis for any Government F/EA reporting agent/subagent performance review protocol developed and implemented by program staff.

Challenges for States Implementing a Government F/EA

Implementing a Government F/EA may present a number of challenges for state and local government program staff.

- State and local government program staff may lack the knowledge, staff resources and needed infrastructure, and/or the desire to perform as a Government F/EA with or without the assistance of a reporting agent or subagent.
- Some program staff have reported difficulty implementing the IRS' Government F/EA authorization process due to incomplete and/or conflicting information received from IRS regional office staff.
- Using only one reporting agent or subagent could present difficulties for the Government F/EA in ensuring seamless delivery of financial management services to participants should it or its reporting agent or subagent choose to terminate the reporting agent's or subagent's contract for any reason.
- When states implement self-direction programs using a Government F/EA, the costs associated with providing FMS, and any reporting agent or subagent services, must be billed as an administrative expense for the purpose of claiming federal Medicaid matching funds. This is because participants' freedom of choice of provider is limited.³⁴ Thus, when evaluating the feasibility of implementing a Government F/EA, a state's Medicaid agency and program staff should assess the economic impact of using this model on the receipt of federal Medicaid matching funds and the administrative costs to the state associated with monitoring multiple F/EA operations.
- Current state and local income tax withholding and employment tax filing and depositing policies, procedures, and forms are not easily applied to self-direction programs. Moreover, some state and local tax agency staff are unfamiliar with Government F/EAs and are unsure how to apply their policies, procedures, and forms to these entities and what the liabilities may be. It is critical that program staff meet with key state and local tax agency staff early on to receive input and guidance regarding policies, procedures, and issues, and to avoid problems in implementing the self-direction program and Government F/EA services.³⁵

Vendor Fiscal/Employer Agents

Under the Vendor Fiscal/Employer Agent ("Vendor F/EA") model, a vendor entity must apply for and obtain authorization from the IRS to act as an employer agent for each participant it represents. Vendor F/EAs operate under §3504 of the IRS code and the tasks they perform are similar to the Government F/EA. However, Vendor F/EAs operate under different IRS provisions (Revenue Procedure 70–6, 1970–1 C.B. 420 and as modified by Proposed Notice 2003–70). Vendor F/EAs

also may contract with and delegate tasks to a reporting agent if the program allows this.³⁶

A Vendor F/EA must file for and obtain a separate, “special” Federal Employer Identification Number (FEIN) for the limited purposes of withholding, filing, and depositing federal income tax withholding and employment taxes.³⁷ In contrast with IRS employer agent authorization procedures for Government F/EAs, Vendor F/EAs must submit an IRS Form 2678 to and receive authorization from the IRS for each participant-employer it represents as an employer agent.³⁸ They also must obtain IRS tax information authorization to communicate with IRS staff about participant-employers’ federal tax filings and payments.³⁹

A Vendor F/EA is not liable for any unfulfilled federal income tax and employment tax obligations, including penalties and interest for participant-employers until employer agent authorization is received from the IRS.⁴⁰ Once IRS authorization is received, both participant-employers and the Vendor F/EA are equally liable for any unfulfilled federal income tax and employment tax obligations, including penalties and interest.

Delegation of Employer Agent Tasks

When a Vendor F/EA chooses to use a reporting agent, it must execute an IRS Form 8655, Reporting Agent Authorization, with the reporting agent. The reporting agent is not liable for any unfulfilled federal income tax withholding or employment tax obligations including penalties and interest.⁴¹

Some state and local revenue and unemployment tax agencies also require all participant-employers to execute limited powers-of-attorney granting Vendor F/EAs the authority to file and deposit state income tax withholding and/or unemployment taxes and to communicate with the tax agencies regarding these filings and deposits. As mentioned earlier, it is important that program staff know how the state and local tax and state labor requirements apply to the program and F/EA services prior to implementing F/EA services.

Advantages to States in Implementing a Vendor F/EA

Implementing a Vendor F/EA provides several advantages for state and local government program staff.

- It allows states to engage vendor entities, either under contract or as qualified Medicaid service providers, who have the knowledge, experience, resources, and infrastructure necessary to provide effective financial management services, and to negotiate cost-effective fees for F/EA services rendered, rather than providing these services in-house.
- States have the option to (1) select a discrete number of Vendor F/EAs, using a Request for Proposal or other solicitation process, and bill F/EA costs

as an administrative expense (at a uniform federal matching funds rate of 50 percent), or (2) develop Medicaid F/EA provider standards and provide freedom of choice of provider to participants, and bill F/EA costs as a service expense for the purpose of claiming federal matching funds (at a federal matching funds rate that ranges from 50 to 83 percent).⁴²

- States can further distance themselves from being considered the employer of participants' workers—by workers and state workers' compensation and unemployment insurance agencies—by implementing a contract making the Vendor F/EA equally liable, with the participant-employer, for any unfulfilled federal and state income tax withholding and employment tax obligations, including penalties and interest.⁴³

Challenges for States Implementing Vendor F/EAs

Implementing a Vendor F/EA may present a number of challenges for state and local government program staff.

- In order to select vendor entities and effectively monitor the quality of their performance, designated state program staff must have adequate knowledge of federal, state, and local (as applicable) tax policies, procedures, and forms as they relate to household employers, domestic service workers, and Vendor F/EAs, and understand Vendor F/EA operations.
- Current IRS employment tax policies, procedures, and guidance pertaining to Vendor F/EAs are, in some cases, incomplete and ambiguous.
- IRS staff knowledge of IRS policies and procedures related to Vendor F/EAs varies, sometimes resulting in incomplete and/or inconsistent guidance.
- Current state income tax withholding and employment tax policies, procedures, and forms are not easily applied to self-direction programs. Moreover, some state tax agency staff are unfamiliar with Vendor F/EAs and their operations and unsure of how to apply their policies, procedures, and forms to these entities. State and local tax agency staff also are unsure of what the liability is, if any, for Vendor F/EAs and their reporting agents, relative to any unfulfilled state income tax withholding, employment tax, and locality tax obligations, including penalties and interest. Thus, it is critical that program staff meet with key state tax agency staff early on to present their program and F/EA design and receive input and guidance, preferably in writing, to clarify procedures and issues and avoid problems in implementing its program and Vendor F/EA services.

C. Key Issues For States Using Government and Vendor F/EAs to Provide FMS

State and local government program staff must address several issues when implementing—and monitoring the performance of—Government and Vendor F/EAs.

Need to Obtain F/EA-Agent-Related Knowledge

State and local government program staff must be knowledgeable about (1) federal and state tax, labor, and workers' compensation insurance, locality taxes, and Medicaid rules, policies, and procedures that apply to F/EAs, household employers, and domestic service workers; and (2) federal and state program requirements for F/EA operations for the model it plans to implement. This knowledge is essential for state and local government program staff in order to (a) develop and implement effective Medicaid standards and provider agreements, (b) develop and execute solicitations (i.e., Request for Proposals [RFP] or Intent to Negotiate [ITN]) for F/EA services and administrative contracts with Vendor F/EAs and reporting agents and subagents (as applicable); (c) assess F/EAs', reporting agents', and subagents' readiness to perform the required F/EA tasks; and (d) monitor F/EAs', reporting agents' and subagents' ongoing performance.

Verifying State and Local Tax, Labor, and Workers' Compensation Insurance Requirements

Program staff should meet with applicable state tax, labor, and workers' compensation insurance agencies to present their program and F/EA design and obtain feedback early on. Moreover, it is recommended that feedback be obtained in writing. This is important to determine if any state tax, labor, and workers' compensation rules, policies, or procedures conflict with the state's program and F/EA design (e.g., if the state prohibits participants from being the common law employer of the workers they hire directly).⁴⁴ It also will enable program staff to receive guidance on the best way to implement state employer requirements and complete the required processes and forms. States that have various locality tax requirements should repeat this process with the appropriate local tax authorities.

Need to Assess States' Data and Information Systems Capabilities to Implement F/EA Services

States need to assess their data and information systems capabilities to determine if they are sufficient to implement an effective self-direction program with F/EA services. The assessment should include, but not be limited to: (1) an evaluation of the state's ability to generate and transmit data, including participant service plan, budget, and authorization information to counselors and F/EAs; and (2) its ability to link its Medicaid Management Information System (MMIS) and

Medicaid claims processing system with the Government or Vendor F/EA billing procedures and generate reports, as required. A state should review its capacity not only for the initial submission of budget, service plan, and authorization information to applicable stakeholders, but also its capacity and methodology for submitting edits and updates in an accurate and timely manner.

Determining Whether F/EA Services Will Be an Administrative Function or Program Service

When states implement a self-direction program using a Government F/EA—under either a Medicaid §1915(c) waiver program or the Medicaid State Plan, including under the §1915(j) option—the costs associated with providing FMS and any reporting agent or subagent services must be billed as an administrative expense for the purpose of claiming federal Medicaid matching funds. When states use a Vendor F/EA in conjunction with a Medicaid State Plan self-direction program—either through the personal care option or the new §1915(j) option⁴⁵—the costs for the F/EA and reporting agent services also must be billed as an administrative expense. Given that administrative expenses are matched by the federal government at a uniform 50 percent rate while service expenses are matched from 50 to 83 percent (depending on the state), the decision about which model to use can have major cost implications for a state.

For Vendor F/EA services to be reimbursed as a waiver service, states must meet a number of federal requirements. States must develop a service definition that includes a set of provider qualifications and the tasks that will be performed by the Vendor F/EA and any reporting agent. States must verify a provider’s qualifications before services are initiated and must provide a detailed description of the frequency and methods by which provider qualifications will be re-verified and ongoing performance will be monitored. States must treat Vendor F/EAs as they would any Medicaid service provider. States may not arbitrarily limit the number of Vendor F/EAs available to participants since this would restrict their freedom of choice of provider and disqualify the state from claiming Vendor F/EA expenses for federal matching funds purposes as a waiver service. Finally, states must monitor Vendor F/EAs’ and any reporting agents’ performance on an ongoing basis.

Determining How Many F/EAs to Use

Program staff continue to struggle with determining how many Vendor F/EAs are sufficient to meet participants’ demand for FMS. In determining “how many Vendor F/EAs are enough,” states often must balance several factors with participants’ freedom of choice of F/EA provider and a state’s need to maximize federal matching funds. These factors are: (1) the number of participants; (2) the need to achieve economies of scale and a cost-efficient price for Vendor F/EA services; and (3) the resources needed and associated expenses related to contracting with and assessing

the readiness of and monitoring the performance of Vendor F/EAs, or certifying and re-certifying Vendor F/EAs and their reporting agents and subagents.

A significant number of states limit the number of Vendor F/EA providers and forgo the receipt of federal service matching funds in order to obtain cost efficiencies and effectively manage the monitoring of F/EA service delivery.⁴⁶ The majority use some type of solicitation process (i.e., RFP or ITN) to select one or more Vendor F/EA providers for their program. However, some states report challenges related to this strategy such as (1) the need to write an effective solicitation (i.e., RFP or ITN) document that accurately and completely reflects F/EA requirements; (2) the need to evaluate F/EA knowledge and experience for proposal review and vendor selection purposes; (3) interruptions in the continuity of F/EA providers because a satisfactory F/EA provider must rebid at the end of each contract period and may not be reselected (e.g., if they are not the lowest bidder, which may be a priority for a state's purchase and property department responsible for managing the solicitation process); (4) the resources and time required to complete a solicitation, including addressing any bidder challenges; and (5) developing and executing effective performance-based contracts.

Other states provide freedom of choice of F/EA service providers for participants in order to receive federal service matching funds.⁴⁷ Again, some of these states have experienced challenges such as (1) having sufficient knowledge of federal and state F/EA requirements and operations to prepare Medicaid standards and execute Medicaid provider agreements effectively; (2) preparing effective protocols for certifying F/EA entities as Medicaid providers and monitoring their performance through periodic recertification; and (3) having the staff and financial resources necessary to conduct F/EA certifications and recertification/performance monitoring in a timely and effective manner.

Allowing Sufficient Time to Set Up F/EA Services

Historically, states have underestimated the amount of time it takes to set up F/EA services. (Many states call this process the start-up period.) Poor planning on the part of program staff—or a belief that cost savings can be achieved by minimizing the time allocated to ensure that everything is working as it should—can result in too little time being allocated to set up F/EA services. Without sufficient time, decisions made in haste can lead to mistakes that must be corrected and paid for during the first year of program implementation. Thus, it is important for program staff to allow sufficient time to set up F/EA services to effectively support the implementation of a self-direction program.

Establishing Reimbursement for F/EA Services

Program staff should establish reasonable and adequate reimbursement for Vendor F/EA and reporting agent and subagent services that reflect the costs of

providing these services. CMS has approved a variety of methods for determining reimbursement for FMS.

Basic Transaction-Based Reimbursement Method

The most basic reimbursement method is transaction-based. This approach closely links reimbursement for F/EA services to the actual cost of providing services. Using this method, key F/EA (and subagent or reporting agent) tasks are identified and their associated costs computed by program staff. Then program staff develop a fee schedule for each identified task and pay the F/EA for transactions completed in accordance with the fee schedule.

Some states have found the basic transaction-based F/EA payment system problematic, particularly when program enrollment is low (e.g., during the initial start-up period). This is because the total reimbursement provided for a small number of transactions often does not cover the Vendor F/EA or reporting agent or subagent's initial start-up expenses, costs of base level staffing, and/or other fixed costs.

Modified Transaction-Based (Per Member Per Month) Reimbursement Method

Another CMS-approved reimbursement method is to reimburse a Vendor F/EA (and a subagent or reporting agent, if used) for services rendered, as a function of transaction-based costs and anticipated service volume for a specific period or a modified transaction-based, per member per month (PMPM) rate. Under a modified PMPM rate, a state costs out the F/EA, reporting agent and/or subagent services by tasks and estimates the service volume for the rate period. The state uses this information to compute a total annual reimbursement amount to be paid to the F/EA, reporting agent or subagent, as applicable.⁴⁸ Using that amount, the state then computes a PMPM rate for Vendor F/EA, or reporting agent or subagent services.⁴⁹

Some states have further adapted the modified transaction-based PMPM reimbursement methodology for Vendor F/EAs and reporting agents and subagents by establishing a minimum monthly fee for the initial implementation period (i.e., up to a certain number of active participants), and then implement a PMPM rate after the initial enrollment target is met to address both the costs associated with the initial start-up period and ongoing F/EA operations. This reimbursement strategy provides states with an incentive to efficiently enroll individuals in the program and with the F/EA, while ensuring the Vendor F/EA, reporting agent and/or subagent receives sufficient reimbursement to operate during the initial implementation period and on an ongoing basis.

It should be noted that some participants have questioned the equity of using a flat PMPM rate for F/EA services when the services are paid, in whole or in part,

from their individual budgets. For example, they ask: “Is it equitable to charge a participant who needs two payroll checks and one vendor payment processed in a month the same F/EA fee as a participant who needs six payroll checks and two vendor payments processed in a month?” States need to balance administrative ease and cost effectiveness with equity concerns and participants’ costs when establishing payment methods for F/EA services.⁵⁰

Finally, a number of states have developed discrete payments for the completion of a one-time activity (i.e., development of participant enrollment and worker employment packets, and a state-specific F/EA policies and procedures manual). These payments are in addition to the PMPM rate paid to the F/EA for services delivered on an ongoing basis.

Percent of Budget Reimbursement Method

Finally, some states use an F/EA reimbursement method—the percent of budget method—that is not approved by CMS.⁵¹ Under this method, a Vendor F/EA, or a reporting agent or subagent, is reimbursed on the basis of a percentage of the total dollar volume of services that an FMS entity processes. This is not an optimal approach because the amount paid does not reflect the actual costs of providing the F/EA services.

Transitioning Participants From One F/EA to Another

When states have to transition participants from one F/EA to another for any reason, the process can be complicated and costly for the state and the F/EA.⁵² States need to develop policies and procedures for transitioning participants from one F/EA to another that address all the possible contingencies, reflect these policies and procedures in the Medicaid provider agreement and/or contract it executes with the F/EA, and then price the transition function accordingly.

Coordinating FMS with Counseling Services and Ensuring Effective Communication Between F/EAs and Counselors

Program staff continue to struggle with the decision of whether to provide counseling (also known as support broker or support coordinator) services and Vendor F/EA services separately or under one or more “umbrella” organizations.⁵³ Two advantages of providing F/EA and counseling services together include: (1) the seamless provision of supportive and financial management services to participants, and (2) opportunities for effective communication between the two functions due to their co-location.

One challenge for states using this approach is making sure that an umbrella organization does not put undue pressure on participants and try to steer them toward using the umbrella organization’s services exclusively, particularly when the services provided by the umbrella organization do not meet all of a

participant's needs. Another challenge for states is if both counseling and F/EA services are provided under the same umbrella organization, a state would have to find a new provider for both types of services if the organization stops providing services for any reason. One advantage of providing F/EA and counseling services separately is that participants have more choice and control over who provides these services and can mix and match providers, selecting the most capable provider for each service, thereby helping to ensure the quality of both. However, states face two challenges related to providing counseling and F/EA services separately: (1) the amount of training and monitoring that must be provided by the state, and (2) communication between the two entities can be fragmented, resulting in inconsistent service delivery for participants.

Need to Assess Initial Readiness and Monitor the Ongoing Performance of F/EAs

It is essential that program staff develop protocols, assess initial readiness, and monitor the ongoing performance of F/EAs, and any reporting agents and subagents.⁵⁴ To do this, states must ensure that staff are knowledgeable about (1) federal and state tax, labor, workers' compensation insurance, locality tax, and Medicaid requirements for F/EAs, reporting agents and subagents; (2) F/EAs' operations; and (3) federal and state regulations as they pertain to household employers and their workers. These staff also must be comfortable using and staying up-to-date with this information and with financial audit/review techniques that may be different from those they use when certifying and monitoring the performance of traditional HCBS providers.

D. Key Issues for Government and Vendor F/EAs

Government and vendor entities must address several key issues when operating as an F/EA.

Staying Up-to-Date with Federal, State, and Local Tax, Labor, and Workers' Compensation Insurance and Medicaid Requirements

Government and Vendor F/EAs need to have a system in place and written policies, procedures, and internal controls for staying up-to-date with federal, state, and local requirements related to receiving authorization and providing F/EA services in order to comply with these requirements.⁵⁵

Developing and Maintaining a Government or Vendor F/EA Policies and Procedures Manual

Government and Vendor F/EAs must prepare and maintain a policies and procedures manual that describes the systems, policies, procedures, and internal controls for all F/EA tasks. When a Government F/EA uses a reporting agent or

a subagent, or a Vendor F/EA uses a reporting agent, the manual should include the systems, policies, procedures, and internal controls for the tasks delegated to the reporting agent or subagent and those associated with communicating and coordinating with and monitoring the performance of the reporting agent or subagent. This manual should be updated at least annually and should be the basis of any Government F/EA reporting agent/subagent performance review conducted by state program staff.

Developing and Maintaining Effective Information Systems Capabilities

Government or Vendor F/EAs (and their reporting agents or subagents) need to have information systems capabilities that allow them to effectively perform all required F/EA tasks in an accurate and timely manner; receive from and transmit information to the state program, counselors, and participants; and link to the state Medicaid claims processing system. For example, “off the shelf” payroll systems often can not manage payroll for large numbers of employers in accordance with federal, state, and local tax and Medicaid program rules. Thus, F/EA’s information systems must be customized for self-direction programs.

Key to the success of a Government or Vendor F/EA is how well it manages the paperwork related to providing F/EA services. In the case where self-direction programs authorize individual budgets for participants, F/EAs’ information systems must be able to maintain individual budgets and track activity for each participant. F/EAs’ information systems must be transparent for audit purposes to ensure that all required paperwork is collected and processed prior to making any payments. Finally, F/EAs must be able to implement an automated system for documenting all contacts with participants, counselors, workers, and vendors; recording actions taken to resolve issues raised; and complying with any mandatory reporting requirements.

Developing and Implementing Effective Customer Services, Including Orientation and Training for Participants

It is important that Government and Vendor F/EAs develop and implement an effective customer service system that includes orientation and skills training for participants and their representatives. Key elements of effective customer service systems include, but are not limited to, providing participants with (1) clear and complete information about enrolling with the F/EA, using its services and staff contacts, and their role and responsibilities and those of the F/EA; (2) accessible, user-friendly, web-available information about F/EA services;⁵⁶ (3) user-friendly participant enrollment and worker employment packets and assistance with completing and submitting the required information to the F/EA; (4) orientation and skills training that address using F/EA services and the employer role and responsibilities; and (5) an automated system for receiving, tracking, and responding to participant inquiries and complaints. F/EA staff must be able to

communicate in alternative formats and multiple languages and the self-direction philosophy should be applied to all aspects of the delivery of customer service.

Developing Quality Management Systems

Historically, states have worked with case managers and service providers to develop quality management systems to safeguard the health and welfare of participants in the traditional HCBS delivery system. In self-direction programs, a significant amount of the responsibility for quality management is transferred to participants, their representatives (when applicable), their counselor, and, to a certain extent, their FMS provider.

Government and Vendor F/EAs are responsible for monitoring the receipt and disbursement of participants' budgetary funds and ensuring that only authorized hours, goods, and services are paid for. Thus, they need to implement a system, and document policies, procedures, and internal controls for tracking and comparing expenditures with participants' spending plans and for identifying and reporting any incidences of outlier spending behavior. Outlier spending behavior may be due to under- and over-reporting on workers' time sheets and/or purchases of goods and services not approved in the spending plan. Mandatory reporting of this information to program staff should be based on pre-determined criteria and made through pre-determined channels.

Vendor and Government F/EAs also need to develop and conduct participant satisfaction surveys, analyze the information collected, and prepare periodic reports for internal quality assurance purposes, for program staff, and for participants. Program staff should work with F/EA staff and participants to develop the survey tool and to determine implementation frequency. Experts suggest that participants be surveyed 60 days after enrolling with the F/EA, to evaluate their satisfaction with the enrollment process, and then annually.

E. Promising Practices Related to the Provision of Government and Vendor F/EA Services

States and Government and Vendor F/EAs have developed several promising practices related to F/EA operations.

Advances in F/EA Information Technology

In response to the lack of "off the shelf" software products available to meet the needs of Government and Vendor F/EAs, a number of Vendor F/EAs have made significant progress in customizing database, accounting, and payroll software to enhance their information technology capabilities and F/EA operations. For example, some systems solutions have been developed for the processing and management of workers' timesheets and for paperwork management, using optical character recognition and electronic document management systems

technologies.⁵⁷ However, developing and testing information technology is expensive and some Vendor F/EAs are struggling to recover these costs through their F/EA fees and still stay price competitive.

The Cash & Counseling National Program has developed a technology solution to support the timely, efficient, and user-friendly flow of information among participants, counselors, F/EAs, and state and local government program administrators as they all assist participants to develop their spending plans, manage their individual budgets, choose and manage employees, and direct their own care. This software solution is called the Consumer Direction Module and is discussed in Appendix II.

Timely Participant Budget Reports

Some Vendor F/EAs have developed easy-to-read financial/budget reports that are at or close to real time, increasing their utility for participants, counselors, and program staff.

Timely Payment of Workers

It is essential that workers be paid on time. The majority of Vendor F/EAs generate “off cycle” payroll checks when necessary. In addition, many now offer a direct deposit option for workers while others offer a debit card option. These options make it possible for workers to receive their pay in a timely manner with minimum delay and/or loss.⁵⁸

Maximizing the Availability of Cost Effective Workers’ Compensation Insurance

States are developing effective ways to arrange for and manage the payment of workers’ compensation insurance premiums for participants and their workers. For example, Massachusetts developed a specific code for household participant-employers and their personal care attendants for workers’ compensation insurance rating purposes (MA-specific code 0918, Domestic Service - Inside Physical Assistance). This code allows for more accurate workers’ compensation insurance rating for support service workers.⁵⁹

In addition, Massachusetts found a workers’ compensation insurance agent who recruited a voluntary insurer to underwrite affordable workers’ compensation insurance policies for the 15,000 participants in the Massachusetts Medicaid Personal Care Assistance Program rather than having to purchase policies through the more costly state assigned risk plan.⁶⁰ To reduce paperwork for the insurance carrier and the Vendor F/EA, the voluntary insurer issues three bills, one to each of three Vendor F/EAs for premiums for the total number of policies held by the participants represented by each Vendor F/EA (instead of issuing 15,000 bills). The three Vendor F/EAs facilitate the receipt of participants’ initial

workers' compensation insurance policies, renewals, and premium payments. They also provide wage information to the insurer so it can determine workers' compensation insurance benefits for injured workers in compliance with state law.

Currently, New Mexico has implemented a state-specific version of MA code 0918 for participant-employers and workers enrolled in its self-direction programs. Illinois and Rhode Island are in the process of implementing a state-specific code 0918 and Pennsylvania is examining the feasibility of doing so for its programs.

Using Credit Unions as Vendor F/EAs

The State of Iowa has implemented self-directed services by contracting with a credit union to provide F/EA services.⁶¹ Contracting with a credit union allows participants to not only receive F/EA services; they and their workers also can use other services the credit union offers.

F. Outstanding Issues

State and local government program staff continue to struggle with a number of issues related to the development and implementation of F/EA services.

Clarifying Federal and State Tax Procedures Related to F/EA Operations

Program staff continue to be frustrated with the status of IRS policies and procedures for Government and Vendor F/EAs. Existing guidance, when available, often is not clear and/or complete, is unavailable in locations accessible to the public, or is not used effectively to educate IRS staff so they can provide consistent, reliable information to the public. In addition, some program and F/EA staff continue to struggle with applying state employer registration, income tax withholding and employment and locality tax policies, procedures, and forms to F/EA operations.

Implementing Effective Data and Information Systems Infrastructure

Developing and implementing effective data and information systems infrastructure and capabilities related to the administration of self-direction programs using F/EAs can be very challenging. For example, program staff need to develop and enhance systems for generating and transmitting individual service plans, budgets, and service authorization information to counselors and F/EAs. They also need to link the state Medicaid claims processing system with Government or Vendor F/EA billing procedures.

Determining Effective Reimbursement Rates for F/EA Services

Determining how much to pay for F/EA services can be challenging. Increasingly states want F/EAs to provide additional services and supports for the state as well as participants, but they often cannot afford the associated costs of doing so. In addition, some states are not prepared to administer programs that use F/EA services, and as a result, rely heavily on their F/EAs, thereby increasing F/EA costs.

Recruiting More Workers' Compensation Insurance Agents to Broker and Carriers to Underwrite Policies for Self-Direction Program Participants

Workers' compensation insurance carriers are concerned that total revenues from low premiums will not cover claims incurred and administrative costs. Although recent research and reports from Vendor F/EAs indicate low workers' compensation insurance claims associated with self-direction programs,⁶² it is difficult to convince state insurance commission staff and workers' compensation insurance agents and carriers of this fact. Thus, many participants end up paying high premiums because they only can obtain coverage through states' assigned risk plans (insurers of last resort). Massachusetts successfully addressed many of its insurance agents' and carriers' concerns; however, its self-direction program benefits from a large number of participants—approximately 15,000 in 2007.

Addressing the Disconnects Between IRS Procedures and Medicaid Freedom of Choice of Provider Rules When a Participant Changes F/EAs Mid-Year

Participants switching F/EA providers in the middle of a calendar tax year has been, and continues to be, problematic for Vendor F/EAs and program staff. Often, when a mid-year switch occurs for any reason, it is difficult to reconcile federal taxes filed and paid by two different F/EAs (i.e., causing a bifurcated federal tax year). The answer is to have participants switch at the beginning of a calendar year after an “open” F/EA enrollment period. However, this strategy violates the Medicaid freedom of choice of provider rule and does not address situations when an F/EA switch can not be delayed until the end of the calendar year (e.g., when an F/EA ceases to provide services due to poor performance or when a participant moves to another part of the state and another F/EA must function in the first F/EA's stead).

Obtaining Health Insurance and Other Benefits for Direct Service Workers

Providing health insurance and other benefits (i.e., disability, dental, and vision insurance; vacation and sick leave; access to retirement savings plans) for participants' workers continues to be a challenge for state self-direction programs. Some efforts have been made to provide some type of health insurance coverage for workers but, to date, the benefits available under these plans are limited.⁶³

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: US Department of Health and Human Services (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>

Doty, P. and Flanagan, S.A. (2002). *HIGHLIGHTS: Inventory of Consumer-Directed Support Programs.* Washington, DC: USDHHS, Assistant Secretary for Planning and Evaluation (ASPE).

This publication describes the results of a 2001 descriptive inventory of publicly funded HCBS programs that use a self-direction approach and various types of financial management services.

Available at: <http://aspe.hhs.gov/daltcp/Reports/highlight.htm>

Flanagan, S.A. (2004). *Accessing Workers’ Compensation Insurance for Consumer-Employed Personal Assistance Service Workers: Issues, Challenges and Promising Practices.* Washington, DC: USDHHS, Assistant Secretary for Planning and Evaluation.

This publication describes the results of a 50-state and seven jurisdictions (District of Columbia, five territories, and one tribal government) study of workers’ compensation laws and systems as they pertain to domestic service workers, and in particular, personal assistance workers.

Available at: <http://aspe.hhs.gov/daltcp/Reports/paswork.htm> and at <http://www.cashandcounseling.org/resources/20060113-121929>

Flanagan, S.A. & Green, P.S. (2000). *Fiscal Intermediaries: Reducing the burden of consumer-directed support.* *Generations.* vol. XXIV (III):94–97.

This publication describes the development of the Fiscal Conduit, Government and Vendor Fiscal Intermediary (Fiscal/Employer Agent) models, and current issues related to the implementation of these financial management service models.

Hughes, S.L., & Sabatino, C.P. (2004). *Addressing Liability Issues in Consumer-Directed Personal Assistance Services (CDPAS): The National Cash*

and Counseling Demonstration and Selected Other Models. Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

This report addresses the liability issues that may arise in government-sponsored self-direction programs, including liability related to the provision of Fiscal Intermediary (Fiscal/Employer Agent) services. The report focuses on programs implemented in Arkansas, Florida, and New Jersey as part of the Cash & Counseling Demonstration and Evaluation and briefly describes an analysis of potential liability for the California In-Home Supportive Services Program and the New York Consumer-Directed Personal Assistance Program.

Available at: <http://www.cashandcounseling.org/resources/20051205-111452>

Web-Accessible Resources

Assistant Secretary for Planning and Evaluation (ASPE)

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

This website contains wide-ranging resources that address self-direction, the design and implementation of self-direction programs, labor, tax, workers' compensation insurance, and liability issues related to self-direction programs, and financial management services.

Cash & Counseling National Program Office

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

This is the official website of the Cash & Counseling National Program Office. It contains extensive information about self-direction programs using the Cash & Counseling model, including the use of Government and Vendor Fiscal/Employer Agents.

Centers for Medicare & Medicaid Services

Web-address: [http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915\(c\).asp](http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp)

This website contains extensive information concerning HCBS waiver programs, including those with self-direction options and financial management services. The website contains technical guidance concerning the design and operation of such programs.

Web-address: <http://www.cms.hhs.gov/PromisingPractices/HCBSPPR/list.asp>

This website contains information about promising practices that states employ to improve the delivery of HCBS to Medicaid participants, including self-directed services.

Clearinghouse for Home and Community Based Services

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

This website serves as a portal to extensive information and resources about the delivery of HCBS to a wide range of Medicaid participants, including self-direction programs that offer a variety of financial management service models to participants and their representatives. For example:

Government and Vendor Fiscal/Employer Agent Workshop: Building Sustainable Fiscal Supports For Self-Directed Service Programs, authored by Susan Flanagan, includes presentations by states, vendors, and subject matter experts from the November 2007 F/EA Workshop. Topics include Promising Practices in Workers' Compensation, CMS Policies, the Role of Reporting Agents, Government and Vendor F/EA Operations, and Design and Implementation Issues.

Available at: *Web-address: <http://www.hcbs.org/moreInfo.php/doc/2092>*

Tasks to Be Performed By a Government and Vendor Fiscal/Employer Agent, prepared by Susan Flanagan, includes information to assist state and local program agency staff in understanding the requirements and key elements of Government and Vendor F/EA operations and developing a Government F/EA policies and procedures manual, when applicable.

Available at: *Web-address: <http://www.hcbs.org/moreInfo.php/doc/1880>*

Internal Revenue Service

Web-address: <http://www.irs.gov>

The official website of the Internal Revenue Service contains extensive information and resources regarding IRS policies, revenue procedures, notices, publications, and forms relevant to Government and Vendor Fiscal/Employer Agents, and household employers and their employees.

Citations, Additional Information, and Web Addresses

- 1 Susan Flanagan, MPH, Ph.D. is the author of this chapter.
- 2 Centers for Medicaid & Medicare Services (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5] Instructions, Technical Guide and Review Criteria: Appendix C: Participant Services, Attachment: Core Services Definitions, Section D, Services in Support of Participant Direction, #2 Financial Management Services*, p.176. See the Resources section in this chapter for a link to this document.
- 3 Ibid. Appendix E: *Participant Direction of Services, Overview: Financial Management Services*, p.201. States may also provide cash to waiver participants by advancing state funds and only claiming federal match after goods and services have been rendered and receipts received.
- 4 CMS will not approve a §1115 waiver solely to offer a self-direction program. States are encouraged to implement self-direction programs either through the §1915(j) option under their Medicaid State Plan and/or the §1915(c) waiver option.
- 5 The term “neutral bank” is used because the F/EA is not providing direct care services to participants so it is “neutral” about which providers they use. Prior to the use of F/EAs, some participants with developmental disabilities found it difficult to move between/among agency service providers because their Medicaid benefit was often allocated to one service organization for the fiscal year, which had a financial interest in who provided services to participants.
- 6 Payroll includes, but is not limited to, the collection and processing of worker timesheets; making sure that workers are paid in accordance with federal and state labor laws; the withholding, filing and payment of federal and state income tax withholding and employment taxes, and locality taxes; processing of the advanced federal earned income credit, when applicable, and any garnishments, liens or levies against workers pay, as required; and generating and distributing payroll checks.
- 7 Also referred to legally as a “joint employer” relationship; the term co-employment is often used to describe the relationship among two or more employers when each has specific actual or potential legal responsibilities to the same worker or group of workers.
- 8 When participants are not able or willing to act solely as their workers’ employer, their representatives can assume this role if they are willing to do so.
- 9 The “Operating Entity” refers to the organization providing the FMS, not the operating entity of a Medicaid §1915(c)waiver.

- 10 June 2002 version of IRS Form 2678, *Employer Appointment of Agent*, Instructions.
- 11 Some local governments are authorized to impose a variety of local taxes from earned income tax to real property taxes to various other taxes. Some of these are imposed on workers and withheld and deposited by their employers. For example, Pennsylvania has both a local Earned Income Tax (EIT) and a Local Services Tax (LST) (formerly know as the Emergency and Municipal Service Tax and before that the Occupational Tax).

All employers with work sites within the taxing jurisdiction are required by law (PA Act 7 of 2007, The Local Tax Enabling Act which amended PA Act 511 of 1965) to register with the appropriate municipal authority. An employer then deducts EIT and LST from their employees' wages and deposits them with the municipal authority if the taxes are listed in the Local Tax Register of the PA Department of Community and Economic Development for the municipality.

- 12 Participants may also interview and select a worker referred by the agency for assignment back to them.
- 13 Based on Scherzer, T., Wong, A., & Newcomber, R. (2007). Financial management services in consumer-directed programs. *Home Health Services Quarterly*, 26(1), 35–36.
- 14 Ibid.
- 15 Doty, P. and Flanagan, S.A. (2002). *HIGHLIGHTS: Inventory of Consumer-Directed Support Programs*. U.S. Department of Health and Human Services, Washington, DC, p.4. Of the 139 self-direction programs reviewed, which reported using some model of financial management services: 45 percent used the Vendor F/EA model, 21 percent used the Agency with Choice model, 12 percent used the Fiscal Conduit model, six percent used the Government F/EA model, and one program (California's In-Home Supportive Services Program) used a Public Authority. Washington State reported using a model of FMS where the state is the statutory employer of participants' workers for the purpose of processing payroll in accordance with §3401(d)(1) of the IRS code.

Staff from the IRS Office of General Counsel for Employment Tax reported that states should implement FMS under §3504 of the IRS code rather than §3401(d)(1) of the IRS code so that the FMS entity may file and deposit federal income tax withholding and FICA in the aggregate, an option not available to statutory employers under §3401(d)(1) of the IRS code.

- 16 IRS Proposed Notice 2003–70, Q&A #18.
- 17 Fiscal Conduit services are provided effectively under the Government

or Vendor F/EA models because of the fiscal nature of their tasks and the fact that participants using the Fiscal Conduit FMS model are the common law employers of the workers they hire directly like participants who use Government or Vendor F/EA services.

- 18 <http://www.irs.gov/businesses/small/article/0,,id=99921,00.html>
- 19 IRS Proposed Notice 2003–70, Q&A #5.
- 20 Flanagan, S. A., & Green, P. S. (2000). Fiscal Intermediaries: Reducing the burden of consumer-directed support. *Generations*, 24(111), 94–95. This publication describes the development of Fiscal/Employer Agents and current issues.
- 21 June 2002 version of IRS Form 2678, Employer Appointment of Agent, Instructions.
- 22 An FEIN is obtained by completing and filing the IRS Form SS-4, *Application for Employer Identification Number* with the IRS. Federal employment taxes include Medicare and Social Security taxes or FICA (Federal Insurance Contribution Act) and FUTA (Federal Unemployment Tax Act).
- 23 Agent approval is obtained by the Government F/EA filing one IRS Form 2678, *Employer/Payer Appointment of Agent*, for the program. Then it must execute (but not submit to the IRS) an IRS Form 2678 with each participant it represents and maintain the form in each participant’s file. When the Government F/EA ceases being the employer agent for a participant permanently, it must revoke the IRS Form 2678 it has with the participant, per IRS instructions, and keep the revoked form in the participant’s file (i.e., not submit it to the IRS).

If the Government F/EA delegates employer agent tasks to a reporting agent, it must execute an IRS Form 8655, *Reporting Agent Authorization*, between itself and the reporting agent. This form should be revoked per IRS instructions if/when the Government F/EA ceases to use the reporting agent.

If the Government F/EA delegates employer agent tasks to a subagent, the subagent must execute and submit to the IRS an IRS Form 2678, *Employer/Payer Appointment of Agent*, with the Government F/EA to obtain authorization to be the employer agent to the Government F/EA. This form should be revoked per IRS instructions if/when the Government F/EA ceases to use the subagent.

- 24 The Government F/EA also obtains federal tax information authorization to communicate with the IRS regarding federal taxes it files and deposits on participants’ behalf by executing an IRS Form 8821, *Tax Information Authorization*, with each participant it represents as employer agent and

submitting it to the IRS.

If the Government F/EA uses a reporting agent or subagent it should list this entity as a second appointee on the Form 8821 it executes with the participant.

If the Government F/EA uses a subagent, it should execute an IRS Form 8821 between itself and the subagent and submit it to the IRS so that the subagent has authorization to communicate with the IRS regarding federal taxes it files and deposits on the Government F/EA's behalf.

Each IRS Form 8821 executed needs to be renewed periodically and should be revoked if the Government F/EA no longer represents the participant permanently, per IRS Form 8821 instructions.

- 25 10/07 IRS Form 2678, *Employer/Payer Appointment of Agent*, Instructions.
- 26 A subagent, is defined by the IRS in Proposed Notice 2003–70, Section II, *Definitions*, as “an individual or entity designated as agent by a state agent in accordance with Rev. Proc. 70–6 and this revenue procedure.”
- 27 A reporting agent, is defined by the IRS in Proposed Notice 2003–70, Section III, as “an accounting service, bank, service bureau or other entity authorized to perform one or more acts on behalf of an employer, including sign and file IRS Forms 940 and 941 and make federal tax deposits for the taxes reported on those forms.”
- 28 Paperwork reductions granted to Government F/EAs and their reporting agent and subagents, when applicable, include: (1) applying for and receiving employer agent approval for all participants enrolled in a self-direction program through one authorization application, rather than filing for and obtaining IRS employer agent authorization for each participant as Vendor F/EAs have to; (2) filing and depositing FUTA in the aggregate using its special FEIN (this also applies when a Government F/EA is using a reporting agent or subagent); and (3) being able to deposit federal income tax withholding, FICA, and FUTA when they are filed using the IRS Forms 941 and 940, respectively. Item 3 applies only when Government F/EAs use reporting agents—but not subagents.
- 29 IRS Proposed Notice 2003–70, Q&A-19. In addition, a Government F/EA can only use one reporting agent or subagent. The Government F/EA or its reporting agent or subagent files and deposits federal income tax withholding, FICA and FUTA in the aggregate using the IRS Forms 941 and 940, respectively, the Government F/EA's contact information and its special FEIN.
- 30 IRS Proposed Notice 2003–70, Q&A-19 and 10/07 IRS Form 2678, *Employer/Payer Appointment of Agent*, Instructions.

- 31 IRS Proposed Notice 2003–70, Q&A 25. The Government F/EA’s separate FEIN should be reported in Part 2 of the form and the subagent’s corporate FEIN reported in Part 3 of the form. A Government F/EA can only use one subagent as discussed in Endnote 28.
- 32 IRS Proposed Notice 2003–70, Q&A-26.
- 33 See Endnote 28.
- 34 Participants’ choice of provider is limited because per IRS regulations, only one entity (a Government F/EA or its reporting agent or subagent if it chooses to use one) can file and deposit the required federal taxes for participants and their workers under the same entity name and FEIN on the required IRS Forms.
- 35 It is important for state program agencies and F/EAs to obtain state and local tax information and guidance in writing so that policies and procedures are consistent even when there is a change in state and local tax agency staff.
- 36 IRS Form 2678, *Agent/Payer Authorization*, (rev. October 2007). Although the IRS has clarified that Vendor F/EAs may use reporting agents, some states may require a Vendor F/EA to perform all employer agent tasks itself.
- 37 This FEIN should be in addition to the entity’s corporate FEIN and only participants’ and their workers’ federal income tax withholding and employment taxes should be reported and deposited using this FEIN.
- 38 A Vendor F/EA must revoke its employer agent authorization with the IRS when it no longer represents a participant-employer permanently.
- 39 This is accomplished by executing an IRS Form 8821, *Tax Information Authorization*, with each participant it represents as an agent and filing it with the IRS. The Vendor F/EA must renew this authorization periodically and revoke it if and when it no longer represents a participant permanently per Form 8821 instructions. If the Vendor F/EA uses a reporting agent, it should list the entity as a second appointee on Form 8821.
- 40 IRC §31.3504–1 as described in the 8/13/07 IRS letter to Ellen Wendt, F/SE Manager at MRCI in Mankato, MN, from Curtis L. Freedman, Chief of the Business Forms and Publications Branch. During the period of operation before Vendor F/EA authorization is received, the taxpayer (the participant or his/her representative) is liable for the payment of any unfulfilled federal income tax withholding, including penalties and interest. However, IRS Office of General Counsel for Employment Tax reported that if these taxes and associated penalties and interest can not be collected from the taxpayer, the IRS will follow the flow of funds to the original source (e.g., the self-direction program agency or Medicaid agency, as applicable).

- 41 IRS Proposed Notice 2003–70. Q&A-19.
- 42 If a state implements a Medicaid State Plan self-direction program in accordance with §1915(j) of the Social Security Act, the costs associated with Vendor F/EA services must be billed as an administrative expense for the purpose of claiming federal matching funds.
- 43 Staff at the IRS Office of General Counsel for Employment Tax reported that if there is any unfulfilled federal income tax withholding or employment tax obligation, including penalties and interest, that can not be addressed by a Vendor F/EA, or for that matter a reporting agent or subagent under contract with a Government or Vendor F/EA, the IRS will follow the flow of funds back to the original source (i.e., the state’s Medicaid program) to recover these obligations.
- 44 Minnesota had and Montana has a state unemployment insurance law that prohibits individuals receiving publicly funded services from being the common law employer of their workers. Minnesota Unemployment Insurance Law §268.035 Definitions subd. was subsequently amended to allow participants in self-direction programs to be the common law employers of their workers. Montana currently is reviewing its law to determine what, if any, amendments can be promulgated to facilitate the implementation of self-directed services using a Vendor F/EA.
- 45 Under §6087 of the Deficit Reduction Act of 2005.
- 46 States that limit the number of Vendor F/EA providers available to participants include, but are not limited to, Alabama, Idaho, Iowa, Illinois, Maryland, Massachusetts, Missouri, New Jersey, New Mexico, Tennessee, Virginia, and Vermont. Alabama has implemented its pilot self-direction program under its Medicaid State Plan by using the §1915(j) authority of the Social Security Act. New Jersey converted its Personal Preference Program from operating under a §1115 Medicaid Demonstration Waiver to the §1915(j) authority effective July 1, 2008. The Missouri Division of Developmental Disabilities has implemented a Government F/EA and performs all tasks internally. West Virginia’s Bureau of Medical Services and Florida’s Department of Elder Affairs and Agency for Persons with Disabilities have implemented a Government F/EA and use a subagent. States that restrict participant choice of F/EA provider, including states that implement Government F/EAs or programs using §1915(j) of the Social Security Act, are reimbursed for F/EA costs at the federal administrative matching rate.
- 47 States include, but are not limited to: Pennsylvania (53 percent Medicaid service match rate), Michigan (58.10 percent Medicaid service match rate), Minnesota (50 percent Medicaid service match rate), and Rhode Island (52.35 percent service match rate).

- 48 Massachusetts implemented an abbreviated Vendor F/EA cost report for a two-year period to determine the costs of providing Vendor F/EA services. During that period, the Vendor F/EAs were paid based on an initial F/EA rate that was retroactively adjusted at the end of the rate year based on the allowable costs reported on their cost report. Once a historic cost base was determined, the State implemented a flat PMPM rate for all Vendor F/EAs. In FY 2006, the State converted its PMPM F/EA rate to a per diem rate (\$1.72/day for an annual cost of \$627.80 per participant per year).
- 49 CMS guidance for acceptable FMS payment methodologies for services provided under a Medicaid §1915(c) waiver is contained in the waiver application instructions with an acknowledgement that these policies are continually evaluated for their efficacy.
- 50 At least one state (Utah) has implemented a two-tiered PMPM rate schedule to reflect the potential variation in F/EA transactions. Effective July 1, 2008 the low usage cluster rate for F/EA services will be \$30.08 PMPM and the rate for the high usage cluster will be \$98.30 PMPM, according to Paul Day, MPA at the Utah Department of Human Services Division of Services for People with Disabilities.
- 51 CMS §1915(c) HCBS Waiver Application Instructions, Appendix E, Item E-1-I Provisions of FMS, version 3.5, p.204. See the Resources section in this chapter for a link to this document.
- 52 Transitioning a participant from one F/EA to another at any time other than at the beginning of a calendar year will result in a bifurcated federal tax year, which creates problems that are difficult for F/EAs to resolve due to the aggregate filing and depositing of federal income tax withholding and employment taxes. In addition, the new F/EA may have to resolve errors and omissions made by the previous F/EA, which can be time consuming and costly. Finally, customer service costs can increase due to increased calls from participants who are transitioning.
- 53 Although both counselors and F/EA entities provide employer orientation and skills training—depending on the program—opinions differ about which entity should provide these supports.
- 54 Some states report that they perform audits of F/EAs. However, a true financial audit is costly as it must meet the requirements of generally accepted accounting principles which are extensive. To address the fiscal issues related to F/EA operations, state program staff often enlist financial audit staff resources to assist in the development of the protocol and participate in the performance of either ongoing performance reviews, often referred to as “agreed-upon procedures reviews,” or F/EA recertifications.

- 55 These include, but are not limited to: (1) obtaining federal agent authorizations; (2) obtaining F/EA's special FEIN and participant-employers' FEINs; (3) withholding, filing, and depositing federal and state income tax withholding, employment taxes and locality taxes for participants and their workers; (4) establishing state/local employer accounts and powers of attorney, as required, for state income tax withholding and employment tax filing and depositing any required locality taxes; (5) ensuring workers are paid in accordance with federal and state department of labor rules; (6) registering workers in accordance with state new hire reporting requirements; (7) performing US Bureau of Citizenship Services requirements for verifying workers' citizenship and legal alien status; (8) verifying workers' social security numbers; and (9) brokering workers' compensation insurance coverage for participants in accordance with applicable laws.
- 56 Materials should be available in alternate formats such as Braille, large print, and audiocassette.
- 57 Optical character recognition, usually abbreviated to OCR, is defined by Wikipedia as "the mechanical or electronic translation of images of handwritten or typewritten text (usually captured by a scanner) into machine-editable text." The OCR term has been broadened to include digital image processing as well. Electronic document management is defined by Wikipedia as "a computer system (or set of computer programs) used to track and store electronic documents and/or images of paper documents. The term has some overlap with the concepts of content management systems and is often viewed as a component of enterprise content management systems and related to digital asset management, document imaging, workflow systems and records management systems."
- 58 Losses can occur if workers are not paid on time and checks they have written bounce, leading to bank charges.
- 59 Prior to the development of this code, Massachusetts used National Council on Compensation Insurance (NCCI) codes 0908, Domestic Service, Inside, Part-time and 0913, Domestic Service Inside (full-time) to rate personal care workers for workers' compensation insurance purposes. These codes did not accurately reflect the tasks performed by workers. NCCI subsequently inappropriately amended these codes by deleting personal assistance workers and including them in NCCI code 8835, *Homemaker Services*, with home health industry providers. This resulted in excessive workers' compensation insurance premiums for personal care/support service workers.
- 60 The insurance agent was C.J. McCarthy Insurance (now Hub International) and the insurer was Atlantic Charter. For the rating period (2/1/07–2/1/08), the cost per household policy for all workers working in the home was approximately \$292.46.

- 61 Veridian Credit Union, Waterloo, IA.
- 62 Flanagan, S.A. (2004). *Assessing Workers' Compensation Insurance for Consumer-Employed Personal Assistance Service Workers: Issues, Challenges and Promising Practices*, for US Department Health and Human Services, Washington, DC: June 7th.
- 63 One Vendor F/EA in Pennsylvania—a Center for Independent Living—was able to broker limited health insurance coverage for workers employed by participants the CIL represents as their F/EA. They added the workers to a group policy offered by the PA Council on Independent Living to its members.

Chapter 8: Quality Management in Self-Direction Programs

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Chapter 8

Quality Management in Self-Direction Programs¹

Whether a self-direction program is funded by the federal government or the state, by Medicaid or the Older Americans Act, quality has the same meaning: it is the degree to which services and supports for individuals increase the likelihood of attaining desired health and quality of life outcomes.² Many stakeholders have assumed that ensuring quality is more difficult in self-direction programs because agencies will not be supervising home care workers or protecting participants from fraud, abuse, and neglect.

The Cash & Counseling Demonstration and Evaluation (CCDE) showed that participants and their families care deeply about quality, that the programs had the same or higher quality as those using agency-delivered services, and that quality management strategies were successful *because* participants directed their own services. Successful quality management strategies in self-direction programs view participants as the experts on their services, respect the need for accountability in publicly funded programs, and place a strong emphasis on quality improvement.

Key lessons learned from existing self-direction programs are that quality assurance requires states to: (1) design quality management strategies as part of program operations, (2) provide support for participants to obtain high-quality services, and (3) use data to continually improve the program.

This chapter provides practical information about quality management elements that are relevant for *all* service delivery models; those that are unique to self-direction programs are identified as such. It also describes the key components and principles of quality management for self-direction programs. Throughout this chapter, the term *participant(s)* categorically includes representatives and families unless a distinction is being made among them.

A. Elements of a Quality Management System: Overview

The elements of a quality management system have been developed and refined for many decades beginning with concepts first articulated by Walter Shewhart and Dr. W. Edward Deming. In the 1950's, Deming proposed that business processes should be analyzed and measured through a continuous feedback loop to enable the identification of problems and changes in processes to achieve continuous improvement. To illustrate this concept, he created the “Plan, Do, Check, and Act Cycle.”

- **Plan**—Design or revise business process components to improve results

- *Do*—Implement the plan and measure its performance
- *Check*—Assess the measurements and report the results to decision makers
- *Act*—Decide on changes needed to improve the process³

While Deming’s conceptual framework was designed for business operations, it is applicable in other settings as well, including programs that provide home and community-based services (HCBS). Somewhat mirroring Deming’s work, CMS describes the primary functions of a quality management (QM) strategy as

- assessing program activity and participants’ experience to evaluate the ongoing implementation of the program,
- identifying issues and immediately addressing or remediating them, and
- improving the program based on an analysis of data and other quality monitoring information.

In a State Medicaid Directors letter dated August 2002, CMS first distributed a draft of the HCBS Quality Framework to State Medicaid Agencies.⁴ This framework applied the basic functions of quality management by using design, discovery, remediation, and improvement concepts. While CMS has modified its initial approach to quality management significantly (described further in Section B of this chapter), the original functions have become accepted standards for HCBS programs and continue to provide guidance to states as they create QM strategies. The functions are:

Design. Designing an effective QM strategy is a critical first step to ensure quality in all HCBS programs, including those with participant-directed service options. When designing a new program, however, competing demands can result in quality issues not being addressed at this stage. When this happens, quality may not be effectively addressed until participants begin receiving services and problems arise.

When an effective QM strategy is an integral part of the initial program design, that strategy lays the foundation for achieving the program’s desired outcomes. Incorporating QM activities into program policies and processes during the design—or redesign—phase will help to ensure quality during implementation and beyond. For example, having methods for obtaining participant input in program design and evaluation from the outset is a QM strategy that improves the potential for the new program to meet the needs of the target population.

The development of an organized and well-conceived program design should incorporate specific quality assurance or monitoring activities and improvement strategies into every aspect of the program’s processes and procedures. Quality assurance and monitoring activities can be incorporated into service standards,

provider qualifications, service planning processes, program eligibility processes, risk assessment and monitoring, and safeguards to protect health and welfare. It is important to remember, however, that service standards and provider qualifications for participant-directed services and supports may differ from traditional criteria.

Discovery. Discovery is the process of finding out how the program is working: Is it meeting its intended purpose? Is it operating as required by its funding source? The process includes collecting data, analyzing results, assessing performance, and identifying areas needing improvement. These activities permit assessment of the ongoing implementation of the program and associated policies and procedures. They also produce information that can be used to inform and guide management and policy development.

Remediation. Any problems identified during the discovery process are corrected during the remediation process. Remediation is problem-solving for individual situations as they arise and for system level issues. Information about persistent problems and their solutions can inform system-wide quality improvement efforts. Typically, problems are identified during the discovery process.

Improvement. Improvement is the process of using the information collected to enhance overall agency operations. Rather than focusing on one specific individual or situation, the objective of quality improvement is to modify overall program performance to ensure that system changes are made that will help to prevent reoccurrences of problems.

B. Design Elements of a Quality Management Strategy

In the traditional service delivery model, state staff and provider agencies work together to develop and implement a system of checks and balances to safeguard individuals receiving HCBS and to monitor quality. The state, in part, relies on formal provider communities to work collaboratively in developing and implementing quality management activities.

In a self-direction model, many of the responsibilities historically assumed by provider agencies and their staff are transferred to participants and counselors. For this reason, existing certifications, standards, policies, regulations, reviews, and audits that are implemented in a traditional service delivery model may no longer be applicable. In fact, the very nature of self-direction is incompatible with many traditional health and welfare safeguards. For example, strict provider qualifications may severely limit participants' ability to select the individuals they want to work for them.

Since the traditional agency providers' role in assuring and monitoring health and welfare generally is not operative in a self-direction program, or is substantially

Definitions

The terms quality assurance, quality improvement, and quality management are widely used in industry, health care, and long-term services and supports settings, but the terms have many meanings and are sometimes used interchangeably. This chapter uses the following definitions.

Quality Assurance (QA) refers to efforts to make sure that services are provided according to pre-determined standards. An example of a quality assurance activity in an agency-provided service model is licensed nurse supervision of the performance of specific tasks by a home health aide in a participant's home. In a self-direction model, participants supervise workers' performance and thus provide quality assurance.

Quality Improvement (QI) is concerned with quality assurance, but goes beyond compliance with pre-determined standards. It is an ongoing process in which an entity continually uses information to review processes and outcomes, with the goal of minimizing or eliminating defects in the service. For example, if a program wants to develop a worker registry where participants can advertise job descriptions and personal assistants can advertise availability and qualifications, the program would pilot test the registry, periodically evaluate and re-evaluate its usefulness to participants and personal assistants, and make improvements accordingly.

Quality Management (QM) refers to strategies and processes that encompass both quality assurance and quality improvement. A QM system in self-direction programs integrates a range of QM processes to measure, assess, and improve service quality, participants' outcomes, and overall program performance.

reduced through the transfer of responsibility to the participant, counselors, and financial management services (FMS) entities, states need to consider flexible and creative means to ensure quality.

The following discussion of key design elements of a quality management (QM) strategy focus on self-direction. However, all but the last one are relevant for *all* service delivery models.

Ensuring that Service Plans Reflect Individual Needs Through Use of a Person-Centered Planning Process

Self-direction programs are based on the philosophy that participants have the right and the ability to direct the process for assessing their needs, deciding how these needs will best be met, and evaluating the quality of the services they

receive. Putting this philosophy into practice has implications for many aspects of program operations.

Regardless of the service delivery option—traditional agency or self-direction—person-centered planning (PCP) should be initiated to ensure that the service plan addresses participants’ identified needs and goals. The planning process involves the participant, family members if desired, their representatives, counselors, required state staff, and other individuals participants choose. The person-centered plan becomes the “roadmap” for delivering, managing, and monitoring services. Both informal and formal methods are used as part of the PCP process to:

- identify needs and develop a plan to meet those needs;
- address key aspects of service provision;
- identify shared responsibilities, and
- identify, assess, and manage risks, and establish a backup plan.

Quality assurance activities to ensure that service plans meet assessed needs and that services are delivered in accordance with the service plan include: reviewing documentation in the case file to determine whether participants’ preferences are identified; comparing services and supports identified in the service plan with participants’ preferences; and obtaining feedback from participants on the planning process and the services they received.

Vermont’s and Florida’s self-direction programs have a participant goal setting (PGS) process to ensure that service planning is participant-centered. In this process, participants identify their personal goals, and determine—with help if needed from family members and/or counselors—which services and supports they need to help them to meet their goals. The process includes an evaluation component, which asks participants if they met the goals they identified, and, if not, whether any additional steps can be taken to assist them to meet their goals.

The follow-up also includes more structured questions about the program, such as “Do you have enough say in choosing your workers? If not, is there anything we need to do about that?” The PGS process supports the participant-centeredness of the program, and documents the involvement of participants in the planning process. A detailed discussion about collecting and using participant data is presented in Section E of this chapter.

Establishing Operational Policies, Procedures, and Practices

Policies, procedures, and practices specific to self-direction should be clearly specified to set realistic expectations and provide clear direction. These should be consistently applied throughout the program. Each of the 15 states that received Cash & Counseling (C&C) grants developed specific manuals or

operational protocols that specify the day-to-day operations of the program and clearly articulate processes and procedures. Examples of these protocols can be found on the C&C website. See the Resources section at the end of this chapter for direct links.

Informing Key Players of their Rights, Roles, and Responsibilities

Self-direction works best in an environment where the rights, roles and responsibilities of participants, family members, representatives, providers of services and supports, and state staff are clearly defined. Programs need to educate participants, representatives, and families about their rights and responsibilities. Most programs have developed an explicit “Bill of Rights” for participants and have developed charts or lists to specify roles and responsibilities. Participants should also be informed of their right to appeal decisions made by the state regarding program participation and how to file complaints. All materials should be available in a variety of alternative formats and written at an appropriate reading level.

Providing Criminal Background Checks

Typically, self-direction programs provide a mechanism for participants to obtain criminal record checks on potential workers. Many programs do not require criminal background checks when participants hire relatives or family members, but their use depends on state laws and specific program requirements. If they are not required for workers in the traditional system, states must decide whether or not to mandate their use in self-direction programs.

For example, some programs require criminal background checks only for individuals who advertise their availability as personal assistants through registries. Others require criminal background checks for all workers except family members. States that require criminal background checks must also decide whether to prohibit participants from hiring anyone with a criminal record or to designate the circumstances under which someone with a record may or may not be employed (e.g., making distinctions between misdemeanors and felonies as well as between recent crimes and those committed many years ago).

Support should be available to help participants understand and analyze the background check results to determine if findings are significant relative to the services that the worker will provide and if the potential worker poses a risk.

States must also decide whether criminal background checks will be conducted on a state, regional, or national level. Usually the cost and time to conduct the search increases as the scope of the search broadens. Programs may also consider implementing an abuse registry that participants can check before they hire a worker.

Managing Risk

Managing risk is a process that (1) assesses participants' exposure to potentially harmful situations and (2) develops a plan to prevent such exposure and to address it quickly if it occurs. It is a key component of an overall quality management strategy.⁵ A risk assessment is generally conducted as part of the needs assessment and service planning process. Requiring that risk assessment be part of service planning is an example of how states can design their programs to include policies and processes that help to ensure health and welfare.

A standardized risk assessment process is preferable and many tools are available, which can be modified as needed. One example is New Jersey's Personal Preference Program Risk Assessment Profile. This instrument collects information about an individual's environment, functional limitations, mental status, ability to communicate, and other characteristics that expose him or her to harmful or potentially harmful situations.

Each assessment area is assigned points based on the degree of risk (i.e., the likelihood of a potentially harmful situation occurring). The score can be reduced by risk reduction factors such as having a live-in caregiver or friends and relatives nearby. Once the final score is calculated—risks minus reduction factors—a plan to address remaining risks is developed. See the Resources section at the end of this chapter for information about risk assessment tools.

Once risks are identified, an individualized strategy to prevent or reduce risk should be developed. If the major risk is that a scheduled worker will not show up, then the backup plan (discussed below) becomes part of the risk management strategy. Developing such a strategy should be part of service planning for all participants, whether in the traditional or self-directed services system. In both systems, risk management strategies must be complemented by periodic and ongoing monitoring processes to determine if they are working at the individual and/or system levels.

Monitoring can take many different forms. Programs can and do use their existing quality monitoring staff—as long as training is conducted on self-direction—to oversee the performance of providers unique to self-direction, such as participant-directed workers, counselors, and FMS entities. They also may identify other staff or techniques to conduct monitoring activities. States also may require counselors or traditional case managers to assume quality oversight responsibilities to ensure that participants are receiving authorized services and that these services are adequate to meet their needs.

Components of a Risk Management System

- Develop specific program policies and procedures clearly outlining roles and responsibilities of participants, case managers and/or counselors, state support staff, and participants' workers.
- Develop a process to formally identify situations that could pose harm and assess the likelihood of their occurrence (e.g., a worker not arriving on time to administer medications).
- Discuss these potential situations with participants.
- Develop a plan to reduce or eliminate the possibility that these situations could occur and a backup plan to prevent harm should they occur.
- Ensure that a process is in place to protect participants' right to assume risk and honor their decisions.
- Monitor the service plan to ensure health and welfare.

Ensuring the Availability of Backup Services

Every participant receiving HCBS—whether through the traditional agency system or a self-direction program—should have an individual backup plan to handle situations when providers of services and supports that are essential to participants' health and welfare become unavailable.

Typically, programs create this backup process as a function of the person-centered planning process during the development of the service plan—which should include a risk assessment process. An individual's service plan should identify issues or situations that jeopardize health and welfare and specify actions to prevent and/or correct them. All participants should be educated about the availability of backup resources.

Even though a worker may have a legitimate reason for not arriving, such as illness or a childcare crisis, the consequences of worker tardiness or absenteeism can be more than merely inconvenient for some participants. In addition—although comparatively infrequent—serious situations can arise when a worker quits without giving notice.

Participants' service plans need to include individualized strategies to deal with such situations should they occur, and to prevent and lessen risks whenever possible. Not only do participants need to have already identified backup workers or agency providers that they can call for assistance, they must also have a means of summoning assistance. The latter can be especially problematic for participants with certain types of impairments, such as quadriplegia.

Components of a Comprehensive Backup Plan

- Identifies circumstances that could lead to harm if not addressed.
- Provides detailed procedures for obtaining backup support and services.
- Provides detailed procedures for obtaining assistance during an emergency or a crisis or if the backup plan fails.

Potential strategies for addressing such critical situations include purchasing a personal emergency response system (PERS) or a voice-activated telephone to enable a participant with a severe mobility impairment to summon help in the event of an emergency, arranging for a neighbor or a friend who lives nearby to serve as a backup until another worker arrives or another can be found, or both. Some participants are able to rely on family and friends to fill in whenever their worker is absent. For others who lack sufficient family support, the backup plan might include a prearranged plan with a traditional agency to provide emergency assistance or the use of a worker registry to obtain immediate access to workers.

If the backup plan includes hiring alternate workers, all of their payroll paperwork must be on file in advance. Also, having generic terms in the individualized budget (e.g., the number of hours of assistance from a worker, rather than naming a specific worker) makes it easier to handle day-to-day changes while keeping the service plan intact. The effectiveness of backup plans should be tested periodically and changes made as needed. See Chapter 9 for a discussion of concerns about health and safety risks and liability for poor health outcomes.

Managing Critical Incidents

Critical incidents include (1) abuse, neglect, and/or exploitation; (2) unexpected or frequent hospitalizations; (3) deaths;⁶ (4) serious injuries that require medical intervention or result in hospitalization; (5) medication errors; (6) inappropriate use of restraints; and (7) other incidents or events that involve harm or risk of harm to participants.

Reports of abuse, neglect, and/or exploitation by participant-directed workers in the CCDE were extremely low. Similarly, in a study comparing the experiences of California In-Home Support Services participants who employed their own workers with those who used agency services, reports of abuse, neglect, and mistreatment were very low for both groups.⁷

To ensure participants' health and welfare, states need to have a system for timely identification and remediation of critical incidents. States must have a designated entity with the responsibility and authority to take whatever actions are needed to

resolve and remedy critical incidents and prevent recurrences.

For such a system to be effective, participants and their employees need to be educated about the risk of critical incidents and what to do when one occurs. The program must ensure that everyone who has contact with participants—counselors, service and support providers, and anyone else responsible for quality monitoring—are trained to know what steps to take if they identify or suspect that abuse, neglect, and/or exploitation is occurring. Everyone involved in the program must have contact information for the entity charged with investigating and remediating critical incidents, and service providers—including participant-hired workers—must understand their legal responsibility to report such incidents.

Because critical incident reporting ultimately depends on the willingness of participants to report incidents whose occurrence may be known only to them, it is vital for states to establish policies and procedures for incident reporting that will encourage reporting and make participants feel safe doing so.

Developing Responsive and Timely Methods to Meet Changing Needs

In the traditional agency-delivered service model, when participants can no longer meet their needs with the allocated resources, the provider generally identifies and reports the increased need. In a self-direction program, participants have primary responsibility for reporting changed circumstances and increased needs to the appropriate person or agency—especially during the periods between regularly scheduled meetings with their counselor.

States need to establish a process for revising service plans and individual budgets in a timely manner to ensure that participants' needs are met.

Providing Orientation and Training for Workers

Participants—with assistance from individuals or agencies providing supportive services when needed—assume the role of orienting new workers. They need to ensure that workers understand their duties and how to interact with them. Participants also negotiate the workers' work schedule and—in some programs—their wages.

States may also require a standard orientation for all new workers (e.g., one that discusses basic principles of hygiene and safety and provides information on how to identify and report instances of abuse, neglect, or exploitation). Community educational opportunities such as courses offered by the American Red Cross should also be considered as resources.

Most participants need personal care workers to assist them with activities of daily living and homemaker activities. In many instances, this work requires minimal training and participants often are fully capable of providing it. If special

skills or knowledge are required, states need to have policies and procedures regarding who will provide the necessary training; for documenting that appropriate training has been provided; and for ensuring that workers demonstrate the ability to perform required tasks before being hired or before they are allowed to perform them independently.

Establishing Policies and Procedures for Participants to Return to the Traditional Agency Model— Voluntarily and Involuntarily

Successful self-direction requires participants to assume responsibility for multiple tasks with support and assistance as needed. When participants are not able to handle these responsibilities, states need efficient policies and procedures to enable participants to either return to the traditional agency-directed model, or to change to a mixed model in which they continue to direct some services and receive others from an agency. Policies and procedures are needed for both voluntary and involuntary transitions.

C. Discovery Elements

Discovery is the process of identifying which aspects of a program are working well and which need improvement. The discovery process has three key elements—obtaining information from participants, monitoring, and critical incident management systems.

Obtaining Information from Participants

Accurate and timely feedback from participants is the foundation of any QM strategy. Without an effective and reliable mechanism to obtain participants' feedback, programs will be unable to fully assess their performance in order to develop improvement strategies. States have many different options for seeking participant feedback, including telephone interviews, in-person interviews, and mailed surveys. For simplicity, in this section we refer to the general process of seeking formal input from participants as a survey.

States need to consider several factors when developing and implementing a participant survey. First and foremost, the purpose of the survey should be explicit. Establishing clear objectives regarding the content of the survey, why it is being conducted, and how the information will be used is the first step, and will have an impact on every other decision about what kind of participant survey process to implement. It is important to ask probing questions about the level of satisfaction with participants' supports (e.g., are they satisfied with their counselors and the FMS entity?).

Several standardized instruments are available to assess participants' experiences and satisfaction with self-directed services. Other measures ask about outcomes, or seek feedback about a specific aspect of the program. Available instruments

include the Participant Experience Survey (PES), the Participant Goal Setting instrument (PGS), the National Core Indicators, and a host of state and agency participant satisfaction surveys. See the Resources section at the end of this chapter for links to more information about these instruments.

Each of these instruments may have a slightly different focus and may ask questions in different ways. Once the purpose of the participant survey is decided, the ways in which the data will be used, and by whom, should be specified.

Additional decisions about the participant survey process include: (1) whether to survey the entire population of participants, or to select a sample; (2) which data collection strategy to use; (3) which strategies to use to include participants in the development of the survey tool; (4) who should collect the data; and, (5) how to analyze, report, and use the data. Many different approaches are possible—each with advantages and disadvantages—and states need to assess which will work best in their program.

Other means of obtaining participant feedback include the use of focus groups, public forums, telephone contacts, complaint lines, and comments expressed directly to the program staff.

Monitoring

Comprehensive QM strategies implement more than one level of monitoring. The specific staff involved will depend on whether participants direct their services as well as other program features. States can employ case managers, counselors, FMS providers, state QA staff, or all or some combination of these individuals. States may also use family and peer monitoring and/or advocacy agencies, such as family council organizations as adjuncts to the state monitoring system. All individuals and organizations charged with monitoring should be formally trained in person-centered planning and the philosophy of self-direction.

Critical Incident Management Systems

While critical incident management is described above as a program design element, the focus in this section is more on state systems for collecting and analyzing data on critical incidents. When the health or welfare of a participant has been jeopardized, local and state program administrators must have a system for gathering timely information and tracking the remediation of identified problems. Often these systems are called “Incident Reporting” or “Critical Event Tracking Systems.”

Several state waiver programs have developed automated reporting and tracking systems that provide virtually real-time information on critical events, including the status of the event, how it is being addressed, and by whom. Automating the collection of these data allows for analyses of patterns, such as the characteristics

of persons at risk, categories of critical events, and types of alleged perpetrators.

This information can be used to identify specific areas that should be targeted for quality improvement initiatives. For example, if several individuals experience the same type of incident—such as a fall or the failure of a backup plan—then there may be an underlying common problem that can be identified and addressed through quality improvement. (See discussion of remediation and improvement below). By identifying trends, the system could then help the state determine if a specific QI initiative is having the intended effect.

Over the years, many states have developed systems to report and address critical incidents. Often, the hub of these systems is the state’s Adult Protective Services (APS) Unit or the State Offices on Aging, although they often reside outside the administering agency for HCBS programs and are responsible for addressing the needs of all vulnerable adults, not just public program participants.

Because managing critical events or incidents is a pivotal function in the administration of any HCBS program, CMS encourages states to build on existing systems to improve their emergency response capacity. However, at the same time, states need to have a critical incident management system to handle critical incidents specifically for HCBS program participants.

D. Remediation Elements

The remediation process involves activities to solve specific problems as they arise as well as system level problems. The process provides information about persistent problems as well as effective solutions to address these problems. Once a problem with the quality of services or supports comes to the attention of administrators, it must be addressed and rectified as quickly as possible to protect participants, especially those in immediate jeopardy.

Remediation efforts can include educating or helping participants to deal with the problem themselves or intervening on their behalf. As remediation proceeds, an evaluation or investigation of the situation is usually warranted to determine the factors that contributed to the problem. The key elements of a remediation strategy are:

- A quick response to protect participants
- Evaluation or investigation of the situation
- Communication with appropriate entities
- Actions to prevent additional occurrences

Once there is an understanding of causative and contributing factors, then a plan can be devised to prevent similar problems from occurring in the future—not

just for a single participant but for others as well, particularly those in similar circumstances.

E. Improvement Elements

Improvement involves using the information collected to enhance overall agency operations. Rather than focusing on specific participants' problems, quality improvement (QI) activities focus on the program as a whole. Four broad and interrelated strategies are available for doing so—systematic collection and review of data; integrating, analyzing and using data to improve quality; establishing a quality improvement committee; and developing targeted quality improvement projects.

Systematic Collection and Review of Data

The systematic collection and review of data is the crucial first step not just in the discovery process (discussed above) but also in the improvement process because a program cannot be improved without knowing where improvements are needed. Data are essential for understanding a program's problems, issues, and patterns, and for targeting areas where changes would be beneficial. While anecdotal information can be illuminating, effective quality improvement relies on a well-established mechanism for obtaining data on participants' experiences and integrating these data with other information collected, such as results of participant experience surveys or assessments of participant under- or over-spending.

Integrating, Analyzing, and Using Data to Improve Quality

The ability to use data to improve a program is a critical QI principle. While programs have progressed in their ability to collect data needed for QI activities, many do not have the means to integrate, analyze, and use data to actually improve program performance. In order to use data, programs need a mechanism for entering and analyzing the information collected. Although data entry is not difficult, it requires a routine method for recording information. For example, one self-direction program kept a detailed log of critical incidents for several years and was diligent about responding to each problem as it arose. But it never systematically looked at the array of incidents to see if there were common problems that might have been prevented with a systemic solution.

Participant satisfaction surveys typically have more complicated data entry challenges. There are a number of options available for facilitating data entry such as the use of scannable forms, direct entry on lap top computers, and web-based tools. Whatever the option, it is important for programs to think carefully about the data entry approach prior to data collection.

Once data are entered, programs need to have a mechanism to analyze the information. The program may need to partner with a research unit or develop internal capabilities. Changes in computer technology and software have made internal efforts more feasible, but staff time and expertise are still required.

In the analysis phase, programs can ask questions about how the results can be used to improve program quality. See the box below for examples on how information can lead to program improvement.

Using Data to Improve a Program

Case 1. A self-direction program that collected systematic information on critical incident reports found that falls were the most common problem recorded, accounting for almost half of all incidents. In response, the program developed and implemented a falls prevention program. In the initial analysis, it was determined that the falls prevention program had some success. However, the program managers decided to conduct a more in-depth review of the data. During a second round of analysis the program identified more detailed information about individuals most at risk of falling. Based on this data, the program developed a more intensive prevention program for this group and is now collecting follow-up data to assess its effectiveness.

Case 2. An area agency on aging (AAA) that administers a self-direction program has its case managers collect satisfaction data from all participants in both the traditional and self-directed services options. The case managers collected satisfaction data on the five home-delivered meals providers in the service area. A surprising finding was that the provider that had been considered the best because of high scores on food quality, scored very low on delivery reliability. When the AAA consulted the meals provider, it found that the provider used a large number of volunteers to make deliveries. Because the schedule was typically set based on volunteer availability, delivery times varied considerably throughout the week. Bringing this problem to the attention of the meals provider led to improvements. The following year, the provider received higher reliability scores from participants.

Establishing a Quality Improvement Committee

A Quality Improvement Committee comprising a wide range of program stakeholders can help states improve program quality for two reasons. First, program staff members typically focus on their program roles or responsibilities, without necessarily seeing how separate units intersect, overlap, and duplicate or contradict each other. A committee that involves key program stakeholders provides a mechanism to ensure that quality is viewed from all perspectives,

facilitates consensus on improvement strategies, and maximizes buy-in for the strategies devised to address identified problems. Second, a committee focused on quality improvement is advantageous because it creates a group with the authority to continually challenge the administering agency to improve the program.

To ensure a committee's effectiveness, states need to carefully consider its composition, responsibilities, and the need for training and support. A committee of between eight and twelve members is a workable size. These members should represent the full range of program stakeholders. Core members should include participants and their representatives, program staff, counselors, FMS staff, community advocates, and other state officials. Additional or ad hoc appointees should be added to the committee based on the need for expertise to address specific topics.

Committee responsibility must be clearly articulated at the beginning. Reaching consensus on the scope of responsibility and the time frame for committee activities is a critical first step. In order to be an effective part of the QM strategy, members must have a clear idea about how the committee fits within the overall QM strategy and the extent of their authority.

Training and support are essential to committee success to ensure that all members have the information needed to be active and effective. Resources to support travel costs are essential and a stipend to compensate members for their time makes an important statement about the value of their activities. The committee also needs assistance from program staff to organize and implement activities by producing accessible documents and ensuring meeting space is accessible. Staff members who are asked to allocate time to support committee work should have this specified in their job responsibilities.

The committee should have an opportunity to (1) routinely review data and reports on program performance, (2) hear and comment on how the program intends to use this information to improve quality, and (3) recommend improvement strategies. Although committee members may occasionally become involved in a specific quality improvement project, the committee's primary charge is to be responsible for the program's overall quality vision and strategy.

Targeted Quality Improvement Projects

A quality improvement project that employs an in-depth examination of one problematic aspect of a program is one avenue for improving the quality of the program across the board. Often quality improvement projects are designed as pilot projects and may be restricted geographically or by some other criteria. Following a thorough review of data and stakeholder input regarding the various factors that contributed to a specific problem, a strategy may be developed to alleviate the problem by applying specific interventions.

The strategy might outline proposed changes, data collection methods, anticipated effects, measurable outcomes, and timelines for evaluation. Program changes should be tracked to determine if the modifications implemented have had the intended beneficial effects. If so, the modifications may be adopted. If not, other strategies should be considered to address the problem. It may be necessary to undertake a targeted data collection effort to measure the impact of the intervention. Once the results of a pilot project have been reviewed and the impact of the intervention assessed, the Quality Improvement Committee may decide to recommend that the strategy be implemented more broadly or applied system-wide.

The design of a program's QM strategy might require quality improvement projects at all levels of program administration and delivery. In self-direction programs, these activities might be contractually negotiated with counselors and FMS providers or managed by state staff or case managers. Collectively a state's discovery, remediation, and improvement strategies should create an ongoing circular flow of data and feedback to keep participants, other stakeholders, and the administering agency informed about the overall operation of the system and its component parts.

F. Overview of Federal Medicaid Requirements for HCBS Quality Management

In early the 2000's, CMS developed an HCBS Quality Framework to guide quality management in Medicaid HCBS waiver programs.⁸ The framework was developed with broad input from multiple stakeholders and with the collaboration of the National Association of State Medicaid Directors, the National Association of State Units on Aging, and the National Association of State Developmental Disability Directors. While CMS has not required states to use the framework, it is an excellent tool to guide the development of—or serve as a foundation for—a QM strategy in their self-direction programs. Additional information about the framework may be obtained at <http://www.hcbs.org/moreInfo.php/doc/952>.

CMS has strengthened its commitment over the past few years to improve the overall quality of services provided to Medicaid participants and to clarify federal requirements and their relationship to assurances states must provide regarding quality. CMS requires states to have systems in place to maximize the quality of life, functional independence, and well-being of participants in Medicaid HCBS programs.

While requirements vary by statutory authority—§1915(c), §1915(i), and §1915(j)—at a minimum, states must have systems in place to measure and improve their performance to ensure that:

- Service plans (plans of care) reflect individual needs

- Qualified providers meet state requirements
- Participant health and welfare are maintained
- The state Medicaid agency retains overall administrative authority and oversight of the program
- States operate their programs with financial accountability

Each authority—waiver or State Plan option—specifies required assurances that states must provide and furnishes guidance to states for describing their quality management strategies in detail, including discovery, remediation, and improvement activities. Generally, states are required to describe the

- Roles and responsibilities of entities and persons involved in collecting and analyzing information pertaining to quality and oversight
- Type, source, and frequency of data collected
- Activities to correct problems identified through the discovery process
- Strategies to enhance and improve program performance

CMS provides technical assistance to state programs to help them match quality requirements for HCBS services (under §1915(c), §1915(i), and §1915(j) authorities) to Medicaid statutory assurances, and to focus on continuous quality improvement. To aid states with their quality management plans, CMS asks programs to articulate quality improvement strategies by specifying: (1) performance measures, including those specific to self-direction; (2) data sources to collect information on the performance measures; (3) parties responsible for data collection/analysis; (4) frequency of data collection; and (5) sampling approaches.

An example of a program performance measure is the number and percentage of applicants and participants whose case files document that a choice was made between traditional services and self-directed services. The data sources are applicants and participants' files; the parties responsible for collecting and analyzing the data are the Medicaid state agency staff; the frequency is every two years; and a representative sampling approach is used.

States must provide this information when applying for or renewing a waiver program or applying for a State Plan amendment.

Resources

Publications

Applebaum, R., Schneider, B., Kunkel, S., and Davis, S. (2004). *A Guide to Quality in Consumer Directed Service*. Prepared by Scripps Gerontology Center, Miami University for USDHHS, Assistant Secretary for Planning and Evaluation.

This publication is based on a philosophy that the views of the major program stakeholders—consumers, families, program staff, regulators, funders—are the necessary starting point for the design of a quality system. A practical handbook on ensuring and improving the quality of services, it provides a detailed guide for self-direction programs as they work to establish a quality management system.

Available at: <http://www.cashandcounseling.org/resources/20060111-143548>

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. The Version 3.5 application contains substantive changes to the Version 3.4 application in the area of quality, and contains minor, clarifying improvements throughout the document in other areas.

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>

Foster, L., Dale, S., Brown, R., Phillips, B., Schore, J., & Lepidus Carlson, B. (2004). *Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities?* Prepared by Mathematica Policy Research, Inc., for USDHHS, Assistant Secretary for Planning and Evaluation.

This study of Florida’s Cash & Counseling demonstration program, Consumer Directed Care, compares children’s use of services and quality of care under traditional versus participant-directed approaches to Medicaid HCBS.

Available at: <http://www.cashandcounseling.org/resources/20060120-102143>

Fralich, J., Booth, M., & Keith, R. (2006). *Data Quality and Analysis: Managing and Using Home and Community-Based Services Data for Quality Improvement*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This report describes the activities needed by programs to analyze and use data for quality management activities. It is important for a program manager to understand

the process and to provide the time and resources necessary to produce reliable and accurate data. The paper focuses on ways to ensure accuracy, discusses tools for analyzing trends and patterns, and provides tips on interpreting results.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1555>

Fralich, J., Booth, M., Gray, C., Bowe, T., & Bratesman, S. (2005). *Discovery Methods for Remediation and Quality Improvement in Home and Community-Based Services*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This paper synthesizes the ideas and practices of states as they seek to improve the quality of HCBS services. The purpose of this paper is: to promote the exchange of information among states regarding the use of discovery methods for HCBS services; to identify and share the various approaches that states are using to identify gaps, redundancies, strengths and weaknesses in their HCBS quality systems; and to discuss ways to prioritize activities and select quality improvement activities.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1253>

Freedman, R. & Taub, S. (2006). *Sampling: A Practical Guide for Quality Management in Home and Community Based Waiver Programs*. Produced for CMS by the National Quality Contractors, MEDSTAT Group and Human Services Research Institute.

This report provides advice when a program needs to select a sample of participants as part of its quality management strategy. It provide states with practical information about sampling techniques, what to consider when deciding whether to sample, and the strategies to employ in quality management work.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1552>

Galantowicz, S., Selig, B., Pell, E., & Rowe, J. (2005). *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement*. Produced for CMS by the National Quality Contractors, MEDSTAT Group, and Human Services Research Institute.

This publication contains an excellent overview of risk assessment and mitigation and identifies many useful resources, including risk assessment tools.

Available at: <http://www.cms.hhs.gov/HCBS/downloads/qualityriskmgmt.pdf>

Mahoney, K.J., Simone, K., & Simon-Rusinowitz, L. (2000). *Early lessons from the Cash & Counseling Demonstration and Evaluation*. Reprinted with permission from *Generations* (2004), Vol. 24 (1), 41–46.

The article provides an overview of the implementation of the Cash & Counseling program and discusses early lessons learned. The implementation lessons are

divided into categories pertaining to the different aspects of the program: program design, outreach, counseling issues, fiscal intermediary, and monitoring quality.

Available at: <http://www.cashandcounseling.org/resources/20051202-175625>

Simon-Rusinowitz, L., Loughlin, D., & Mahoney, K. (2006). *Do Consumers get Good Quality Care in a Consumer-Directed Program? Experience from the Cash & Counseling Demonstration and Evaluation*. Boston, MA: Cash & Counseling National Program Office.

This article discusses the quality of care received by participants in the Cash & Counseling Demonstration and Evaluation, including health outcomes, the potential for fraud and abuse, and participant satisfaction.

Available at: <http://www.cashandcounseling.org/resources/20080111-144811>

Web-Accessible Resources

Cash & Counseling National Program Office

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

This web-site contains several resources on quality and self-direction, for example:

Quality Crosswalk Table with the Required Waiver Assurances authored by Barbara Scheinder is a summary of nine quality initiatives, followed by a crosswalk between the required Medicaid assurances, the HCBS quality framework, and quality initiatives and tools relevant to implementing the quality framework in Cash & Counseling programs. Available at: <http://www.cashandcounseling.org/resources/20060111-144320>

Expansion of the Cash & Counseling Demonstration, Performance Indicators: Report Shells and Instructions. During the second round of C&C grants, the C&C National Program Office developed a list of performance indicators for the twelve C&C replication grantees to track how well their programs were doing. This document contains report shells and instructions for the Cash & Counseling replication project. Available at: <http://www.cashandcounseling.org/resources/20070604-123348>

Participant Goal Setting Tool. This tool was developed by Scripps Gerontology Center to help participants in Cash & Counseling programs set personal goals. The tool's three major objectives are: to provide a structured process to ensure that the participants' goals are clearly articulated and that the spending plan represents their needs and wishes; to ensure and improve quality at the individual level; and to use data collected for quality improvement at the program level. Available at: <http://www.cashandcounseling.org/resources/20080303-130304>

Centers for Medicare and Medicaid Services

Web-site address: <http://www.cms.hhs.gov/HCBS/>

The website provides an overview of quality and links to additional information about quality and HCBS, in particular:

Quality Oversight at http://www.cms.hhs.gov/HCBS/05_Quality_Oversight.asp#TopOfPage and

CMS Communications at http://www.cms.hhs.gov/HCBS/04_CMSCommunications.asp#TopOfPage

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 of all ages with disabilities. The site has several publications and resources regarding the quality of services in HCBS generally and in self-direction programs specifically. For example:

CMS State Medicaid Directors Letter: Risk Management and Quality in HCBS is one of a series of quality letters and progress reports. This, the eighth letter, addresses the interrelated steps for successful risk management for individuals in HCBS waivers.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1151>

Home and Community-Based Services: Quality Management Roles and Responsibilities is the first in a series of papers from Rutgers Center for State Health Policy synthesizing the ideas and practices of states as they improve the quality of HCBS and supports for older persons and persons with disabilities.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1132>

Measuring Consumer Outcomes and Satisfaction in California: Identifying a Survey to Provide a Foundation for Quality Management. Included in the report are a comparative review of consumer satisfaction survey instruments considered for use and an analysis of California's information system with respect to the requirements of participation in National Core Indicators.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1808>

Negotiated Risk Agreements in Long-Term Support Services. This article evaluates the potential for using negotiated risk contracts in consumer-directed home and community-based long-term services and supports.

Available at: <http://www.hcbs.org/moreInfo.php/doc/144>

Participant Experience Survey (PES) Tools. The PES is an interview tool developed by MEDSTAT under a contract from CMS. The surveys capture data that can be used to calculate indicators for monitoring quality within the waiver programs. Two versions of the PES are included, one for frail elderly and adults

with physical disabilities and another for adults with MR/DD. A users' guide accompanies each PES. Each survey can be conducted in a face-to-face interview in 30 minutes or less.

Available at: <http://www.hcbs.org/moreInfo.php/doc/652>

State Satisfaction Surveys. This site provides a number of reports by states that generally contain their survey tool, methodology, findings, and recommendations to improve satisfaction among key stakeholder groups. (Search for Keyword: Stakeholder Involvement—Type/Tool: Survey)

Available at: <http://www.hcbs.org/advancedSearch.php>

National Core Indicators

Web-site address: <http://www.hsri.org/nci/>

The National Core Indicators (NCI) is a collaboration among participating National Association of State Directors of Developmental Disability Services member state agencies, and the Human Services Research Institute, with the goal of developing a systematic approach to performance and outcome measurement. The website provides access to reports that describe NCI activities, methods, and results of data collection. Final or summary reports describe methods and present results for a particular set of indicators or survey tool (e.g., consumer outcomes, family surveys, provider survey).

Citations, Additional Information, and Web Addresses

- 1 Suzanne Crisp, Robert Applebaum, Suzanne Kunkel, and Janet O’Keeffe co-authored this chapter, which is based on a draft technical guide chapter developed in 2004 by Beth Jackson and Suzanne Crisp, Thomson Healthcare, under contract to CMS.
- 2 Quality Overview. May be accessed at www.cms.hhs.gov/HCBS/
- 3 <http://www.balancedscorecard.org/TheDemingCycle/tabid/112/Default.aspx>
- 4 CMS Center for Medicaid and State Operations, Disabled and Elderly Health Programs Group (August 29, 2002). *Quality in Home and Community-Based Services: The Quality Matrix and Framework*. Letter to State Medicaid Directors. Available at <http://www.hcbs.org/moreInfo.php/doc/952>.
- 5 Galantowicz, S., Selig, B., Pell, E., and Rowe, J. (2005). *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement*. Prepared for CMS by the MEDSTAT Group and Human Services Research Institute.
- 6 While all deaths may need to be reported as part of a critical incident management system, when serving an elderly population—some of whom are terminally ill—some deaths will be expected and will not require an in-depth investigation once the facts surrounding the death are known.
- 7 In multivariate models that controlled for risk factors such as level of disability, there were no statistically significant differences in reports of abuse, neglect, or mistreatment by self-directing participants as compared to those receiving agency-delivered, professionally supervised aide services. However, there were some statistically significant differences indicative of lower reported incidents of abuse, neglect, and mistreatment when aides were family members rather than un-related individuals (regardless of whether the unrelated aides were participant-directed or agency employees). Matthias, R. & Benjamin, A.E. (2003). Abuse and neglect of clients in agency-based and consumer-directed home care. *Health and Social Work*, 28 (3): 174.
- 8 CMS Center for Medicaid and State Operations. (August 29, 2002). Op. cit.

Chapter 9: Self-Direction and Health Care

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Chapter 9

Self-Direction and Health Care¹

This chapter discusses ways in which self-direction programs, especially those that provide individual budgets, can facilitate participants' access to health care and maintain and improve their health and functioning. The chapter also discusses how Nurse Practice Acts can hinder or facilitate self-direction, how states can address safety risks when participants have extensive health care needs, and how a few states have incorporated self-direction options into managed care plans.

A. Health Care Needs of People with Disabilities

Because chronic diseases and medical conditions can limit functioning—and functional limitations (particularly those due to mobility impairments) can increase the risk for medical complications and secondary disabilities—many people with functional limitations need and receive considerably more medical care than the average person in their age cohort.² Medicaid beneficiaries with functional limitations, in particular, are heavy users of medical care as well as long-term term services and supports.³

Additionally, although personal assistance services (PAS) are generally non-medical in nature, PAS can include the provision of assistance with routine health or health-related tasks, some of which may be under the purview of state Nurse Practice Acts (NPAs). If so, by law, they can only be performed by licensed nurses, with some exceptions (discussed below). PAS can also include tasks generally performed by physical and occupational therapists, such as range of motion exercises to prevent contractures and to improve or maintain functioning.

Some health-related PAS includes routine activities that do not require special skills, such as reminders to take prescription medications and physical assistance in taking medications (e.g., opening a container). Other activities include procedures that require special training and skill (e.g., urinary catheterization and tube feeding). The need for assistance with at least one health or health-related task is very common among Medicaid program participants (hereafter, participants) who need long-term services and supports.⁴ The Cash & Counseling Demonstration and Evaluation (CCDE) found that between 86 and 92 percent of primary informal caregivers of working-age adult and elderly participants reported providing some health-related PAS.⁵

B. Ways in Which Self-Direction Can Facilitate Access to Health Care

Participant-directed PAS and the ability to direct an individual budget, in particular, have been found to reduce unmet needs, reduce the likelihood of

adverse health events, and reduce the use of nursing homes and other medical services.⁶ However, to maximize the likelihood of these positive outcomes, states need to ensure that participants have flexible budgets and the authority to purchase a wide range of goods and services that meet their health and rehabilitative needs and improve or maintain their functioning.

In states that provide flexible budgets, the goods and services that may be purchased include assistive technologies and related repair services; environmental modifications; medical and personal care supplies, including prescription and over-the-counter drugs not covered by Medicaid or Medicare; rehabilitation services; and transportation services. Not only do such goods and services often reduce dependence on family caregivers or paid workers and promote independence, they often meet medical needs or have a health promotion role.

Participants in New Jersey’s Personal Preferences Program used their budgets to purchase air conditioners (for individuals with respiratory conditions); special mattresses and chair pads to help prevent pressure sores; and equipment and home modifications to prevent falls, scalding, and other injuries.⁷ While some of these items are coverable as Medicaid benefits, they may not be covered in a particular state or waiver program, or the particular brand or model that best meets a participant’s needs may not be covered. Sometimes an item is coverable under the traditional waiver program but only after a lengthy prior-authorization process.

Improved Access to Long-Term Rehabilitative Therapies

A sizable subgroup of CCDE participants used their budgets to purchase physical, speech, occupational, and respiratory therapies. While these services are provided in the traditional health care system, their amount, scope, and duration are typically limited and choice of therapists may also be limited. A striking feature of participant-directed approaches to rehabilitation is that families and professionals—freed from the usual coverage restrictions—often work together to devise therapeutic regimens that not just maintain and improve function, prevent secondary disabilities, and prevent medical complications, but have recreational and social features that make them enjoyable for participants, their families, and workers. Enjoyment improves perseverance with therapy and also satisfies the desire of people with disabilities and their families to “have a life, not just a care plan.”⁸ The CCDE qualitative case studies include many additional examples.⁹

Improved Access to Medical Transportation

Lack of transportation is a barrier to obtaining medical care in the community. The burden of providing transportation and escorting Medicaid beneficiaries to and from medical appointments falls disproportionately on family members because agencies typically will not permit employees to drive participants in their own or the participant’s car.¹⁰

The CCDE found that complaints about the standard Medicaid-authorized providers of medical transportation services were common. Procedures for obtaining medical transportation services were often described as cumbersome and the services themselves as unreliable, causing participants to miss medical appointments. Lack of transportation that interferes with timely medical care can lead to nursing home admissions, particularly for persons with serious and/or multiple chronic illnesses.¹¹

When individuals have control over their individual budget, they can use it to obtain medical care when they need it by paying friends, neighbors, or workers to drive them to medical appointments. They can also use taxis or more reliable paratransit services than those authorized by Medicaid. In one of the CCDE states, a participant purchased a used collapsible wheelchair that could be put in a car trunk so that he could be transported in an ordinary car instead of requiring a specialized van to accommodate his regular wheelchair.

Reduced Costs of Dependence on Medical Technology

Self-direction can also reduce the costs associated with dependence on medical technology such as respirators, which requires caregivers—paid and/or unpaid—to be capable of operating and keeping the equipment functioning at all times. Some medically fragile individuals (many of whom are children) need to have awake and alert caregivers 24-hours a day. In the traditional service system, Medicaid will typically pay for a registered nurse to provide care at night—and at other times to provide respite for unpaid caregivers.

In self-direction programs, participants and their families can choose who will provide this skilled care and in the CCDE parents often preferred to hire someone other than a nurse—often a family member—to provide respite care. Thus, self-direction programs can reduce the cost of providing care to technology dependent individuals. Children in Florida’s CCDE program had 30 percent lower costs for private duty nursing than children not in the program.¹²

Some concerns may be raised about unlicensed workers assuming responsibility for skilled nursing care; however, informal caregivers who provide care to technology-dependent family members are rarely licensed nurses and research has shown that parents of medically-fragile children do not perceive licensing to be either necessary or sufficient. Rather, they want workers to meet *their* standards, that is, before leaving their child in the care of another person, they want to be sure the person understands their child’s condition, what care the child needs, and can calmly and competently deal with an emergency.¹³

Because knowing what to do in an emergency can have life or death consequences, parents often want to train respite caregivers themselves and observe them providing care repeatedly before entrusting their children’s care to them. Home health agencies operate with a staffing model similar to that of

hospitals and nursing homes, which assumes that licensure guarantees that nurses can substitute for another. Although they may assign the same nurse(s) to a case, whenever they can, the agency's standards for quality care do not accord the same value that families do to the development of long-term relationships and rapport between individual nurses and patients and their families.

Employing unlicensed personnel to perform skilled nursing tasks is only possible if a state's Nurse Practice Act has provisions permitting them to do so under certain conditions (e.g., when provided in self-direction programs). Nurse Practice Acts and their importance for self-direction programs are discussed in the next section.

C. Nurse Practice Acts: How They Can Hinder or Facilitate Health-Related Personal Assistance Services

The nursing profession is regulated at the state level through state Nurse Practice Acts (NPAs), which differ by state. NPAs determine which nursing services must be provided by or under the direct supervision of licensed nurses, generally referred to as "skilled" nursing services. Because NPA provisions may present barriers to community living for individuals with skilled nursing needs—including those who direct their own services—states need to determine whether their own NPAs present such barriers and, if so, take steps to remove them.

Individuals with skilled nursing needs who are dually eligible for Medicare and Medicaid can receive skilled services through the Medicare Home Health Agency (HHA) benefit or the Medicaid State Plan HHA benefit. States may also use the private duty nursing optional State Plan benefit, and skilled nursing services not otherwise available under the Medicaid State Plan may also be made available through §1915(c) waiver programs.

Despite the availability of these services, participants with skilled nursing needs are often admitted to nursing homes because it is impractical and prohibitively expensive to send licensed nurses to their homes to administer medications and perform other tasks that must be done daily or multiple times daily.

As described above, health-related personal assistance services can include procedures that NPAs consider to be skilled services, such as urinary catheterization and tube feeding. To enable unlicensed workers to perform such procedures, states can amend their NPAs to permit nurse delegation or to exempt certain individuals from the NPA's provisions under certain circumstances.

Nurse Delegation

Nurse delegation refers to the legal authority that permits and defines requirements for a licensed nurse to train and supervise unlicensed assistive personnel (UAP) (e.g., nurse aides, personal assistants) to perform certain tasks that otherwise only a licensed nurse may perform.

Requirements for nurse delegation differ across states. Some NPAs list specific skilled procedures that may or may not be delegated and others give broad discretion to the licensed nurse with respect to decisions about appropriate delegation of procedures. However, there is a clear consensus across states that activities requiring the exercise of professional judgment as distinct from procedural skills may not be delegated.

Delegation is case-by-case; that is, tasks are delegated to a particular UAP with respect to specific individuals only. Generally speaking, a skilled task that can be delegated needs to be highly routinized and its outcome must be highly predictable, especially insofar as the task can be safely performed without life-threatening consequences. NPAs typically require the nurse to document the teaching provided, to observe the satisfactory performance by the UAP of the tasks taught, and to provide written instructions for the UAP.

However, requirements for subsequent nurse supervision vary. Often NPAs require periodic, onsite supervision but may permit telephonic monitoring or (more rarely) only require that the nurse be available for follow-up if needed. Supervisory requirements may also vary by task. Because the nurse retains overall accountability for nursing care, the nurse must transfer delegation responsibility to another licensed nurse if he or she will no longer be available for oversight.

Delegation is more widely practiced in nursing homes and residential care facilities than in home care because the opportunities for frequent, ongoing supervision of UAPs performing delegated tasks are greater in these settings, especially those that have licensed nurses on site. Experimentation with nurse delegation in home care agencies is only just beginning. However, some states, most notably Washington and Oregon, have successfully used nurse delegation in home care in combination with participant-directed services for many years. Oregon, for example, makes extensive use of contract nurses who are independent providers of nursing consultation. They specialize in teaching Medicaid participants, their family caregivers, and paid workers the specific skills required to meet participants' needs. Although they are required to make periodic monitoring visits, the emphasis is on teaching and being available for consultation.¹⁴

The major reason nurses are unwilling to delegate more responsibility for health-related tasks to UAP—even when the state's NPA permits them broad discretion to do so—has been uncertainty about the nurse's professional or civil liabilities for any adverse consequences of poor performance of delegated tasks.

Thus, NPAs with vague nurse delegation requirements may appear permissive, but these statutes leave too much uncertainty for nurses to feel able to delegate with confidence. Oregon and Washington State have dealt with such concerns very effectively by including clear language in their NPAs that exempts nurses from professional liability—that could result in the loss of their licenses—as long as they follow clearly defined NPA requirements for delegation. Oregon’s statute also exempts both nurses and UAP from potential civil liability if they comply with NPA requirements.

Exemption

Exemption means that NPA restrictions on who may perform or teach nursing tasks are not considered applicable. NPAs traditionally have exempted family members and often have exempted “domestic employees” of clients and their families as well. In recent years, a number of states have amended their NPAs to exempt participant-directed personal assistants specifically, or more generally, individuals whose services are financed under Medicaid or another public program.

For example, Colorado’s Consumer-Directed Attendant Support program operates under an NPA exemption.¹⁵ New York’s NPA includes both a general exemption that would apply to private payers as well as public program participants; and an explicit, more specific, exemption for the participant-directed services option under its Medicaid State Plan personal care service program, called the home attendant program.¹⁶

Under an exemption, participants or their family members who routinely perform certain tasks may train paid and unpaid caregivers to perform these tasks. The individuals who provide the training also provide ongoing supervision. Because family members are almost always exempt from NPA restrictions, nurses may train them to perform what are otherwise classified as skilled nursing tasks only to be performed by licensed nurses within their legal scope of practice.¹⁷ Moreover, licensed personnel who train family members are not legally required to provide ongoing supervision of their performance, nor held legally liable for any adverse consequences that result from any errors they make. Family members and others who have been trained can determine when they need to consult with a nurse or have the nurse provide training for others.

Oregon and Washington were among the first states to include participant-directed services in their “Age and Disabled” waiver programs, and to pioneer Nurse Practice Act reforms to allow widespread nurse delegation to UAPs—including participant-employed home care workers—to perform what would otherwise be defined as skilled nursing tasks that only a licensed nurse would be authorized to perform.¹⁸

In both states, Medicaid officials and other advocates for NPA reform had to convince their State Boards of Nursing to support the reforms. They encountered

initial resistance which had to be overcome via negotiation, and reforms occurred in phases. The process was more overtly contentious in Washington than in Oregon, but one positive result of having to convince skeptics and opponents in Washington was that research was carried out to ensure the safety and efficacy of allowing participant-directed aides to perform skilled nursing tasks.¹⁹

States that need to amend their NPA to facilitate the provision of health-related PAS can use other states' experience to support their efforts. A number of state boards of nursing have held "summits" to which they invited outside experts, including representatives of other states' boards and the National Council of State Boards of Nursing, as well as prominent nurse experts from academia to consider reform options.²⁰

D. Concerns about Health and Safety Risks and Liability for Poor Health Outcomes

State officials, health and social services professionals, and some advocates often express concerns about health and safety risks associated with participant-directed services. They worry that self-direction programs will cover-up self-neglect and allow poor judgment free reign. They envision worst case scenarios in which poor quality participant-directed attendant care and/or self-neglect and "bad choices" result in adverse health outcomes, perhaps even death.

State officials' concerns about self-direction programs are often based on their statutory duty to ensure the health and welfare of HCBS waiver participants and some fear that their states may be sued over adverse health outcomes allegedly caused by the negligence of participant-directed aides.²¹ However, research from the CCDE found that on four out of five measures of adverse health events (contractures, bedsores, respiratory problems, urinary infections, and falls), the differences in reports of such incidents for participants were lower than for non-participants.²² Although concerns have been raised that self-direction is risky for elderly persons, especially those with dementia or for individuals with mental and behavioral health diagnoses in addition to physical disabilities, the research evidence does not corroborate such concerns. Indeed, several studies indicate that outcomes can be even more positive for individuals in these subgroups, who can designate a representative to handle some or all participant responsibilities.²³

The low incidence of adverse health events among CCDE participants does not mean that state program administrators or participants themselves can afford to ignore the potential for their occurrence. Participants with certain kinds of conditions may be particularly vulnerable to adverse health events generally, and more at risk for adverse health events due to poor quality attendant care and/or failure to access timely medical care. Such vulnerabilities must be addressed. However, persons at greater risk for adverse health events often make excellent candidates for self-direction programs because they themselves can facilitate

access to both health and rehabilitative care. Additionally, having greater control over their services will help them ensure that all their needs are met.

Risk Management Strategies in Self-Direction Programs

Both the traditional service delivery system and self-direction programs need policies and procedures to manage risk for all participants, not just those with health care needs. However, risk management is a particularly salient issue when participants need skilled nursing services on a daily basis. So, although backup and critical incident management is discussed in this chapter, the discussion is applicable to all participants in all self-direction programs. Chapter 8 also discusses backup plans and critical incident management as key components of a quality management system.

The appropriate strategies for ensuring that necessary backup services are available, and for minimizing and managing other risks, are somewhat different for self-directing participants than for those receiving traditional services, but there is no reason to impose stricter requirements on participant-directed services. CMS initially urged states to adopt “systemic” approaches, such as having one or more contracts with home care agencies to provide backup attendant care to self-directing participants. However, based on state and participant feedback, the emphasis now is on more individualized approaches; in particular, having participants identify risks and develop risk management and backup care plans to prevent and address risks as part of a person-centered planning process.

With the revision of the HCBS waiver application, CMS now requires that an individualized “contingency” or backup plan be established as part of a service plan developed using a person-centered planning process. The focus on individualized planning and risk management means that states are not required to establish a systems response (except for natural and man-made disasters). Such plans must address all risks identified during the planning process and provide alternative arrangements for the delivery of critical services, taking the participant’s preferences into account.

The essence of the plan for self-directing participants typically involves identification of individuals who can be called on to provide backup assistance on an emergency basis or during a period when the participant has lost a regular worker and needs assistance while recruiting a replacement. If and when backup workers must be paid (often family, friends, and neighbors will agree to fill in temporarily without pay), the key task is to complete the employment paperwork (including Medicaid provider agreements) for backup workers in advance.

In some cases, participants may be able to obtain emergency backup by calling a worker registry that is already a qualified Medicaid provider or whose individually listed workers are already qualified Medicaid providers, but this option is usually only available in large metropolitan areas.²⁴ Another essential

element of the contingency plan is to ensure the ability to summon help in an emergency. This is where a flexible budget can be of considerable help. For example, a participant with paralysis might decide to purchase a voice-activated telephone to summon assistance from bed, whereas someone with a different kind of disability might prefer a device that does not require speech but operates by pushing a button.

It is also important to bear in mind that traditional and participant-directed services are not in separate, water-tight compartments, requiring beneficiaries to choose to be wholly in one or the other system at any given time. States may permit waiver participants to direct some but not all of their services. The backup plan for a participant in Kentucky who receives “blended” services—that is, some agency and some self-directed PAS—designates a participant-directed attendant who will work when agency services are unavailable.²⁵

There is a growing body of self-help literature and other resources designed to empower individuals with disabilities (and providers) by teaching them how to manage risks associated with personal assistance services. For example, the Institute for Social Research (ISR) at California State University/Sacramento developed both participant and provider handbooks for the State’s In-Home Supportive Services Program (IHSS).²⁶

The IHSS participant handbook addresses such topics as (1) how to locate, interview, and screen personal care attendants for hire; (2) how to establish and maintain appropriate boundaries between themselves and their IHSS workers; (3) safety precautions; (4) and how to recognize and report abuse, neglect, and mistreatment. The provider handbook covers similar topics. The ISR also developed shorter brochures on the same topics. These materials have all been published and made available online in multiple languages. The participant and provider handbooks are available in English and four other languages and the participant brochures are available in nine languages.

CMS’ position on how to address emergency backup care, risk management, and critical incident reporting has evolved considerably over the past six years since CMS first sought to promote expansion of self-direction through the Independence Plus initiative. CMS and many state officials initially perceived participant-directed services as riskier than traditional services and sought accordingly to impose special requirements on programs that offered them.

However, they came to realize that issues such as inadequate backup; poor quality care; and abuse, neglect, and mistreatment also affect traditional case-managed services provided by licensed agency providers. In fact, many participants who want to self-direct do so because of negative experiences with traditional services. They feel that they are better able to obtain backup services and manage the risks associated with community living when they have the choice and control that comes with self-direction.

Both CMS and the states have learned a great deal from work done under the Real Choice Systems Change grants. Colorado used a Systems Change grant to conduct participant focus groups and stakeholder interviews to obtain input on the development of a planned statewide emergency backup system. However, a consensus emerged that an individualized plan of participant safeguards is most appropriate for self-direction programs. (See box below for more information.)

Colorado’s Study of Risk Management Approaches

The purpose of Colorado’s Systems Change Independence Plus grant was to develop a state strategy for attendant backup and critical incident reporting that would both satisfy CMS Independence Plus requirements and meet the approval of self-directing participants. Colorado had earlier received a §1115 Research and Demonstration waiver to implement a small pilot program—Consumer-Directed Attendant Services (CDAS)—that allowed participants to hire their own attendants. Budget authority for goods and services was only available at the end of the year to pilot participants who did not use all of their allotted funds for attendant care. Participants were allowed to use half of their savings to purchase other goods and services; the other half was returned to the state and credited as Medicaid program savings.

The program was particularly well suited for studying risk management strategies because pilot participants would otherwise have received attendant care from Medicare/Medicaid certified home health agencies under the Medicaid Home Health Services benefit. Those eligible for the CDAS option were heavy users of home health services (averaging about \$2,500 per month when Colorado first applied for the §1115 waiver). Most had conditions such as paraplegia or quadriplegia, some used respirators, and all required skilled nursing care. Colorado amended its Nurse Practice Act to allow participants to train and supervise their individually hired attendants to perform certain nursing tasks such as cleaning and replacing urinary catheters.

Because of their extremely high level of physical disability and their need for skilled nursing tasks, the participants in the Colorado CDAS program appeared to be particularly vulnerable to adverse health consequences if abandoned or otherwise abused, mistreated, neglected, or given poor quality care by their hired attendants. The State conducted a series of focus groups with 42 attendant care users (including both CDAS program participants and home health agency clients) to elicit their views on how to secure backup attendant care as well as requirements for critical incident management reporting systems.²⁷ The findings are summarized below.

Backup

- Participants did not want to be required to use home health agencies as backup for attendant services because, in their experience, these agencies failed to provide backup workers even when they had signed Medicaid provider contracts in which they guaranteed the State that backup services would be provided.

(continued)

- Most individuals attracted to self-directed services prefer a “customized” backup approach and are willing to arrange their own backup services.²⁸
- For individuals with mobility impairments, assistive technologies can enable them to call for backup assistance when needed (e.g., cell phones carried at all times, wearable personal emergency response call systems, and voice-activated telephones). Such systems are particularly important for participants with severe mobility impairments, such as persons with quadriplegia.

Critical Incidents

- Participants defined critical incidents as including—but not limited to—instances of abuse, neglect, or mistreatment by attendants.²⁹
- Participants expressed frustration with past attempts to report critical incidents to home care agencies, case managers, and state program officials. They felt that adult protective services (APS) officials might be more likely to take incidents seriously, but were wary of reporting to APS because they feared that they would no longer be allowed to direct their care or would be pressured to enter a nursing home or residential care setting.
- Participants would not hesitate to report criminal incidents to the police and felt that the police would take such complaints seriously, but recognized that criminal behavior could be difficult to prove in a “he-said-she-said” situation with no other witnesses.³⁰
- Most participants felt that they could solve their own attendant problems by simply firing problem workers, but they wanted to be able to protect other participants from hiring the aides they fired through a system that would enable them to file a complaint or file a negative employment reference without those having to be officially substantiated and sanctioned.³¹
- Most participants strongly favored preventive strategies that would make critical incidents much less likely to occur. They neither favored or opposed criminal background check requirements—primarily because most of the critical incidents they had personally experienced did not involve criminal behavior. Even when it did (e.g., theft) it was so difficult to prove that they felt similar past behavior would have been unlikely to have been prosecuted and show up in a criminal background check.
- Participants favored strategies that emphasized networking among self-directing participants, enabling them to make referrals to each other and to share aides. They wanted the CDAS program to develop a registry (a job bank) where they could advertise and which would facilitate their ability to screen potential hires. This approach could be compatible with encouraging participants to write references (positive or less favorable) for former employees that could be made available in connection with web-based worker registries such as *www.RewardingWork.org*.

In general, consumers preferred risk management strategies that they considered to be effective and, especially among the CDAS participants, that they perceived as giving them more control and, therefore, more ability to take actions to ensure their own health and welfare.

Most people, whether disabled or non-disabled, want to be independent, healthy, and safe and the evidence suggests that self-direction can promote all of these goals simultaneously. Thus, many people with disabilities are attracted to self-directed services options because, in their experience, having minimal choice or control also means they have little ability to protect themselves from harm. A young woman in Iowa who had been living in an institution transitioned to the community with a roommate and paid workers using the State's new self-direction option. In the institution, she had been repeatedly frightened and injured by the aggressive behavior of other residents, which had exacerbated her own behavioral issues. When asked about the biggest change the program had made in her life, she said simply: "I feel safe."³²

Legal Liability: A Review of Court Cases

With regard to concerns about liability, the empirical evidence does not support the notion that directing one's services is inherently riskier than receiving agency-provided services, or that it requires an acceptance of trade-offs between enhanced independence and protecting health and safety. A law review article addressing liability issues in self-directed services found a dearth of reported court cases involving allegations of adverse health outcomes resulting from poor quality home care services.³³

With only two exceptions, all recorded court cases involving home care involve either agency providers or, less frequently, individual providers hired by private payers. All of the aides or nurses whose incompetent or negligent care was alleged to have caused harm were unrelated to the plaintiffs. The authors theorize that most lawsuits are directed at agencies because individual aides or nurses have few assets and the likelihood of recovery is too low to make legal action worthwhile.

They also theorize that suits involving publicly funded participant-directed services—directed either at the workers themselves or at the state—may be rarer than suits against agencies (or privately paid home care workers) because a significant percentage of participant-directed workers in public programs are family members. Family members who provide unpaid assistance are not legally liable for accidental harm, but could be held liable for accidents that occur while they are "on-the-clock" as paid aides.³⁴ Both paid and unpaid family members (as well as unrelated individuals and agency workers) could be criminally liable under adult protective services statutes if abuse or neglect is determined to have been intentional.

In the only two cases involving public program participants with non-agency providers, the suit was directed exclusively or primarily at the state and/or a state-employed case manager rather than the worker. Only one of the cases reviewed involved a participant-directed worker—a licensed practical nurse (LPN) who had been hired by a public program participant. The participant filed suit against the

state, not the LPN. Another case involved an “individual provider” (i.e., someone who was not employed by an agency). However, this paid worker was selected by the public program participant’s case manager, not by the program participant. The suit was directed at the case manager, the government agency, and the aide. See the box below for a description of these two cases and the legal reasoning that produced opposite outcomes.

State officials may find it useful to study the other cases in the law review article, even though they all involved agency workers or private pay situations.³⁵ So often, negative views about self-direction are based on concerns about “risk” and “liability”—terms which are rarely, if ever, explicitly defined. The cases discussed in the article are instructive because they make clear that quite simple actions could have prevented the adverse outcomes. According to the authors, the “most common negligent caregiving scenarios involve some variation on leaving the consumer unattended...[which] may involve anything from failing to show up at the scheduled time or leaving early, to momentary lapses of monitoring that resulted in injury to the consumer.”

In one such case, a home care worker failed to show up as scheduled and the client who was recovering from a hip fracture tried to transfer without assistance from his wheelchair to his walker, fell, and re-fractured his hip. (This was apparently a miscommunication; the agency worker thought he was supposed to provide services five days a week instead of seven and failed to show up the first weekend). The agency was held liable.

In another case, a woman with Multiple Sclerosis did not receive timely emergency medical care because she had been left unattended by her home care worker. The worker’s defense was that her only duties and obligations to the client involved cooking, cleaning, and other household tasks. The court ruled for the plaintiff, noting that the home care worker had been instructed regarding the patient’s medical condition and the circumstances under which she might need emergency care. While the court’s judgment was that the homecare worker owed a “duty of care” beyond contractual obligations to cook and clean, they noted that the worker’s failure to honor that duty was “ordinary negligence” not a more specific type of professional or health care-related negligence (also known as “malpractice”). The authors of the law review article note that this was true of all of the cases where the court ruled against a provider of home care aide services. They also note, however, that some cases could well qualify as “criminal negligence” under adult protective services statutes if the negligence is willful and the resulting harm is significant.

Even though the authors found no evidence of lawsuits having been brought as a result of participant-directed aides abandoning their employers, such incidents are known to have occurred. In one egregious case, a Medicaid participant with quadriplegia in Utah had his own apartment and received personal assistance

Reeder v. State of Nebraska. Reeder, paralyzed in an auto accident, enrolled in a self-direction program under Nebraska's Aged and Disabled waiver. An LPN hired by Reeder was approved as a paid Medicaid provider in the capacities of personal care aide (PCA) and LPN. After this LPN had been providing care for Reeder for about two months, he developed decubitus ulcers on his feet. Although he consulted a podiatrist and the LPN followed the podiatrist's treatment orders, the ulcers did not heal and became infected. After a lengthy hospitalization and facing possible amputation, Reeder filed suit against the State based on two theories of liability: that the LPN was an "employee" of the State, which was vicariously liable for her negligent care or, alternatively, that the State had breached an independent duty to select and train a nurse who was competent to provide the care required.³⁶

The case was ultimately decided by the Nebraska Supreme Court, which ruled against Reeder. The court found that the State's statutory duty was to provide compensation for health services, not a duty to provide the actual services. The court also determined that by maintaining periodic contact with clients receiving health care benefits and maintaining a general interest in their welfare, the State's case managers were nevertheless neither trained or authorized to make medical judgments as to the quality of care provided to clients or to intervene in the provision of care, and therefore had no legal duty to do so.

The law review authors noted that the well-established "public duty doctrine" protects states from lawsuits alleging a breach of a general duty to the public. This obstacle is difficult for plaintiffs to surmount absent a "special relationship exception," which refers to a situation in which the state has, in fact, assumed a responsibility and, thus, a duty with respect to the welfare of a particular individual. The one successful lawsuit against the state discussed in the law review—*Caulfield v. Kitsap County, Washington State*—illustrates the

requirements that must be met to establish such a special relationship exception.

Caulfield v. Kitsap County, Washington State.

Caulfield had Multiple Sclerosis, needed 24-hour care, and lived in a nursing facility until his state Department of Social and Health Services-employed case manager arranged for his transfer to in-home care and an aide to care for him—considered an "independent provider," not a home care agency employee. The case manager failed to visit him for more than a month after his transfer to home care, despite having given him assurances that she would continue to be his case manager. When she did finally visit him, she observed major changes in his condition and heard his complaints about his aide. Pursuant to an inter-agency agreement between the state agency and Kitsap County, the State's case manager transferred the case the following day to a county social worker who noted problems requiring "immediate attention." Nonetheless, the county social worker did not promptly contact or visit the plaintiff.

Eight days later, the aide called the county social worker because he was concerned about the plaintiff's deteriorating condition, and the social worker told him to call 911. Upon admission to the hospital, the plaintiff (according to the appellate court's written opinion) had "urosepsis, pneumonia, saline depletion, contractures, was malnourished, suffered severe weight loss, and had severe bed sores that cut through his flesh to his bone." Also according to the ruling, "Even though Caulfield had Multiple Sclerosis, he had previously had some ability to function at levels that allowed an appreciable amount of independence and freedom. But because of negligent caregiving, he lost most of his previous ability to function independently."

At trial, the jury in *Caulfield* returned a verdict finding that the county, the State agency, and the worker were negligent and proximately caused the plaintiff's injuries and apportioned damages totaling \$2,626,707. The county appealed but the appellate court sustained

the verdict on the grounds that Caulfield's relationship with his case manager involved an element of "entrustment" by virtue of the dependent and protective nature of the relationship. This judgment was based on various facts of this particular case, including Caulfield's inability to get out of bed or reach a telephone to call for assistance; the case manager's knowledge concerning Caulfield's illness, disabilities, recent nursing home discharge, and vulnerable circumstances; and, perhaps most importantly, that a case manager, not Caulfield, had selected and hired the paid worker and had been unresponsive to Caulfield's complaints about the worker. Further, the case manager did not make good on her assurances to Caulfield with regard to the level of involvement, monitoring, and supervision she would provide.

These two contrasting cases are especially interesting because they illustrate the point that service provision by "independent providers" is not always synonymous with "participant-directed services" and that courts are capable of perceiving the distinction. *Caulfield* can also be read as a cautionary tale about how much responsibility for selecting and supervising "independent providers" case managers could or should attempt to assume. The facts presented at trial indicate that Caulfield was not prepared to assume the responsibilities of self-direction and had no family member or friend who could serve as his representative. The case manager knew this, which is why she chose the independent provider and promised Caulfield that she would monitor his care. Instead, she did not even visit as frequently as state rules required for any case, let alone one involving an individual recently discharged from a nursing home, with no informal supports, who did not feel up to assuming the responsibilities inherent in self-directed services.³⁷

The *Reeder* case illustrates another key point: adverse health events cannot always be attributed to poor quality, negligent, or abusive care. Courts want to see evidence

that poor care was at fault. Nor is an adverse health event (e.g. a bedsore with serious complications) indicative, in and of itself, that a participant was incapable of self-direction and should not have been permitted to self-direct.³⁸ Many of the lawsuits reviewed that resulted in judgments against home care agencies or even individual caregivers did, in fact, involve bedsores, and evidence was presented that the type of care necessary to prevent bedsores was not delivered.

The facts presented at trial in *Reeder* were, however, ambiguous; they did not clearly indicate that the LPN provided poor care or that Reeder was self-negligent. Reeder sought medical help when the bedsores appeared and his caregiver followed the advice provided.³⁹ The judge's decision in *Reeder* also indicates that courts are likely to be reasonable with respect to interpreting the state's statutory obligation to "ensure the health and welfare" of an HCBS waiver program participant. Courts are unlikely to hold states strictly liable for any and all adverse health events that befall self-directing program participants.

In sum, the principle take-away lessons from *Reeder* and *Caulfield* are: In a self-direction service delivery model, participants must truly be in charge; they must know that the responsibility as well as the authority is theirs, and they must be willing—or have representative decision makers willing—to accept this responsibility. Representative decision makers could be a family caregiver or, as is more common in self-determination programs for persons with profound mental retardation, may take the form of a "circle of support" that may even be formally constituted as a "microboard."⁴⁰ States need to have some kind of support and quality assurance mechanisms; courts are unlikely to specify what those should be, but will expect the state to have them and to follow and enforce their policies and procedures.

services from an attendant whom he directed. When the participant and his attendant had an argument, the attendant left and did not return. Left immobile in bed, the participant had no way to call for assistance and several days elapsed before he was found and taken to the hospital. During the period he spent alone in bed, he had no food or water and received no bowel and bladder care. Although he experienced serious medical complications and nearly died, he did recover and expressed a desire to continue living alone with a new self-directed attendant. He had to appeal the state's original determination that he not be allowed to do so, but eventually prevailed.⁴¹

Note that in this particular case, the problem was not lack of backup workers, but the lack of a communication device to signal the participant's need for help. If the participant had been able to purchase a voice-activated telephone with funds from an individual budget, he would have been able to call for help. In fact, it would be prudent for states to cover the cost of such phones as an "assistive device" for any waiver participant who cannot move without assistance. In other words, this anecdote would be misinterpreted if it is used to illustrate the "riskiness" of participant-directed attendant care rather than the need to identify creative ways of enabling people with very severe disabilities to communicate their needs for assistance.

The second most common type of negligent caregiving scenario involves inadequacies in the provision of care. Again, only a handful of litigated cases were found. One involved hot water scalding, which happened while the aide was giving the care recipient a bath. Another case involved a fire that killed both the participant and the aide—caused by household clutter in too close proximity to a space heater, which, it was alleged, the aide should not have permitted.

Several cases involved falls; for example, an aide who was assisting an elderly man who used a walker to go outside for a walk, allegedly failed to notice water on the floor of his apartment building's elevator; the man fell, broke a hip, was hospitalized, and died. The authors note that, whereas people with chronic illnesses and disabilities may be more susceptible than others to such accidents, the risk potential is scarcely unique to situations involving the provision of paid personal assistance services to this population. These are among the most common household accidents and, as such, are classic causes of action in tort liability. This is also why even when paid care providers are the defendants, such cases are litigated as "ordinary negligence" not health care-specific negligence ("malpractice").

It is noteworthy, that the types of accidents that give rise to such litigation are highly preventable. For example, hot water scalding can be prevented by installing inexpensive technologies to prevent water temperatures in showers and baths from becoming high enough to cause scalding. Similarly, falls can be prevented by fixing water leaks, repairing broken stairs, etc., and fire and fall

hazards caused by excessive clutter (e.g., piles of newspapers) can be eliminated by hiring aides who will do heavy cleaning.

Typically, home care agencies do not permit their aides to do heavy cleaning or trash removal, and no one expects home care agency aides to know how to perform “handyman” chores such as installing scald guards, fixing minor plumbing problems, or repairing broken steps. Use of specialized heavy cleaning, chore, handyman/home repair, or trash removal services are advisable if an individual aide could be injured performing such tasks. These are all goods and services that self-directing participants with flexible individual budgets would be able to purchase.

Arguably, state policymakers and program officials may be more afraid of and, rationally, have more to fear from, bad press involving allegations of negligent care-giving than from lawsuits. At the beginning of the CCDE, it was anticipated that the demonstration programs might well experience an incident that could become a public relations nightmare. The participating states were encouraged to rehearse “damage control” strategies for dealing with bad press. As it turned out, none of the CCDE states or the 12 replication states experienced such an incident.

In closing this discussion of legal liability, it is important to realize that even with the best precautions, negligent caregiving will never be 100 percent preventable. CMS’ position is that risks associated with the possibility of negligent caregiving do not preclude self-direction.⁴²

E. Incorporating Self-Direction Options in Managed Care Plans

When the CCDE was in the planning stages, in the mid 1990s, the conventional wisdom was that self-direction and managed care represented conflicting philosophical approaches to service delivery and were, therefore, incompatible. It was thought that managed care organizations (MCOs) epitomized the ultimate in professional management, whereas self-direction exemplified individuals’ empowerment. When approached in the mid-1990s about participating in the CCDE, officials from several states explained their lack of interest as a consequence of their state’s intent to develop managed care plans that integrated health care and long-term services and supports.

Since that time, however, surveys have found that many MCOs are now open to incorporating self-direction options.⁴³ Moreover, as will be described below, some managed care plans have already incorporated significant opportunities for self-direction, proving that managed care and self-direction can be compatible. Experience to date with self-directed services in managed care plans suggests that it may be more difficult to combine self-direction and managed care in states and localities where there is no prior history of offering self-direction and where MCO leaders do not perceive it might benefit both the MCO and plan members.⁴⁴

Managed Care in Medicaid and Medicare

Managed care organizations (MCOs) are funded through capitation payments to provide a category of services (e.g., primary and acute health care, long-term services and supports, or mental health services) or a combination of services (e.g., primary, acute, and long-term care). MCOs are financially at risk to provide services to plan members within the total amount of capitated funding.

Medicare beneficiaries (both elderly and younger adults receiving Social Security Disability Insurance who qualify for Medicare coverage) cannot be required to enroll in Medicare managed care plans (called Medicare Advantage and Medicare Advantage Plus). However, Medicare Advantage and Advantage Plus plans cover certain services that are not otherwise covered by Medicare.⁴⁵

Dual Medicare/Medicaid eligible individuals (called dual eligibles) and people with disabilities who qualify only for Medicaid may, at state option, be required to enroll in managed care plans to receive Medicaid covered services. Voluntary enrollment into Medicaid managed care plans takes place under §1915(a) authority. Mandatory enrollment of Medicaid beneficiaries into Medicaid managed care plans requires federal approval of a §1915(b) “freedom of choice” waiver and, if HCBS waiver services are included, states must seek federal approval for a “(b)(c) combination” waiver.⁴⁶

To date, only a small number of managed care plans have been federally authorized to integrate Medicare as well as Medicaid-funded coverage, including long-term

services and supports coverage. These include several Minnesota Senior Health Options available statewide; Wisconsin Partnership county-based plans; the Mass Health Senior Care Options, which is mostly statewide; and local PACE (Program for All-Inclusive Care for the Elderly) sites located in a number of states.⁴⁷

Thus, dual eligibles enrolled in Medicaid plans who elect to receive Medicare services under a managed care plan will generally have to enroll in two separate plans. Medicaid managed care plans may be offered by Medicare Advantage MCOs (called “companion” plans), but Medicaid beneficiaries may choose to enroll in a Medicaid plan run by a different organization, and they might have to be in Medicare and Medicaid managed care plans under different auspices if the beneficiary’s Medicare Advantage MCO does not sponsor a Medicaid companion plan. These separate Medicare and Medicaid managed care plans may “coordinate” coverage but they cannot fully integrate Medicare and Medicaid funds by treating them as fungible. Medicare part D drug coverage, in many cases, must be provided under yet another plan.

Thus, dual eligibles could find themselves enrolled in three separate managed care plans: one for Medicare-covered primary and acute health care services other than prescription drugs, one for drug coverage, and another for Medicaid “wrap-around” coverage. Moreover, even the most comprehensive plans tend not to assume full risk for nursing home care, coverage for which is typically limited to 90 or 180 days.

Self-Direction Options in Fully Integrated Health/Long-Term Care Managed Care Plans

Minnesota requires all Medicaid-eligible persons over age 65 to enroll in a Medicaid managed care plan. Dually eligible seniors may choose to enroll in a plan that covers all of their Medicare and Medicaid benefits or they may elect to receive their Medicare covered services on a “fee-for-service” basis. For younger disabled persons, enrollment in both Medicaid managed care and Medicare managed care (if they are Medicare eligible) is voluntary.

Dual eligibles under age 65 may elect to enroll in a single plan that covers both Medicaid and Medicare services. Managed care plans include State Plan personal care services and §1915(c) waiver services. Coverage for nursing homes under Minnesota’s Medicaid managed care plans ranges from 90 to 180 days.

In 2005, when Minnesota first began to offer the Consumer-Directed Community Supports (CDCS) option to Medicaid beneficiaries eligible for §1915(c) waiver programs, the programs were still in the fee-for-service system. As of 2006, however, §1915(c) waiver coverage was folded into managed care and MCOs were told that they had to make CDCS available to their members. The timing of the introduction of CDCS in Minnesota was not ideal because the program had scarcely begun when it had to be integrated into Medicaid managed care as a result of the mandatory Medicaid managed care enrollment policy. This also happened at the same time that Medicare Part D was being launched.

As a result, dual eligibles in Minnesota had to make several decisions at once: which Medicaid managed care plan to join, which Medicare drug plan to join, and whether or not to opt for CDCS. Possibly because of decision overload, enrollment in CDCS has grown slowly. Some MCO care managers are more comfortable than others in recommending CDCS to their clients or supporting clients’ decisions to join CDCS. In this respect, the attitudes of MCO care managers toward self-direction are not much different than those previously observed among case managers in traditional fee-for-service §1915(c) waiver programs, when they have been asked to offer self-direction options to their clients.⁴⁸

Minnesota CDCS program officials contracted with an evaluator to conduct “key informant” interviews (in 2006) and focus groups (in 2007) to gauge the attitudes prevalent among health/social services professionals from MCOs, counties, provider organizations, and financial management services entities. Both the key informants and focus group participants voiced overall support for the self-direction philosophy. Support increased between 2006 and 2007, apparently as care managers began to have personal, positive experiences with CDCS. Nevertheless, the 2007 focus group participants revealed some hesitations and concerns about the CDCS option.

The focus group responses suggest that, whatever hesitations they may have about the CDCS option specifically, most participants perceive self-direction as something that should and will grow over time. Most focus group participants thought that CDCS would be especially helpful in overcoming labor shortages and—for this reason—would be especially useful in serving older persons in rural areas, which often have shortages of traditional providers. However, most focus group participants wanted CDCS enrollment to grow slowly so as not to overwhelm the capacity of care managers and MCOs to learn how to work well with CDCS participants.

Apart from Minnesota, only a few managed care programs cover a comprehensive range of primary, acute, and long-term care services and incorporate self-directed services options. These are: the Arizona Long-Term Care System, Texas Star Plus, and the Wisconsin Partnership Plan, which are Medicaid-only plans; dual eligibles either continue to receive Medicare-covered services through the fee-for-service system or they must enroll in a separate Medicare MCO. In these plans, self-direction appears to be largely limited to allowing plan members to select, manage, and dismiss independent providers of personal care, homemaker/chore, and/or respite services.

Self-Direction Options in Long-Term Care Managed Care Plans

Wisconsin Family Care—a managed care plan covering only Medicaid-funded long-term services and supports—also offers self-direction options. About one third of Family Care participants direct at least one covered service by employing personal care, homemaker, chore and/or respite aides directly. Participant-directed workers may be family members.

Independence Care Systems (ICS) is one of several New York managed long-term services and supports plans and the only one that offers its members the option to hire their own aides or use agency-based personal care or home health services.⁴⁹ Cooperative Home Care Associates—a 20 year old worker-owned home care agency—is the preferred provider for agency-delivered PAS, although members may use other Medicaid-participating agencies. Self-directed services are provided through Concepts for Independence, an agency that serves as the employer-of-record (using the agency with choice self-direction model) for home care workers recruited by self-directing ICS members.

ICS provides training on a voluntary basis for self-directing plan members on how to recruit and manage personal assistants. ICS also has plans to launch its own agency with choice as well as a registry to assist members in locating personal assistants who want to work directly for plan members. Approximately 20 percent of ICS members (i.e., 200 of 1,000 members) direct their personal assistance services at any point in time. Workers are exempt from the New York State Nurse Practice Act and are able to perform nursing tasks such as medication administration, catheterization, and tracheotomy suctioning.

Unlike traditional managed care providers, ICS maintains an open network. If members have providers from whom they want to obtain disability-related services, but who are not network members, ICS is often willing to add those providers to its network. Except for its relationship with Cooperative Home Care Associates, ICS rarely provides services directly or through close affiliates. However, ICS will develop new services if no good providers are available. One such example is its member-responsive wheelchair service and wheelchair repair service.⁵⁰

Some of the specialized support services that ICS provides highlight the resources that a managed care plan (perhaps only a managed care plan, which has flexibility to cover services not normally available in fee-for-service Medicaid) can mobilize to empower participants and promote their involvement in peer networking and support, day-to-day plan operations, and policy-making. For example, ICS provides a “clubhouse” for plan members to attend classes and support groups, and to engage in many other social activities. It has also developed alternative activities to substitute for traditional adult day care, including seminars on health issues and disability culture, support groups for women, Weight Watchers groups, classes in English as a Second Language, and classes to obtain a General Equivalency Degree (in lieu of a regular high school diploma), as well as social events.

These activities often address health issues and social needs simultaneously; even when they have little or no health focus and are either educational or almost purely social, they promote mental health among ICS members, particularly those at risk for depression and substance abuse. They have enabled members to form mutually supportive relationships, learn new or improve existing skills, and gain critical health-related information. Several participants have significantly reduced their weight. ICS also employs some plan members who participate in developing the plan’s coverage policies.

Resources

Publications

Hughes, S.L., & Sabatino, C.P. (2004). *Addressing Liability Issues in Consumer-Directed Personal Assistance Services: The National Cash and Counseling Demonstration and Selected Other Models.* Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

This report addresses the liability issues that may arise in government-sponsored, consumer-directed personal assistance programs (CDPAS). In analyzing these issues, the report focuses on the programs implemented in Arkansas, Florida, and New Jersey as part of the Cash & Counseling Demonstration, but also briefly describes an analysis of potential liability for two well-established CDPAS programs, California's In-Home Supportive Services Program and New York's Consumer-Directed Personal Assistance Program.

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

A shorter article based on this report is available at: <http://www.cashandcounseling.org/resources/20060303-104025>

Mahoney, K.J., Meiners, M.R., Shoop, D., and Squillace, M.R. (2003). *Cash and Counseling and managed long-term care? Case Management Journals, 4(1), Spring: 18-22.*

This article presents the results of a survey on the interest of managed care organizations in developing a Cash & Counseling option for delivering long-term personal assistance services.

Available at: <http://www.cashandcounseling.org/resources/20060126-112344>

Reinhard, S. C., & Farnham, J. (2007). *Nurse Delegation and Consumer Direction in Home/Community Settings.* Presentation to the North Dakota Board of Nursing in Bismarck, ND: May 17, 2007.

This is one of several presentations that staff from Rutgers Center for State Health Policy make when invited to meet with a State Board of Nursing to discuss nurse delegation and self-direction. Typically, the invitation for such a meeting and presentation is initiated by state program administrators. Available at: <http://www.cshp.rutgers.edu/Downloads/7360.pdf>

Reinhard, S. C., & Farnham, J. (2006). *Invitational Forum: Advancing Consumer Choice Through Better Understanding Of Nurse Delegation.* New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This summary report (with background material) is an example of one of several nurse delegation summits that staff from Rutgers Center for State Health Policy

have convened to bring together nursing leadership from around the country to discuss nurse delegation in relation to self-directed services.

Available at: <http://www.cshp.rutgers.edu/cle/Products/NDIFPaperWEB.pdf>

Appendix available at: <http://www.cshp.rutgers.edu/cle/Products/NDIFAppendixWEB.pdf>

Reinhard, S.C. & Young, H. (2006). *Guiding Principles for the Nurse-Consumer Relationship: Improved Collaboration and Support of Consumers' Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy.

In April 2004, Rutgers Center for State Health Policy convened national and state leaders in nursing practice and regulation to develop consensus principles to guide the profession's collaboration with people who want to live in their homes and communities. This discussion paper summarizes the work of multiple participants over the course of two years. The 2004 draft principles were revised and endorsed by the American Academy of Nursing's Expert Panel on Aging in November 2005. They are offered as a foundation for further dialogue within and across states.

Available at: <http://www.cshp.rutgers.edu/Downloads/6590.pdf>

Reinhard, S.C. & Quinn, W.V. (2004). *Consumer-Directed Care and States' Nurse Practice Policies*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

State policy with respect to nurse delegation varies considerably. A review of state nurse practice acts and regulations was first conducted in 2001 and, as of 2004, few states had, as yet, made substantial progress in developing nurse practice policies that specifically address self-direction, although most states do have more flexibility for nurse delegation than nurses and consumers realize. This issue brief summarizes a follow-up study conducted with the executive staff of state boards of nursing.

Available at: [http://www.cshp.rutgers.edu/cle/products/](http://www.cshp.rutgers.edu/cle/products/QuinnConsumerDirectedCare.pdf)

[QuinnConsumerDirectedCare.pdf](http://www.cshp.rutgers.edu/cle/products/QuinnConsumerDirectedCare.pdf)

Web-Accessible Resources

National Council of State Boards of Nursing

Web address: www.ncsbn.org

Historically, the National Council of State Boards of Nursing has supported the concept of nurse delegation. State officials who want to enable self-direction for individuals with health care needs by modifying Nurse Practice Acts, can find information about nurse delegation at this website. Use the search term "nurse delegation." The site also includes reports on a wide range of nursing practice issues, some of which are relevant to the delivery of home and community services, such as information on State Nurse Aide registries.

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty is the lead author of this chapter. Janet O’Keeffe is the co-author.
- 2 For example, see Fried, T.R., Bradley, E.H., et al. (2001) Functional disability and health care expenditures for older persons. *Archives of Internal Medicine*, 161(21), 2602–2607. A longitudinal cohort study of a representative sample of community dwelling persons aged 72 or older linked clinical data with data on two years of expenditures for Medicare-reimbursed hospital, outpatient, and home care services and Medicaid-reimbursed nursing home services. The 19.6 percent of older persons who had stable functional dependence or who declined to dependence accounted for almost half (46.3 percent) of total expenditures.
- 3 Among “aged/disabled” participants in the original Cash & Counseling Demonstration and Evaluation, over 80 percent were dually eligible for Medicare and Medicaid, and the average share of their combined Medicare/Medicaid expenditures that went toward medical care greatly exceeded the costs associated with their use of personal care services, home and community-based services, or other long-term services and supports.
- 4 In Florida and Arkansas, 70 and 76 percent, respectively, of directly hired workers provided assistance with medications, as compared to 26 and 20 percent of agency workers. In New Jersey, the percentage of agency workers who said they helped with medications was higher (54 percent) but still significantly less than the percentage of directly hired workers who said they did (81 percent). Dale, S., Brown, R. Phillips, B., & Carlson, B.L. (2005). *Experiences of Workers Hired Under Cash and Counseling in Arkansas, Florida, and New Jersey*. Available at <http://aspe.hhs.gov/daltcp/reports/workereexp.htm>

In the Florida CCDE, parents of minor children with MR/DD in the treatment group reported fewer missed doses of medication than parents of children in the control group and the difference was statistically significant. Among other related findings (not all cited here), a statistically significant increase in access to medication assistance for minor children with MR/DD was found among the subgroup of treatment/control group participants who, though receiving other traditional waiver services, had not been receiving paid aide care at baseline. Foster, L., Dale, S., Brown, R., Phillips, B., Schore, J., & Carlson, B.L. (2004). *Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities*. Available at <http://aspe.hhs.gov/daltcp/reports/ddkidsMss.htm>

In all three states, significantly higher percentages of participant/family-directed workers reported providing wound care (for pressure sores). Almost a quarter of such workers in Arkansas and New Jersey said they provided assistance with pressure sores, whereas only 9 to 10 percent of agency

workers said they did so. Participant-directed workers also were significantly more likely than agency workers to report providing help with physical therapy exercises (Arkansas and Florida) and with ventilators, feeding tubes, and special care of the feet (Arkansas). Dale, S., Brown, R., Phillips, B., & Carlson, B. L. (2005). Op. cit.

- 5 This finding was at baseline, prior to random assignment to treatment/control groups. Ibid.
- 6 Carlson, B.L., Dale, S., Foster, L., Brown, R., Phillips, B., & Schore, J. (2005). *Effects of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey and Florida*. Available at <http://aspe.hhs.gov/daltcp/reports/adultpcw.htm>
- 7 Kitchen equipment and modifications can make it easier for individuals to follow special diets, eat healthier meals, lose weight, and manage medical conditions such as diabetes. Although not designed specifically for use by people with disabilities, some kitchen equipment may not be affordable to Medicaid beneficiaries, especially those eligible for SSI, (e.g., microwave ovens and grills). Meiners, M., Loughlin, D., Sadler, D., & Mahoney, K. *Clarifying the Definition of Personal Care*. Available at <http://www.cashandcounseling.org/resources/20060126-102403>
- 8 Quote from Jackie Golden, mother of a son with Angelman's Syndrome, enrolled in Maryland's self-determination program, funded under a Medicaid Independence Plus §1915(c) waiver. Jackie Golden spoke at a national conference on self-direction in 2001; see <http://aspe.hhs.gov/daltcp/reports/01cfsum.htm>
- 9 P., Simon-Rusinowitz, L, Loughlin, D., Eckert, J. K., & Mahoney, K.J. (2007, February). Case histories of six consumers and their families in Cash and Counseling. *Health Services Research*, 42(1), 533–549.
- 10 In the CCDE, transportation was the most commonly reported unmet need among demonstration participants at baseline (prior to random assignment to treatment/control groups) and the reductions in unmet need for transportation were statistically significant for treatment group members compared to controls, especially in Arkansas. Carlson, B.L., Dale, S., Foster, L., Brown, R., Phillips, B. & Schore, J. (2005). Op. cit.
- 11 Ibid.
- 12 Ibid. In the CCDE, children “not in the program” refers only to children in the control group.
- 13 Lee Zacharias. (1997). Unpublished findings of focus group in Tampa, Florida with parents of children with MR/DD prior to CCDE implementation.

- 14 Oregon's statute explicitly distinguishes between teaching and delegation. The former, unlike the later, does not involve ongoing, periodic supervision.
- 15 The Colorado legislature granted the exemption when it authorized the State to seek a §1115 waiver for the program. Dulio, A. & Perry, M., Claypool, H., O'Malley, M. (2008). *Consumer Direction of Personal Assistance Services Programs in Medicaid*. (Kaiser Commission on Medicaid and the Uninsured). Washington, DC: Kaiser Family Foundation.
- 16 Reinhard, S. C., & Farnham, J. (2007). *Nurse Delegation and Consumer Direction in Home/Community Settings*. Presentation to North Dakota Board of Nursing in Bismarck, ND: May 17, 2007. Available at: <http://www.cshp.rutgers.edu/Downloads/7360.pdf>; Reinhard, S. C., & Farnham, J. (2006). *Invitational Forum: Advancing Consumer Choice Through Better Understanding Of Nurse Delegation*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/cle/Products/NDIFPaperWEB.pdf> Appendix: <http://www.cshp.rutgers.edu/cle/Products/NDIFAppendixWEB.pdf>
- 17 Physicians can also train family members to perform nursing tasks, but generally, it is nurses who train family members in home settings. Many younger adults with disabilities report having been trained to perform paramedical tasks and instructed also in how to train others to perform these tasks while in rehabilitation hospitals. See ADAPT website: <http://www.adapt.org/>
- 18 Reinhard, S.C. & Young, H. (2006). *Washington's Nurse Practice Policies for Home and Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/cle/Products/WashNursePracPolicyWEB.pdf>. Reinhard, S.C. & Quinn, W.V. (2004). *Oregon's Nurse Practice Policies for Home and Community Living*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange. Available at: <http://www.cshp.rutgers.edu/cle/products/QuinnOregon.pdf>
- 19 Sikma, S.K. and Young, H.M. (2003). Nurse delegation in Washington state: a case study of concurrent policy implementation and evaluation. *Policy, Politics, and Nursing Practice*, 4 (1): 53–61. Young, H.M. and Sikma, S.K. (2003). Self-directed care: an evaluation. *Policy, Politics, and Nursing Practice*, 4 (3): 185–195. Young, H.M., Sikma S.K. (2002). *Evaluation of the Implementation of Self-Directed Care in Washington State: Final Report*. Seattle, WA: University of Washington, School of Nursing. Available at: <http://www.dshs.wa.gov/pdf/EA/GovRel/Leg1102/SDC.pdf>

Young H.M., Sikma S.K., Eyres S.J., et al. (1998). *Nurse Delegation Study Final Report*. Seattle, WA: University of Washington. Available at: <http://www.doh.wa.gov/hsqa/uwstudy.doc>

- 20 Susan Reinhard, R.N., Ph.D., Director of AARP's Public Policy Institute in Washington, D.C., has organized numerous state nurse delegation summits both national and state specific since the late 1990s. These meetings have brought together nurses on state Boards of Nursing, staff of the Chicago-based National Association of State Boards of Nursing, university-based nurse researchers and educators, state Medicaid disability and aging program officials, and prominent disability activists, such as Bob Kafka of ADAPT, who was highly influential in bringing about NPA reform in Texas, his home state. Two of the states in the CCDE—New Jersey and Arkansas—obtained regulatory flexibility from their Boards of Nursing as a result of nurse delegation summit meetings.
- 21 These concerns can pose barriers to developing programs and to enrollment, if, for example, health and social services professionals discourage eligible individuals from enrolling. In 2000, Arkansas held a series of focus groups with social workers, nurses, pharmacists, and physicians to determine if they would be willing to refer Medicaid beneficiaries to IndependentChoices—the new Cash & Counseling program participating in the CCDE.

Although many comments were positive, some participants (especially nurses) expressed concerns about the competence of participant-directed aides and the potential for abuse and participants' reluctance to report it. The inclusion of older persons in self-direction programs in particular raised these concerns. Interestingly, physicians and pharmacists were more open than nurses to the idea of referring patients to the program and distributing brochures. However, they wanted to have all of their questions and concerns addressed by program staff before making referrals.

- 22 Non-participants refers only to individuals in the control group.
- 23 Tilly, J. (2007). *Consumer-directed Home and Community Services for Adults with Dementia*. Washington, DC: Alzheimer's Association. Available at http://www.alz.org/documents/advocacy_public_policy_issue_brief_71107.pdf

Wiener, J. & Khatutsky, G. (2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *The Gerontologist*, 47: 763–774.

Kunkel, S. R. & Nelson, I.M. (2005). *Profiles of choices consumers*. Scripps Gerontology Center. Miami University of Ohio. This paper is available at: http://www.scripps.muohio.edu/research/publications/documents/Final_Choices_Report.pdf

Shen, C., Smyer, M., Mahoney, K.J, Loughlin, D.M., Simon-Rusinowitz, L.S., & Mahoney, E.K. (2008). Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling Program. *The Gerontologist*, 48: 93–104.

- 24 Many of the California In-Home Supportive Services county public authorities operate worker registries as do some Centers for Independent Living. For a list of and links to direct care worker registries servicing 22 states, see <http://dswresourcecenter.org>.
- 25 See Kentucky’s Consumer-Direction Option Video at <http://www.cashandcounseling.org/resources/20070622-141705>
- 26 Available at: <http://www.csus.edu/isr/reports.stm>. Select: Educational Materials for IHHS Consumers and Providers. Prepared for the California Department of Social Services (September 2006)
- 27 Colorado’s program made an excellent “laboratory” for exploring risk management issues and strategies because it had only a few hundred participants. As a result, participants who attended focus groups to discuss risk management strategies represented a more sizable percentage of all participants than is usually the case when focus group methods are employed to obtain open-ended participant feedback. The State also interviewed key stakeholders to obtain their input on the same topics. A report that weighs the pros and cons of alternative approaches to risk management is available at http://www.chcpf.state.co.us/hcpf/syschange/ip_grant.asp
- 28 One CDAS participant described an approach that was prevalent among CDAS participants: “I have several aides who work for me, and I have different people who are available at different times of the day. I have two people who are almost always available early in the morning. Those are the times when we have the shortest time to be able to find somebody. But I’ve also had times when my chair has broken down, so I’ve just gone through my list of aides and called until I’ve found somebody to come and take me to the repair shop, or take me to the ER, or whatever is necessary. It’s just a matter of having enough staff. I don’t just have one or two people working for me. I actually have about 14 people on my list. I don’t have a hard time finding someone to cover at the last minute.”

Another CDAS participant talked about her strategy for ensuring coverage if her morning attendant must cancel. “I’ve set up a system where she has a backup person if she’s sick. It’s her responsibility to call the backup person, to make sure I can get out of bed.” This same participant emphasized the importance of hiring and retaining reliable attendants—“I pay everyone pretty decently and treat them well”—and firing unreliable attendants—“If somebody does a no-call-no-show, they don’t ever come back again.”

In a true emergency, when no other help is available, consumers reported relying on “911” police and fire/rescue services. Savvy consumers planned ahead for this contingency. One CDAS participant said that when he first moved into his neighborhood, he wheeled over to the local fire station and introduced himself. “I told them I might call if I needed help,” he said. “They encouraged me to call if I needed to.” He has done so, about half a dozen times, without a problem.

- 29 Most acknowledged having experienced such incidents, though none reported having suffered adverse health consequences. The reported incidence of theft and disrespectful behaviors (mockery, verbal abuse) was much greater than for physical abuse or neglect that could cause physical harm. Thus, harm was primarily psychological; program participants felt anxiety and fear.
- 30 Focus group members also said that the incidents they had experienced rarely involved criminal behaviors. Focus group members recommended that the state establish some kind of registry where consumers could report abusive, neglectful, poor quality attendants.
- 31 A formal abuse reporting system and registry (such as those that already exist for nursing home abuse or elder abuse in general) typically require authorities to investigate and make a positive “finding” before someone can be labeled an abuser, which may require a standard of proof that cannot be met.
- 32 Recounted by an Iowa state official at the Cash & Counseling Annual Meeting in Albuquerque New Mexico (October 4, 2007).
- 33 In most of the small number of cases reported, the defendants were either home health/home care agency providers or individual aides, hired and supervised on a private pay basis, typically by the families of disabled adults or children. Hughes, S.L., & Sabatino, C.P. (2005). Addressing liability issues in consumer-directed personal assistance services: The National Cash and Counseling Demonstration. *Stetson Law Review*, 35(1), 251–382.

This article is based on the report prepared for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy and for Boston College. The report is available at <http://aspe.hhs.gov/daltcp/reports/cdliab.htm>

Hughes and Sabatino note that “reported” cases are those in which a judge, usually of an appellate court, has written an opinion with factual findings and legal holdings, and the opinion has been published in an official or unofficial law reporter system or has otherwise been made generally available (most often by inclusion in one of the two main commercial legal data bases, Westlaw and LexisNexis).

- 34 However, suing a family member clearly has additional consequences with respect to family relationships that are not present when a worker is unrelated to the plaintiff. Moreover, suing a family member could cause economic harm to the plaintiff (especially if the plaintiff lives in the family member's home) even if the plaintiff is awarded a judgment. However, the broader literature on tort claims, including medical malpractice suits, strongly suggests that the nature of the relationship between the service provider and service recipient—both before and immediately following the behavior that is perceived by the service recipient (or service recipient's family) to have caused harm—greatly affects whether or not a suit will be filed and whether or not the suit will be dropped or settled prior to going to court.

That is, a longstanding relationship, previously perceived to be a good one is less likely to result in litigation; similarly, if service providers do not prepare to defend themselves legally by cutting off contact, withholding information, and otherwise behaving very defensively and, instead, express concern and “sorrow” in regard to adverse outcomes (without, however, accepting responsibility for having negligently caused those outcomes), the likelihood of litigation decreases.

- 35 Reeder had also sued the state on the theory that the LPN, because she was paid by Medicaid, was a “state employee.” However the legal ruling was that she was an “independent contractor.” Note that as a licensed (i.e. professionally trained) nurse, this individual could be considered an independent contractor rather than the participant's domestic employee, even though she was providing more aide care than skilled nursing.
- 36 Why did Caulfield's case manager hire an independent provider rather than refer him to an agency which would presumably have provided more supervision than the case manager did? The most likely explanation seems that Caulfield, who was paralyzed and had no family, required paid home care almost around-the-clock and that would have cost more than nursing home care. This is the dilemma: for some high-need individuals, only self-directed services can be a cost-effective alternative to nursing home care, but the participant must either be capable of self-direction or have a representative who is available and willing to assume the responsibility.
- 37 Reeder's lawsuit rested on arguments that claimed he was not really “self-directing” his care because the LPN was a state employee and the State was responsible for ensuring that he received high quality care that should have prevented bedsores from developing.
- 38 Information about bedsores provided by the Mayo Clinic notes: “Bedsores can develop quickly, progress rapidly, and are often difficult to heal. Yet health experts say many of these wounds don't have to occur. Key preventive measures can maintain the skin's integrity and encourage healing of bedsores,

(yet) ... Even the most conscientious care can't always prevent serious or life-threatening infections ...” The Mayo Clinic website also points out that individuals with paralysis are at high risk of developing bedsores and that the actor and disability advocate Christopher Reeve died from complications of a bedsore. See information at: <http://www.mayoclinic.com/health/bedsores/DS00570>

- 39 A Microboard—which comes out of the person-centered planning philosophy and is therefore created for the sole support of one individual—is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people address the person’s planning and support needs in an empowering and customized fashion.
- 40 Hughes, S.L., & Sabatino, C.P. (2005). Op.cit.
- 41 Helen Roth, personal communication to Pamela Doty, September 2, 2008.
- 42 The §1915(c) HCBS waiver template instructions are available at https://www.hcbswaivers.net/CMS/help/version_35_1915c_Waiver_Application_and_Accompanying_Materials.zip
- 43 A few years after the original CCDE pilot programs began, MCO surveys were conducted to explore how they viewed the compatibility of self-direction and managed care. In one survey of 64 MCOs, 69 percent reported that self-direction was under discussion within the organization and about 45 percent indicated that they were open to the idea at least for some plan members. Organizational factors associated with greater openness to self-direction include: larger size, covering populations broader than just elderly persons, and not being PACE programs. Mahoney, K.J., Meiners, M.R., Shoop, D., and Squillace, M.R. (2003). Cash and Counseling and managed long-term care? *Case Management Journals*, 4(1), Spring: 18–22. Available at: <http://www.cashandcounseling.org/resources/20060126-112344>

In a more in-depth profile of 38 MCOs, 12 reported allowing plan members to employ their own workers, including nine that permitted employment of friends and relatives. Most of the MCOs that did not allow plan members to exercise employer authority or even to have much input into the professional care plan perceived little or no interest among plan members in self-direction. Overall, the 38 managed care organizations were evenly split as to whether they perceived self-direction to be a threat to plan profitability. Few of the plans that allowed members to employ workers perceived self-direction as threatening their profitability, but the plans that reported giving members a “major say” in care planning but not employer authority (87 percent), were quite worried about self-direction as a potential threat to profitability. Meiners, M.R., Mahoney, K.J., Shoop, D.M., and Squillace, M.R. (2002). Consumer

direction in managed long-term care: An exploratory survey of practices and perceptions. *Gerontologist*, 42 (1): 32–8.

- 44 Wisconsin offered self-direction options in its HCBS waivers prior to instituting its managed care program—Family Care—which also allows participants to direct their services. In contrast, Texas had no tradition of self-direction, but Americaid—one of the managed care plans under Texas Star Plus—offered participant-directed aide services because one of its executives believed that the option could be more cost-efficient and increase participant satisfaction. Texas officials then decided that Americaid should not have a competitive advantage by virtue of offering self-directed aide services and made this a requirement for all Texas Star Plus plans. The employer authority has since become available in the fee-for service sector in Texas as well. Beginning in 2001, the State gradually added self-direction options in its State Plan personal care services program and in all of its HCBS waiver programs.
- 45 The Medicare Modernization Act of 2003 created a new type of Medicare Advantage coordinated care plan focused on individuals with special needs, who are identified as (1) institutionalized, (2) dually eligible, and/or (3) individuals with severe or disabling chronic conditions. Milligan & Woodcock (Op. cit.) outline three different approaches and their pros and cons for coordinating acute and long-term care for dual eligibles by linking state Medicaid programs with Medicare Advantage Special Needs Plans (SNPs): (1) a voluntary integrated program, (2) a mandatory Medicaid managed care program with potential side agreements with Medicare Advantage SNPs, and (3) a model involving an administrative services organization (ASO) arrangement. In an ASO arrangement, Medicaid pays a case management fee to Medicare Advantage SNPs or to another entity to coordinate the delivery of Medicaid services with the Medicare Advantage SNPs operating in the state (this third model is a “non-risk” contract for performance of Medicaid administrative functions).

Some observers hoped that this legislation would result in proliferation of integrated acute/long-term care managed care plans to serve the nation’s approximately 7 million dual eligibles who, on average, are in poorer health and more likely to have chronic diseases and disabilities than other Medicare beneficiaries. Provost Peters, C. (November, 2005). *Medicare Advantage SNPs: A New Opportunity for Integrated Care?* National Health Policy Forum, Issue Brief, No. 808. Washington DC: George Washington University.

As of September 2007, there were a total of 478 SNPs, including 320 for dual eligibles. Of 1,021,800 enrollees, 722,286 were dual eligibles. Milligan Jr., C.J. & Woodcock, C.H. (February 2008). *Medicare Advantage Special Needs Plans for Dual Eligibles: A Primer*. Commonwealth Fund Issue Brief, Commonwealth Fund Publication 1108, Volume 31. Available online at

http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=670364

Unless reauthorized by Congress, however, the SNP program will sunset December 31, 2010. <http://www.cms.hhs.gov/SpecialNeedsPlans/>. Thus, the future of SNPs remains uncertain. In addition, even though SNPs were authorized, in part, to encourage coordination of Medicare and Medicaid benefits for dual eligibles, only seven states currently have operational programs to coordinate Medicare and Medicaid benefits and of these seven states, only three have dual eligible enrollment in Medicaid managed care programs of at least 10,000 enrollees (Minnesota: 35,000; Arizona: 24,000; and Texas: 20,000). Milligan Jr., C.J. & Woodcock, C.H., Op. cit.

- 46 Federal Medicaid officials have been reluctant to approve (b)(c) combination waivers unless states provide assurances that one plan would not be given a monopoly in perpetuity with respect to Medicaid managed care enrollment. This emerged as an issue in Wisconsin and Michigan with respect to county-based managed care plans for HCBS waiver services.
- 47 For more information about PACE, see <http://www.medicare.gov/Nursing/Alternatives/Pace.asp> and the National Pace Association website <http://www.npaonline.org/>.
- 48 This is expected because when §1915(c) waiver coverage was required to be integrated into managed care in Minnesota, MCOs often hired or contracted with the same waiver care managers who had worked in the fee-for-service system. Although this enabled MCOs to staff up quickly to assume responsibility for the waiver program, the drawback is that it may also take some time for care managers who are used to working in a fee-for-service environment to become aware of the opportunities that managed care has to offer for synergy between self-directed HCBS and improved access to health care. (For example, many managed care plans have been quicker than physicians in private practice to see the value and cost-effectiveness of delegating some medical tasks to nurse practitioners and other physician extenders. They may similarly be more open to and better able to implement nurse delegation in combination with self-direction of unlicensed assistive personnel than traditional HCBS providers.)
- 49 ICS serves only adults with disabilities who became disabled in adulthood prior to age 65. ICS medical care managers coordinate services with fee-for-service medical providers (i.e. physicians and hospitals). ICS currently manages only long-term services and supports, but its goal is to become a “disability competent integrated system of care” that can manage acute medical care as well as long-term services and supports for its members. Surpin, R. (2007). Independence care system: A disability care coordination organization in New York City. *Journal of Ambulatory Care Management*

30(1):52–63. Information about ICS is available at http://www.icsny.org/about_us_mission.html.

50 http://www.icsny.org/building_a_community_wheelchair.html

Chapter 10: Looking Ahead

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Chapter 10

Looking Ahead¹

Self-direction is now a well-established model of service delivery. While states continue to expand their self-direction programs and develop new ones, they need to be aware of emerging issues that might affect their programs as well as new opportunities to offer participant-directed services.

Some components of efforts to increase quality assurance in home and community-based services programs may not be compatible with self-direction programs. For example, self-directing participants define for themselves the employment qualifications their workers need and screen and select among potential workers using these criteria. If training and credentialing requirements for home care workers are mandated to ensure quality, then exceptions may have to be made to ensure that participants in self-direction programs can continue to hire who they want to assist them.

Another issue states may need to deal with is unionization. Unionization has resulted in significant wage and benefit increases, most notably in California, Oregon, Washington, and Michigan. In the first three states, union-negotiated contracts with public third party payers have also resulted in health insurance benefits becoming broadly available, for the first time, to participant-directed independent providers.

While states may have concerns about the impact of these increases on overall costs, they also need to recognize that these increases offer considerable opportunity to improve and expand the labor pool available to individuals who want to direct their services. Research evidence indicates that wage and benefit improvements (especially the provision of health insurance benefits) increase the pool of workers and, in particular, promote worker retention. However, if workers—including participants' family members—are required to join a union, participate in mandatory training, and have a criminal background check, for many, the attraction of self-direction may be lost.

The relationship between participant-directed services and managed care continues to pose both challenges and opportunities. It remains difficult to predict how much managed care will or will not expand to encompass populations, such as the Medicaid “Aged and Disabled” population and dually eligible (Medicare and Medicaid) population that have traditionally been largely exempt from mandatory enrollment in managed care organizations. If individuals who are directing their services are required to enroll in managed care organizations, states need to ensure that they will be able to continue directing their services.

Finally, there are new opportunities emerging to expand the scope of participant-directed services in terms of both services and constituencies. Several states and one large managed care company operating in several other states have pilot projects that allow Medicaid beneficiaries with mental illnesses to use self-directed budgets to purchase services (ones that are not otherwise Medicaid-covered) to facilitate and sustain their recovery.

The Deficit Reduction Act of 2005 has made available a new State Plan benefit for home and community-based services under Section (§) 1915(i) of Title 19 of the Social Security Act. Because these services are not restricted to individuals who would otherwise be at risk of institutionalization at Medicaid expense, this new benefit opens up possibilities for greatly expanded Medicaid funding of non-institutional psycho-social rehabilitation services for persons with frequently recurring or long-term, persistent mental illnesses.² The §1915(i) provision specifically authorizes states to offer the covered services through participant-directed service delivery models, at their option.

Veterans are another potentially growing constituency for participant-directed services. Ironically, the Veterans Administration pioneered participant-directed long-term care in the U.S. immediately following World War II through a cash benefit—called the aid and attendance allowance—for veterans with severe service connected disabilities. Subsequently, however, the Administration developed a wholly different approach that required Veterans hospitals to be direct providers of services for the much larger population of veterans who developed a need for long-term services and supports long after their military service had been completed.

There is an unexpectedly high volume of disabling injuries among recently discharged veterans, including head injuries and stress-related behavioral disorders. The Veterans Administration has recently indicated interest in exploring self-direction for veterans, which could assist the recovery of younger veterans with service-connected disabilities as well as meeting the long-term service and support needs of older veterans.

Resources

National Resource Center for Participant-Directed Services

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

Funding for the C&C National Program Office (NPO) ended with the completion of the C&C Replication Project. A new National Resource Center for Participant-Directed Services has been established to enable other programs to receive the technical assistance the NPO provided to the C&C Grantees—to help them plan, design, implement and evaluate their programs (including help with specific issues such as obtaining workers' compensation coverage.)

The Center is funded by The Robert Wood Johnson Foundation, The Atlantic Philanthropies, the Administration on Aging, and the Office of the Assistant Secretary for Planning and Evaluation, USDHHS. Resources available at the C&C website will remain available and will also be accessible from the new Center's website. The Consumer Direction Module, a secure web-based software application specifically designed to support self-direction programs that provide individual budgets will also be available through the new Center.

The Center provides technical assistance through its staff and affiliated consultants with expertise in specific areas. Technical assistance will be available for all self-direction programs—those that offer only the employer authority as well as those that offer both employer authority and budget authority; Medicaid programs and non-Medicaid programs.

Areas in which technical assistance will be available include: financial management services, counselor activities and training, participant involvement, program design and implementation, quality, oversight, and management information systems.

The pioneer and replication C&C programs served a variety of target populations including elderly persons and younger adults with adult-onset disabilities (both physical and cognitive), as well as adults and minor children with developmental disabilities, including those with intellectual disabilities only, disabling physical conditions only, or both physical and mental disabilities. The new Center will provide technical assistance for programs serving all of these populations.

The Center's goal is to be the "one-stop shop" for training, technical assistance, research, and policy analysis for programs that want to offer, or are already offering, participant-directed services. The Center is already working with states to promote opportunities for participants to direct their services in programs funded by the the Administration on Aging and the Veterans Administration.

One of the Center's objectives will be to help state officials and advocates/activists representing the various disability communities understand the

similarities and differences that are often obscured by the terminology that has been used to characterize self-direction programs. By pulling back from identification with a particular “brand name” self-direction model (i.e., Cash & Counseling), the Center plans to raise awareness about self-direction generally and assist government officials, as well as advocates and activists, to understand the various program design choices and the pros and cons associated with each of them.

For those policymakers and program administrators who want to implement a program that conforms to the C&C Vision Statement (See Chapter One)—even though the program may not use that name—the Center will offer an accreditation program to ensure and grant external recognition that the program fulfills the requirements. Participation in this accreditation program will be strictly voluntary. States and programs that do not seek such accreditation will still be able to obtain technical assistance from the Center in the specific areas with which they need assistance.

Additional Information

- 1 Pamela Doty is the author of this chapter.
- 2 Most individuals between the ages of 18 and 64 at high risk for admission to state mental hospitals are not eligible for coverage under HCBS waivers because the institutions where they are most likely to receive services are ineligible for Medicaid reimbursement.

Appendix I: Using Strategic Communications

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Appendix I

Using Strategic Communications to Ensure the Success of a Self-Direction Program¹

As with any program, a new self-direction program will have its supporters, opponents, and those who fall somewhere in between.² The primary goal of any communications strategy is to convince stakeholders that self-direction is a valuable and desirable addition to the long-term service options currently available.

The ultimate goal—beyond designing and implementing a new program—is to attract and enroll sufficient eligible individuals to sustain the program, providing the base for future expansion. Creating a strategic communications plan for the new program will help to achieve this goal.

Currently, 15 states have self-direction programs begun or expanded with funding from the Robert Wood Johnson Foundation's Cash & Counseling (C&C) Grants Program. All have used a variety of communications strategies to help build support for, launch, and sustain their programs.³ Based on their experiences, as well as the technical assistance provided by the C&C National Program Office (NPO), this appendix describes the essential communications activities states should consider when developing a new self-direction program. These activities include:

- Building support and creating advocates for the new program
- Crafting and delivering effective messages about the program
- Disseminating the program's messages
- Dealing with opposition and countering resistance to the program
- Reaching out to potential participants and their families, particularly those immediately eligible for the new program, to provide them with information and to encourage their enrollment.

When thinking about communications strategies, a good first step is to review other states' sample communications plans. For example, West Virginia's communications plan for its self-direction program, called Personal Options, focuses on a specific goal (enrolling 10 percent of eligible waiver participants) and describes strategies for reaching that goal, including identifying target audiences, understanding and addressing potential opposition, developing communications activities, and establishing a timeline.⁴

Myriad templates for creating communications plans are available on the Internet⁵ and this appendix includes links to sample communications materials created by

C&C grantees and the C&C NPO, which may be used by other states as templates for developing new materials.

Whichever approach a state uses, it is important to view communications as an ongoing process that requires creativity, both consistency and flexibility, and a commitment from the outset to use language that stakeholders can easily understand.

A. Building Support and Developing Advocates for the Program

Among the first steps in any formal or informal communications plan is a “stakeholder analysis”—identifying key stakeholders and determining their needs. Stakeholders are those people who are in a position to influence the new program and whose support and participation are essential to its success. (See Box)

Individuals eligible to participate in the program—and their primary caregivers—are its primary stakeholders. Additional key stakeholders include those who will administer or work in the new program, other service providers (who may oppose the program), state staff, state policymakers, and others.

Examples of Stakeholders

- Potential participants and their families, particularly those immediately eligible for the new program
- Organizations that represent potential participants, such as aging and disability advocacy groups
- Caregivers and the organizations that represent them and their interests
- Aging and disability provider networks, such as Area Agencies on Aging and Independent Living Centers
- Providers of services and supports for the program’s target population
- Legislators and staff, the governor and staff, Medicaid agency staff, and the new program’s staff and administrators
- Individuals who will work in the program, including counselors, case managers, financial management service providers, and state outreach workers.

A stakeholder analysis consists of (1) creating a list of everyone who has a potential involvement, investment, or interest in the new program; (2) analyzing their current level of knowledge about, interest in, or opposition to the program; (3) determining how best to educate them about—and generate their enthusiasm

and support for—the new program; (4) identifying individuals to serve on the program’s advisory groups; and (5) enlisting the support of key stakeholders who can effectively disseminate information about the program to target audiences.

Strategies to Reach and Involve Stakeholders

Stakeholders are always the primary targets of any communications effort on behalf of a new program. Early communications efforts targeted to stakeholders may take the form of mailings and advertising to let potential participants and their families know that a new self-direction program will soon be available or presentations about the program at annual meetings of provider organizations or one-on-one meetings with key state personnel and local legislators.

Inviting stakeholders to serve on a program’s advisory panel not only engages them in its planning and implementation, but also creates a group of knowledgeable individuals who can provide valuable insights, such as the best channels to reach various target audiences or the most effective messages for particular groups. Communicating with potential participants, for example, requires a very different approach than does communicating with state legislators or representatives of provider organizations. Having advisory panel members who represent all the major stakeholders will help program staff target communications efforts more effectively. Stakeholders who are invested in the success of a new program can also help counter opposition and eliminate challenges to the program by carrying a positive message about the program to many different audiences.

Generally, states establish a single advisory panel for stakeholders that can include a majority of potential participants and their family members. Some choose, to create a separate advisory panel solely for potential participants, whose specific charge is to help ensure that their perspectives are incorporated into every program process and component—from design to implementation to outreach and enrollment. Potential participants are the single most important stakeholder group for a new self-direction program and soliciting their input from the beginning will give credibility to the program. See Chapter 3 of this Handbook for an in-depth discussion about involving participants.

Reaching Key Audiences

In addition to stakeholders, a communications strategy needs to focus on reaching key audiences. One key audience is the media, including major statewide media outlets and local media, as well as targeted media such as organizational newsletters and sponsored websites. Another is state and local opinion leaders, including any influential persons whose support can bring attention and lend credibility to the new program. The support of opinion leaders can also help the state reach a broader audience than is generally possible with communications through usual state channels. (See box below.)

Some opinion leaders—such as the state governor, the well-respected head of a local provider association, or individuals active in local advocacy organizations—are also stakeholders. Whether a stakeholder or not, opinion leaders can be enlisted to help reach and influence other stakeholders, their colleagues, constituents, and others. Opinion leaders bring credibility to any communications effort because they attract attention and people listen to what they have to say.

Examples of Opinion Leaders

- A Governor or a high-ranking member of a Governor’s staff
- State legislators, including relevant committee chairs and members
- Medicaid, Aging, and Disabilities Program directors and relevant staff, including press officers
- Heads of other relevant press offices, including a Governor’s press secretary
- Heads of aging, disability, caregiver, and other relevant advocacy groups
- Heads of local long-term services and supports provider associations and individual provider agencies
- Relevant leaders and/or researchers at universities or colleges, such as deans of schools of social work, nursing, or medicine
- Local government officials
- Influential statewide and local business leaders, especially those who are active in state politics and in their communities
- Influential religious leaders
- A newspaper publisher, editor, popular columnist, or other influential media representatives
- Well-known personalities who may be willing to talk about their own personal or family experiences with long-term services and/or caregiving.

In the early days of Arkansas’ self-direction program, state staff successfully enlisted the support of the Governor, who, after a few short meetings, recognized the potential benefits of the program for people with disabilities and their families. While his endorsement was made clear on multiple occasions, it culminated with a signed letter extolling the program to potential participants. The Governor’s endorsement represented a “tipping point” for Arkansas’ program—the point at which it gained broader recognition and significant momentum.

Enlisting the early support of opinion leaders—especially politicians whose support is critical to the program’s success—will help to ensure that they will advocate for the program even in the face of resistance or opposition from provider organizations. Additional information for dealing with provider resistance can be found in Section D of this Appendix.

Recruiting Opinion Leaders in Michigan

In 2007, representatives from Michigan’s self-direction program traveled to Washington, D.C. to meet and establish relationships with legislative staff of the State’s Senators and two of its Congressional Representatives. State staff prepared for the meetings by developing and practicing their key messages, and deciding what specific requests they would make to the legislators. They provided brief background materials in advance of the meeting and brought additional materials with them.

During the brief meetings, they asked each legislator to share information about the new self-direction program through their websites and their local offices. They also asked the Senators to sign a joint letter supporting the program that could be sent to potential participants statewide. All of the legislators agreed to these requests and program staff moved quickly to follow up on the agreed upon actions.

B. Crafting and Delivering Effective Messages

Before meeting with decision makers, preparing presentations for stakeholder audiences, and/or developing informational materials about the new program, state staff should craft key messages about the program for each target audience. In addition to providing basic information, key messages explain why the target audience should care about the new program.

Taking the time to develop effective messages will help program staff to:

- Ensure that all points are made clearly and succinctly,
- Ensure the accuracy of information and reduce misunderstandings,
- Assume control over the discussion and/or information being presented, and
- Generate support for the new self-direction program.

Developing Effective Messages

Message development is often a team effort, and group brainstorming is an effective way to start the process. Begin by listing stakeholder audiences and

then discuss the most important messages for each. Start with the main ideas and develop messages to communicate those ideas. Once several draft messages have been developed, refine and shorten them and select the key messages. The final product should be a succinct set of messages that clearly communicates the most salient points about the new self-direction program to any given audience.

Several additional suggestions for crafting effective messages follow.

- ***Create three or four main messages and use them repeatedly and consistently.*** Don't overwhelm audiences with too much information. Development of supporting messages is also important, but the focus should be on delivering main messages memorably.
- ***Use messages that are clear, compelling, accurate, and short.*** Use precise and compelling words and short sentences for greatest impact.
- ***Avoid jargon, technical information, nuances, or complexities.*** Self-direction is a complex concept. It is best to assume that audience members have never heard of it and try to explain it accordingly.
- ***Anticipate difficult questions and prepare answers before they're asked.*** Develop a supplemental set of messages that are essentially brief, clear, accurate responses to challenging questions.
- ***Always pre-test messages on sample audience members.*** Some states held formal, professionally facilitated focus groups with stakeholders—such as potential participants and their families—to determine which draft messages resonated most with them. Others conducted informal message testing activities, such as seeking feedback on messages from colleagues, relatives, and friends. Focus groups can also be used to pre-test program materials, such as logos, brochures, and participant handbooks.
- ***Revisit and refine messages to ensure effectiveness.*** Even pre-tested messages can sometimes fall flat. If certain messages are not working well, ask sample audience members for feedback and refocus or refine the ineffective messages based on their input.

The states that received C&C grants have all crafted effective messages. A good example of their work is Minnesota's "Key Talking Points" document, which was developed to help staff use clear and consistent language when discussing the self-direction program.⁶ One of Minnesota's main messages about its program—called Consumer-Directed Community Supports—succinctly communicates the important benefits of the program: "Consumer Directed Community Supports is a well-tested and proven service option that can dramatically improve consumer satisfaction and quality of life."

Delivering Effective Messages

Once developed, good messages are only as effective as their delivery. Below are suggestions for delivering effective messages, whether in presentations to large groups or in one-on-one meetings.

- ***Practice delivering messages.*** Role-playing exercises can help the presenter tremendously, especially if a partner asks difficult questions or questions that stray from the point. Consider formal presentation training for principal program staff.
- ***Relax and do not be intimidated.*** Meeting with key stakeholders or presenting to large groups are opportunities not moments to be feared.
- ***Be clear and concise.*** Focus on the two or three main messages you want the audience to remember.
- ***Adapt messages as needed.*** Remember that the same messages do not work for every audience; be sure you are using messages that are relevant to your audience.
- ***Speak simply and clearly.*** Do not use technical terms and other jargon.
- ***Use effective speakers and send the best messenger.*** Assign speakers who are comfortable talking to others and those who are most likely to connect with a given audience. While the message is important, an effective and appealing messenger can help convince people who may be skeptical or defensive and defuse potential resistance.
- ***Tell brief stories about program participants.*** People are moved by stories and the emotion in them more than they are by data. The NPO and several C&C states have developed presentations that incorporate consumers' personal stories and photos to help communicate the need for and/or benefits of self-direction.
- ***Flag main messages with transitional phrases and restate them in several ways,*** for example, "The key thing is..." , "What's important to remember is..."
- ***Anticipate tough questions and practice the answers.*** Always be prepared to respond to challenges and never get caught off guard. And always have specific action steps in mind if someone suddenly asks "How can I help?"
- ***Be prepared for meetings that do not follow the planned script.*** Assess the audience, be prepared for the subject to change, and learn how to redirect the discussion.
- ***Bring Supporting Materials*** to all meetings and presentations, no matter how

large or small. Information on developing these materials is discussed later.

C. Developing and Disseminating Program Information

Once program staff have identified stakeholder audiences and developed key messages, the next step is to begin thinking about the best ways to disseminate information about the new program. Whether the program is in the earliest planning stages or is ready to begin enrollment, program staff need to know how and when to use basic communications tools. This section provides advice on developing informational materials and working with the media.

Developing Informational Materials

One of the most frequent questions program staff will hear when talking to others about the new program is: “Do you have any materials on the program?” Developing and providing information in multiple formats helps stakeholders and other audiences to better understand the program. Here is a list of useful materials and tips for creating them.

- ***Program name and logo.*** These items will help establish a unique identity for the new program. They will help target audience members differentiate the new program from already existing long-term service options. A catchy, easily recalled name and/or logo are particularly helpful for potential participants and their families, who can be overwhelmed by the variety of similarly named (and heavily acronymed) government programs available to them.

For example, with input provided by focus groups, New Mexico invested significant effort in creating a distinct, consumer-friendly, cross-cultural identity for its self-direction program—called “Mi Via” (or “My Way”).



The name and logo for New Mexico’s C&C program, Mi Via, were carefully created through an inclusive process that solicited input from stakeholders statewide.

- ***Fact sheets and frequently asked questions*** (FAQs) with answers about the new program are extremely helpful and relatively easy and inexpensive documents to produce. Fact sheets should explain the program’s primary

features in easy-to-read language on a single page in bullet form. An FAQ can be longer and should include the questions that readers are most likely to ask with succinct answers. Iowa has developed an excellent consumer fact sheet and an FAQ for its self-direction program.⁷

- **Letters and postcards** are important documents to develop, particularly to promote the self-direction program to potential participants and their families. More information and samples of these documents are provided in Section E of this appendix.
- **Brochures.** An easy-to-read, visually interesting, versatile brochure that explains the new program clearly and answers the most important questions will be very useful to program staff. It is the document that will be used the most, and should be developed with multiple audiences in mind. It should present information about the program in clear, conversational language; include quotes from influential opinion leaders and/or consumers; and feature engaging photographs of the types of people and their families who could benefit from the program.
- **Brief user-friendly publications.** The C&C NPO developed a publication describing the initial findings of the original three-state C&C Demonstration and Evaluation (CCDE)—along with photographs and stories of participants. The second round of states receiving C&C grants used this publication to explain the C&C model to stakeholders, the media, and a variety of audiences.⁸ Because it provided background information about self-direction and the C&C program model, states were able to focus their communications efforts instead on preparing written materials for potential participants and their families. New Mexico⁹ and Iowa¹⁰ both developed brochures targeted toward potential participants and their families, but which can also be used to explain the program to providers and the media.
- **Websites.** An easy-to-navigate website is essential for any new program. While some potential participants and their families may not have access to a computer, a website is an effective and efficient method for providing current information to those who do and all other audiences, including state government officials and their staff, media, providers, and consumer advocates. New Mexico has an excellent website for its Mi Via program, which is clear and easy-to-use.¹¹
- **Videos.** Videos are an effective supplement or alternative to written materials because they make information about the program “come alive.” Videos can be made available through program websites and/or distributed with written materials. Kentucky,¹² Minnesota,¹³ and New Mexico¹⁴ created educational videos about their programs. The NPO also created three videos that tell the stories of participants in Florida,¹⁵ New Jersey,¹⁶ and Minnesota,¹⁷ and how the program has benefited them.

Working with the Media

The media are both an audience and a means to reach other audiences. As an audience, newspaper editors, columnists, talk radio hosts, and other journalists need to understand and see the value of the new program so that they can, in turn, help to educate others about it. As a means for reaching other audiences, the media are very influential and are relied upon as sources of information for everyone from state government officials and their staff to providers, potential participants, and their families.

Examples of various media-related activities that can be used to disseminate information about a new program follow.

- ***Phone calls and one-on-one meetings.*** In most states, generally a few healthcare journalists cover aging and disability issues. As they will likely be interested in writing about the new program, it is worthwhile for program staff to establish relationships with them, call and tell them about the new program, and offer to meet with them in person and become a resource.
- ***Letters to the Editor.*** Newspaper readers send letters to the editor in reaction to a recent news story, column, or editorial. If misinformation about a self-direction program appears in the paper, write a letter to the editor and correct it. Or if you read a story that easily could have mentioned self-direction, but didn't, write a letter to the editor and explain the oversight. Newspapers receive more letters than they can print, but the odds improve when letters are brief and to the point. Submit them within a day or two of the date that the original article appeared. See local newspapers for examples of such letters.
- ***Op-eds.*** Op-eds are opinion pieces that appear on the page opposite the editorials page (thus the term "op-ed"). Intended to influence public opinion, an op-ed piece should make a single point very well. The topic should be timely and relevant to current events, and will be most effective if the article is authored by someone recognized as an authority on the subject.

The governor, a Medicaid director, a program counselor, or participant could put his or her name on a compelling op-ed in favor of the new self-direction program. Op-eds should state their main point up front; use short, clear, active voice sentences; tell a story, if possible; and make specific recommendations. Check with the newspaper regarding submission procedures and requirements, but op-eds should generally be no more than 600–750 words. An op-ed template is available on the C&C website.¹⁸

- ***News Releases.*** News releases are one- to two-page documents that report a news event, such as the launch of a new self-direction program, and also provide contact and background information as well as quotes from relevant commentators. News releases present the most important information up

front, with details regarding “who, what, when, where, why, and how” supplied in the first two or three paragraphs, and quotes and supplemental background information in the remaining paragraphs.

It is important to use standard news release formats and specify whether the information is “for immediate release” or if it is “embargoed” until a specific date and time. News releases can be sent to reporters via mail, fax, or email, and a follow up phone call is always necessary. A sample news release template is available in a Communications Tool Kit available on the C&C website.¹⁹

Communications Tool Kit

The C&C NPO developed a Communications Tool Kit that includes templates for op-eds, press releases, and other materials.

The tool kit is available at <http://www.cashandcounseling.org/resources/20060519-134758/>

- **Press Conferences.** A press conference is a special event in which news is officially released to gathered reporters. Successful press conferences can be difficult to achieve because reporters are very busy and would rather receive information at their desks through news releases. A press conference to launch a new program is feasible only if the governor or another high-ranking state official is making the announcement, and even then, there are no guarantees that the event will be well attended or reported in the newspapers or broadcast on radio or television.

Consider hiring public relations (PR) professionals to manage the event and ensure that they issue a media advisory one week in advance, letting reporters know what will be announced, who will be speaking, and when and where the event will take place. Hold the event mid-morning, and be sure to call reporters in the days leading up to the event to notify and/or remind them. Create a press kit of materials to hand out at the event, including a news release, fact sheet or FAQ document, brochure, background on the speakers, and a list of potential interviewees and their contact information, e.g., participants who will speak favorably about the program. See box below for more information about how PR professionals can help.

- **Television.** Self-direction can make a good television news story if participants are willing to be filmed receiving help at home from their workers. A TV station in Rhode Island did a story about that state’s self-direction program featuring local participants. It is a good idea to create and maintain a database of participants who are having a good experience

with the new program and are willing to talk about it with others, including the media. This will make it easier to respond to reporters' requests for individuals to interview. Arkansas, for example, asks participants for permission to share their names and contact information with the media during the initial assessment.

Professional Assistance with Public Relations

Public relations professionals—whether from a state agency's communications department or a hired PR firm—have valuable communications expertise and can help launch a new program in the following ways.

- Helping conduct a stakeholder analysis and strategize around how best to build support and create advocates for the program.
- Helping develop the program's informational materials, including name, logo, fact sheets, brochures, videos, and website.
- Developing a detailed communications plan for the program, which specifies key audiences, key messages, and the best ways to disseminate the messages.
- Writing and distributing a press release to reporters announcing the launch of the program (or planning a press conference), and arranging media interviews for the program's representatives.
- Helping prepare program representatives for media interviews as well as sitting in on interviews and, afterward, providing feedback on how to improve message delivery in subsequent interviews.
- Editing and placing op-ed articles.

D. Dealing with Opposition and Countering Resistance

Program staff may question the need to invest so much time and energy in the communications activities discussed so far. But, assuming limited government resources for the new program, an early investment in recruiting supporters and developing and delivering strong messages may be the best way to ensure the program's long-term success. Not everyone is supportive of self-direction programs, particularly some providers who express doubts about participants' abilities to manage the responsibilities of the program or who worry about losing their clients or staff. Some opposition may be powerful and well-organized. Most, if not all, states with a self-direction program have experienced some opposition to the program.

Provider opposition to self-direction can be obvious, active, and organized. Program staff might see newspaper op-eds denouncing the program or hear from legislators that the new program is a threat to home health agencies in their districts and to participants' health and welfare. Opposition can also be scattered and less easily detected, possibly coming from individual home care workers or case managers in the traditional service system voicing negative opinions to their clients who might be eligible for the new self-direction program. Frequently it is both, and program staff should assume that it is occurring or will occur on some level.

To help program staff defuse and counter resistance, the C&C NPO surveyed several states to ask what lessons they have learned about dealing with opposition and what messages they have found most effective in reaching providers who oppose a new self-direction program.²⁰

Lessons Learned from the C&C States About Countering Provider Resistance

- Take an active approach rather than reacting to problems. To communicate messages effectively, do not rely on phone calls or letters. Seek out and meet with provider groups in person before any issues arise.
- Enlist providers who see the benefits of self-direction to help deliver information about the new program to other providers. Recruit these providers as early as possible, for example, as soon as the stakeholder analysis is completed.
- Educate providers about the positive outcomes of self-direction. Many are genuinely concerned about the safety and well-being of their clients.
- Provide accurate information to provider organizations. Get on their meeting agendas and make clear and compelling presentations about the benefits of self-direction. Take ample amounts of informational materials for audience members.
- Tell stories and show photos or videos of participants who have benefited from self-direction. Help providers see for themselves that the program can work.
- Address health and welfare concerns directly. Stakeholders want to know how the program will ensure health and welfare and control fraud and abuse. Answer these questions immediately.
- Exchange information with providers. When meeting with providers, ask questions and encourage their input. Do not make it a one-way presentation.
- Schedule a self-direction outreach or enrollment visit when agency staff are at a participant's home. Doing so includes them in the educational process and can help to lessen resistance.

- Invite home care industry representatives to serve on the advisory group for the new self-direction program. Be open and listen to and address their concerns.
- Understand providers' concerns so they will be viewed as partners in the long-term service system, not the enemy.

Messages that Resonate with Providers:

- ***There is enough work for everyone.*** Tell providers: “There is more demand than current providers can satisfy. We can help.”
- ***Self-Direction could result in new referrals for providers.*** Tell providers: “We’ll send you clients who could be better served by the traditional service system.”
- ***Current providers know best who wants to self direct.*** Tell providers: “Send us the clients who aren’t satisfied with your services.”
- ***Self-direction will not put providers out of business.*** Tell providers: “Your dissatisfied customers are our best customers.”
- ***In the current labor market, home health aides are a precious and dwindling resource.*** Tell providers: “You need to conserve your workforce. This program will relieve the pressure and allow you to make the best use of your employees.”
- ***Self-direction can help home care agencies focus on the clients whose needs they are best able to meet.*** Tell providers: “Self-direction can help you become more efficient and improve your bottom line.”
- ***Self-direction has achieved its “tipping point” and is being implemented in virtually every state.*** Tell providers: “Self-direction is here to stay. Let’s figure out how we can best work together.”

Countering Resistance Tool Kit

The C&C NPO has developed a tool kit containing sample materials and advice on countering provider resistance. The tool kit is available on the C&C website (<http://www.cashandcounseling.org/resources/20080415-145147>).

E. Reaching Potential Participants and Encouraging Enrollment

It bears repeating that the most important stakeholders—and the primary target audience for communications efforts—are the individuals who are eligible to enroll in the new program. The program, after all, is for them, and its overall success will be largely dependent on how many of them choose to enroll and remain in the program.

Given that so many people with disabilities are dependent on family members for support and care, families are the second most important target audience. Family members, especially the adult children of frail elderly parents and the parents of children and adults with developmental disabilities, will heavily influence or make the decision to enroll in the program—and many are likely to be paid caregivers or representative decision makers in the program.

Reaching potential participants and enrolling those who are eligible has been a major challenge for the 12 states that received the second round of C&C grants. Helpful suggestions based on their experience with outreach, education, and enrollment activities follow.

Ideas for Reaching Potential Participants and Their Families

- ***Letters and postcards.*** Most of the 12 states have developed and distributed personal letters²¹—Arkansas’ and Florida’s were signed by the Governor—and/or informational postcards²² addressed to eligible individuals. These materials inform them about the new program and tell them how to obtain more information.
- ***Phone calls.*** Create a pre-recorded, automated phone message from the Governor or another trusted name and broadcast it to the phone numbers of eligible individuals. An increasing number of communities are using automated telephone calls to reach residents on a variety of topics.
- ***Targeted newsletter stories or advertisements.*** Think about the numerous ways that individuals and their families receive information and use it. Develop brief news stories or advertisements to appear in church or senior center newsletters, local community newspapers, and through other local information channels. Public service announcements aired on local radio stations and TV stations can also reach the target audiences.
- ***Partner with relevant organizations.*** Minnesota, for example, is partnering with the Meals on Wheels program to distribute materials to seniors about its self-direction program, and with Independent Living Centers to provide information to the individuals they serve.
- ***Communicate through trusted sources.*** After focus groups identified them as trusted sources of information for older persons, Arkansas sent personalized

letters to individual physicians, pharmacists, and ministers to enlist their help in telling seniors about the new self-direction program.²³

- ***Create a statewide network of “peer” counselors.*** Once the new program is operational, participants and their families can be a good source of information and support for potential participants. In Florida, for example, an active network of parents of children with developmental disabilities provides information to eligible families who are not yet enrolled in or who are new to the program.

Tips for Communicating with Potential Participants and Their Families

- ***Keep informational materials short, compelling, and easy-to-read.*** Minnesota, for example, developed a brief, engaging “quiz” to help eligible individuals and their families determine if the program might be a good fit for them.²⁴
- ***Use testimonials from participants.*** Enlist satisfied participants as advocates and have them write endorsement letters or call individuals who want to talk to someone who is already enrolled.²⁵
- ***Pre-test materials to ensure they’re user-friendly.*** As mentioned earlier, New Mexico used consumer focus groups to help develop its program name and logo. Pre-testing all program materials, particularly important documents like participant handbooks, can help to ensure their effectiveness.
- ***Use participants’ photographs and quotes.*** It is important to put a human face on program materials, particularly because the logistics of a self-direction program can be complex and confusing.
- ***Make information available when needed.*** It is not possible to know when an individual or family member will hear about your program and want information. Making information available whenever needed through toll-free telephone numbers and websites is important.
- ***Identify and remove enrollment barriers.*** Successful enrollment requires more than informing individuals and their families about the new program. The program itself must be well-designed and offer clear benefits to participants, and, most importantly, the enrollment process should be easy to understand and navigate. See Chapter 4 for information on factors that can discourage rather than encourage enrollment.

If program resources for outreach, education, and enrollment activities are limited, states can apply for grants to supplement available funds. Many states used Systems Change grants to fund such activities for newly established self-direction programs.

Citations, Additional Information, and Web Addresses

- 1 Teri Larson is the author of this Appendix.
- 2 This appendix uses the term “program.” However, in some states, a new self-direction option is not a separate program but an addition to an existing program.
- 3 Many other states have self-direction programs, which were supported in part by the CMS-funded Systems Change Grants Program. Several of these states used their grants to fund communication strategies for the new self-direction program.
- 4 West Virginia Bureau of Senior Services (2005). *West Virginia Personal Options Communications Plan*. Available at <http://www.cashandcounseling.org/resources/20060209-145455/WestVirginiaPersonalOptionsCommunicationsPlan2.doc>
- 5 For examples, search the Internet using key phrases such as “sample communications plan” or “communications plan template.” See also: Burness Communications (2006). *Cash & Counseling Communications Toolkit*. Available at <http://www.cashandcounseling.org/resources/20060519-134758/>
- 6 Minnesota Department of Human Services (2006). *Consumer Directed Community Supports Key Talking Points*. Available at <http://www.cashandcounseling.org/resources/20060404-120851/talkingpts.pdf>
- 7 Iowa Department of Human Services (2006). *Is the Consumer Choices Option for You?* Available at <http://www.cashandcounseling.org/resources/20061106-103122/HCBSfactsheet102606.pdf>

Developing Choices, Empowering Iowans. Available at <http://www.cashandcounseling.org/resources/20060113-144803/IowaFAQ.doc>
- 8 Cash & Counseling (2002). *Cash & Counseling Demonstration and Evaluation Program*. Available at <http://www.cashandcounseling.org/resources/20060216-154956/CCbrochure.blue.pdf>
- 9 New Mexico’s Mi Via Program. *New Mexico’s Mi Via Program*. Available at <http://www.mivianm.org/docs/pdf/Brochure.pdf>
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- 11 New Mexico’s Mi Via Program. *New Mexico’s Mi Via Website*. Available at <http://www.mivianm.org>
- 12 Cash and Counseling. *Kentucky’s Consumer Directed Option* [Video].

Available at <http://media.cashandcounseling.org/Kentucky.wmv>

- 13 Cash and Counseling. *Minnesota's You decide. Your help* [Video]. Available at http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_058825
- 14 New Mexico's Mi Via Program. *Mi Via: Choosing Self-Direction* [Video]. Available at <http://www.mivianm.org/index.htm>
- 15 Cash and Counseling. *Tanya's Story: One Woman's Experience with Florida's Consumer Directed Care Program* [Video]. Available at http://media.cashandcounseling.org/cash_counseling_320x240.wmv
- 16 Cash and Counseling. *Aisha's Story* [Video]. Available at http://media.cashandcounseling.org/ms_aisha_jackson.wmv
- 17 Cash and Counseling. *Minnesota's You decide. Your help* [Video]. Available at http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_058825
- 18 Burness Communications (2006). *Cash & Counseling Communications Toolkit*. Available at <http://www.cashandcounseling.org/resources/20060519-134758/>
- 19 Ibid.
- 20 Burness Communications (2008). *Working with Providers: A Toolkit for States Implementing Cash & Counseling Programs and Consumer-Directed Services*. Available at <http://www.cashandcounseling.org/resources/20080415-145147/>
- 21 Cash and Counseling. *Sample Letter to Consumers*. Available at <http://www.cashandcounseling.org/resources/20060106-125528/ICGovernorsLetter.doc>
- 22 Cash and Counseling. *Sample Informational Postcards*. Available at <http://www.cashandcounseling.org/resources/20061106-103122/HCBSpostcard92506.pdf> and <http://www.cashandcounseling.org/resources/20060404-120851/postcard.pdf>
- 23 Cash and Counseling. *Sample Personalized Letter to Arkansas Ministers*. Available at <http://www.cashandcounseling.org/resources/20060106-125528/ICLettertoMinisters.doc>
- 24 Cash and Counseling. *Is Consumer Directed Community Supports Right for Me?* [Quiz]. Available at <http://www.cashandcounseling.org/resources/20060404-120851/quiz.pdf>
- 25 Cash and Counseling. *Sample Endorsement Letters from Satisfied Participants*. Available at <http://www.cashandcounseling.org/resources/20060106-125528/ICLettersParticipants.doc>

Appendix II: The Consumer Direction Module

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Appendix II

The Consumer Direction Module¹

Information technology designed specifically for self-direction programs can empower participants by giving them a timely, efficient, user-friendly tool for completing required paperwork and for interacting with their counselors (also called support brokers, support coordinators, and other names) and financial management services (FMS) providers to manage their individual budgets. This same information technology can also be configured to serve as a management information system to assist state program administrators in monitoring participants' use of their budgets and evaluating the program's performance on a wide range of indicators.

Information technology is already widely used to administer Medicaid programs. For more than 25 years, the federal government has required states to have computerized Medicaid Management Information Systems (MMIS) to process provider claims and to generate a variety of reports on service utilization and expenditures; states must also comply with federal data reporting requirements.

With respect to Medicaid-funded home and community-based services (HCBS), many states also employ standardized assessment tools to make coverage determinations and store the assessment data in computerized information systems, which can be linked to the MMIS. This enables program administrators to measure, for example, the service utilization/expenditure patterns of Medicaid program participants by disability profile, and also to monitor whether and to what extent they receive the services authorized on the basis of their individual needs assessment.

These existing information technologies are intended solely for the use of Medicaid program administrators and their contractors and/or providers of traditional Medicaid services. The design of information technology for self-directed services poses a whole new set of challenges because, in addition to these users, some of the functions of the technology must also be available to program participants and/or their representatives (hereafter, participants).

This Appendix describes an information technology developed for and designed specifically to meet certain unique requirements of self-direction programs. This technology—called the Consumer Direction Module (CDM)—is a secure web-based software application specifically designed to support self-direction programs that provide individual budgets. The CDM can also be linked to states' MMIS and assessment databases, if a state elects to do so.²

For participants, the CDM makes it possible to monitor the financial status of their accounts by accessing monthly accounting statements, to develop and revise

their spending plans electronically, and to share their proposed plans quickly and efficiently with their counselors (if the state has delegated authority to them to approve routine expenditures) and with state program officials (who must review and pre-authorize proposed spending on non-routine goods and services).

The use of Excel spreadsheets allows the electronic template to be programmed to automatically add in payroll taxes and other required costs associated with workers' wages (e.g., overtime payments when applicable). Similarly, the template makes it easier to ensure that proposed spending does not exceed participants' allowance or available funds. Moreover, forms filled out electronically—unlike traditional paperwork—are always legible, and therefore avoid some of the delays that can occur when traditional paperwork cannot be processed because it is illegible.

For providers of support services—counselors and FMS entities—the CDM similarly streamlines and speeds up communication both with participants and with each other. The CDM also facilitates record-keeping and can be programmed to generate routine reports and reminders, for example, that a regularly scheduled visit or phone call is due.

Finally, the CDM enables state program administrators to monitor individual participants' enrollment status and their individual accounts as well as to track aggregate statistics such as the number of enrolled and disenrolled participants and reasons for disenrollment; aggregate expenditures by participants; and types of goods and services approved for purchase. Program administrators can also determine, both for individuals and in the aggregate, the time lag from enrollment to development and approval of a spending plan and the start-up of self-directed services. They can also monitor the extent of under-spending and/or savings being accumulated on an individual and aggregate basis. Having such information immediately accessible is invaluable for quality management and continuous quality improvement strategies.

The Consumer Direction Module: Overview

The purpose of the CDM is to:

- Facilitate and simplify communication among participants and program staff
- Facilitate the timely processing of program information
- Provide data in reports that permit timely and efficient monitoring
- Improve quality by creating program efficiencies and providing timely information to program participants and administrators.

The CDM software, initial training, and materials on installation and use are available at no cost through the National Resource Center for Participant-Directed

Services (hereafter, the Center). There is a cost for vendor support during installation and states are responsible for installing and supporting the software as they would any other business system.

The Center is available to assist states that want to implement the CDM to prepare for implementation by reviewing user roles, adapting the CDM to fit a state's program, and providing training and one-time data uploads. States do not have to have received a C&C grant to receive assistance from the Center.

CDM Technical Features

- The CDM is a web-based application
 - The software is installed on one computer, a PC server, which is accessed through the Internet using commonly available web browsers.
 - Some customization for each state is possible.
- The CDM is a local system, with no interfaces allowing communication between the CDM and other computer systems supplied. Each state determines what interfaces it wants and is able to develop.
- The CDM requires some data transfer with the financial management services (FMS) agency (or FMS provider) to provide spending plan information and to gather information about participants' expenditures.
- The CDM meets all applicable HIPAA regulations.
- The CDM does not process receipt and disbursement of funds to and from each state's Medicaid financial system.

Development and Current Use of the CDM

States that received Cash & Counseling (C&C) grants were offered the opportunity to help develop and/or adopt the CDM. Some chose not to do so because they were concerned that the CDM might overlap and prove incompatible with or inferior to their states' own current or planned information systems.

Alabama, Rhode Island, and West Virginia each provided a program and information technology representative to serve on the CDM steering committee during the development phase, and New Mexico joined the steering committee during the testing phase. Participation on the steering committee enabled these states to have input into the development of the CDM and to help ensure that it met their needs.

Currently, Rhode Island and West Virginia are using the CDM. Alabama installed the CDM in a test region and is preparing for implementation in this region. New Mexico installed the CDM in spring 2007 in a test region and is preparing for statewide implementation in 2008.

Who Can Use the CDM?

The following individuals with a role in a self-direction program can use the CDM:

- Participant
- Participant Representative
- Legal Guardian
- Support Broker Agent & Agency
- State and Local Program Office
- FMS Agent & Agency
- State Administrator
- System Administrator
- Guest User

States can customize the terms used to describe various roles in the program. For example, states may use the term “resource consultant” or “counselor” rather than “support broker.” Once the term is changed in the CDM, the change will be reflected throughout the CDM. States need to be aware of the default user names since they will be referred to in the system and state administrator pages as well as the user manuals. Editing the user manuals is discussed later in this Appendix. The ways in which these individuals can use the CDM are described next.

Participants

The CDM serves as participants’ Internet link to people and agencies that help them direct their personal care services. Participants can use the CDM to develop their spending plan and can access their file at any time to view monthly budget statements, edit their file, and enter comments.

Participants are encouraged to use the CDM because it will make it easier for them to obtain forms (e.g., employment forms) and information about the program, manage their budgets, and communicate with those who help them to direct their services. The budget management features include the ability to

- Complete a spending plan form
- Submit a spending plan for approval
- View monthly reports of income and payments made from the account
- Check account balance and savings

Participants' Representatives

Participants may select someone to help them make decisions and manage employees. Once participants designate a representative, that individual's role will be reflected in the participants' file, including whether the participants have authorized the representative to use the CDM on their behalf (e.g., authorization to read, change, or add to pages in the CDM).

Legal Guardians

Participants' legal guardians can use the system in place of the participant, and their authority will be reflected in the participant's CDM file. The support broker will identify the authority of the legal guardian, as specified by the state. Participants with legal guardians are able to read everything in their file, but may not change the information.

Support Broker Agent & Agency

Support brokers can use the CDM to manage their caseloads. The CDM provides immediate access to the files of participants in their caseloads and to other program forms and reports. Additionally, it automates many program communications.

Support brokers can use the CDM to:

- Get information from and submit information to participants' files
- Update participants' information
- Download blank expenditure/spending plan (Excel worksheet) and other forms
- Upload completed participant-directed budgets
- Make changes to participant-directed budgets at the participants' direction
- Enter observations made during contacts with participants
- Check participants' account balances at their request
- Receive alerts and notifications about changes in participants' files
- Generate reports
- Send broadcast messages to other CDM users

In addition to the support broker functions listed above, support broker agency users will also have the administrative authority to add support brokers to the CDM.

State and Local Program Staff

State and local program staff (1) ensure that the program's policies and procedures are reflected in the CDM; (2) work with the state system administrator to configure the CDM to their state's program; and (3) use the CDM on a daily basis for management and administrative tasks such as approving participants' spending plans and monitoring the program. The CDM greatly facilitates program management and administration by providing both real time access to information and aggregated reports.

State and local program staff can use the CDM to:

- Create an entry for a new participant
- Assign a support broker or FMS agency
- Approve participant-directed budgets (responsibility may vary by state)
- Monitor participant-directed budgets, changes in the budgets, and participants' spending
- Review support broker case records
- Review reports from FMS agents
- Edit participants', support brokers', and FMS agencies information included in the CDM
- Send messages to other user groups
- Close a case
- Generate reports

Financial Management Service Agent & Agency

FMS agents are an essential program support for participants. They allow participants who are employers-of-record but who have limited employer knowledge and skills to control their budget and manage their employees. By handling the payroll, check writing, and taxpaying associated with participants' approved spending plans, the FMS agent ensures that the program spends Medicaid funds lawfully and that all spending is accurately documented.

FMS agents can use the CDM to:

- Enter employee information in participants' files
- Receive participants' spending plans and changes made to the plan
- Receive changes in participants', support brokers', and workers' information

- Send the monthly report of income and payments made for participants
- Generate other reports

In the CDM, a person working in an administrative capacity in a financial management services agency is called by the role name “FMSA Admin” or “FMSA.” In addition to all of the FMS agent functions listed above, FMSA users will also have the administrative authority to:

- Create FMS agent users in the CDM
- Determine and input the tax rate for spending plans

State Administrators

State administrators have the same authority as state and local program staff. In addition, they are allowed to configure the CDM for their specific program use and can perform the same administrative functions as system administrator users (see below). State and system administrators are encouraged to work together to configure the CDM for their state program’s use.

In addition to having access to state and local program user functions, state administrators can use the CDM to:

- Add or change users
- Upload the program logo
- Configure spending plan categories
- Establish permissions by role
- Establish state-specific role names
- Add a financial management service agency
- Add a support broker agency
- Determine values for dropdown lists
- Maintain item and service codes
- Add or change affirmations
- Create special fields
- Set required fields
- Set homepages for users
- Set role communications including alerts, notifications, reports, and notes

System Administrators

System administrators are responsible for the initial setup and ongoing maintenance of the CDM. The CDM is a very flexible system that allows system administrators to configure it to accommodate specific state program decisions. This configuration determines whether icons, tabs, and fields appear on the CDM screens viewed by all other users, and what users are able to do. The configuration can also be changed after program implementation.

See the state administrator functions above for examples of functions for system

administrators. With the exception of state and local program user functions, state administrators and system administrator have the same privileges.

Guest Users

The CDM has four guest user roles that can each be configured for use by different groups, for example, contracted assessment personnel or program evaluators. Each guest user role can be configured differently (e.g., to permit access only to specified reports). More than one person may be assigned to each guest user role.

Primary Features of the CDM

The CDM has five unique features: the participant file, the spending plan, the monthly expenditure statement, reports, and state configurability. Each is described below.

Participant File

Participant files have 10 main sections/pages:

- ***Personal:*** Lists personal and contact information.
- ***Program:*** Contains administrative details about program participation, for example, the date of enrollment and the date of last assessment.
- ***Financial:*** Contains the budget, spending plan, and monthly statements.
- ***FMSA:*** Displays the name and contact information for the financial management services agency that will assist with employer-related bookkeeping tasks.
- ***Support Broker:*** Displays the name of participants' support brokers and contact information for them. If the support broker works for an agency, the agency information will also be shown in this section.
- ***Medical Provider:*** Displays a page of information about the participant's primary care physician and other medical providers.
- ***Participant Representative:*** If a participant has a representative, the representative's contact information will be displayed on this page.
- ***Legal Guardian:*** If a participant has a legal guardian, this page will list the contact information.
- ***Employee:*** Contains a list of the participant's employees.
- ***Notes:*** Includes all notes written in a participant's file by all CDM users.

The participant file is described in further detail in the user manual. CDM user permissions can be configured to view, edit, and add information to the participant file as needed.

Participant Spending Plan/Monthly Expenditure Statement

Once their budgets have been approved, participants are able to create a spending plan in the CDM using an Excel spreadsheet. (See sample form below.) When the plan is ready to be reviewed, the Excel spreadsheet is uploaded into the CDM for other users to view as needed.

FMSAs use the same form (with different formulas) to give participants a monthly statement showing how their budget was spent. The statement is downloaded from the CDM by FMS agents to populate with expenditure data. Once completed, the FMS agents are able to upload the monthly statement into the CDM and it will populate the participant's file so other users can view the information.

Reports

The CDM is programmed to provide numerous reports to help states monitor their self-direction programs. The system allows users to easily generate other reports based on information stored in the CDM.

The CDM includes a set of default reports and allows users to create ad hoc reports as needed. The default reports are

1. Demographic Characteristics of Participants
2. Amount of Monthly Budget
3. Spending as of End of Month
 - Participants by Percent of Authorized Budget Spent at End of Month
 - Participants with More than 100% of Budget Spent by End of Month, by Support Broker
 - Participants with Less than 95% of Budget Spent by End of Month, by Support Broker
4. Savings Plan Report
 - Participants by Dollar Amount of Goal of Savings Plan for Specified Purpose
 - Participants by Percent of Authorized Budget in Savings Plan for Specified Purpose
 - Participants by Dollar Amount Saved in Savings Plan for Specified Purpose

State or Local Program Information

ACME Services LLC
 4400 N. Broad St. Philadelphia, PA 19104
 (111)222-4444

Participant Name: First and Last Name
 Participant Address: Address
 City, State & Zip Code
 Representative Name: First and Last Name

Monthly Statment for: mm/yyyy
 Monthly Budget Amount: \$3,000.00
 Medicaid Number: xxxxx
 Effective Date: mm/dd/yyyy

Service Type/Description	Employee	Worker's Comp	Hours per week	Hourly Wage	Total Taxes per Hour	Sum of Hourly Wages & Taxes	# of Hours per Month	Employee Tax Rate	Service Code	Total Monthly Cost
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
		\$0.00			\$0.00	\$0.00				\$0.00
Total :										\$0.00

Back-up Provider	Employee #	Paid (Y/N)	Additional Cost per Month	Unused Funds to be saved for:	Total Monthly Cost
					\$0.00
					\$0.00
					\$0.00
Total :					\$0.00

Service Type/Description	Goal #	Provider Name	Frequency	Unit Cost	# Of Units per Month	Service Code	Total Monthly Cost
							\$0.00
							\$0.00
							\$0.00
							\$0.00
Total :							\$0.00

Description of Item/Good	Goal	Vendor Purchased From	Unit Cost	# Of Units per Month	Item Code	Total Monthly Cost
						\$0.00
						\$0.00
						\$0.00
						\$0.00
Total :						\$0.00

Description of Item/Good	Goal #	One Time Purchase	Vendor Purchased From	Proposed Date of Purchase	Estimated Cost	Est. Months needed to Save	Purchase Amount	Item Code	Monthly Savings
Total :									\$0.00

Total : \$0.00

Total : \$0.00

Total : \$0.00

- Participants by Savings Accumulated as a Percent of Savings Goal
- Participants with More than 100% of Savings Goal Accumulated But No Purchase Made, By Support Broker
- 5. Assessment Report
 - Participants by Time to Next Regularly Scheduled Assessment
 - Participants with Regularly Scheduled Assessments Past Due by 30 Days or More, by Support Broker
- 6. In-Person Monitoring Report
 - Participants by Time to Next Regularly Scheduled In-Person Monitoring
- 7. Incident Tracking Report
- 8. Grievance Tracking Report
- 9. Appeals Tracking Report
- 10. Report on Time from Enrollment to Receipt of First Services under a Budget
 - Number and Percent of Participants by Time to Receipt of First Services under a Budget
 - Percent of Enrollees Who Had Not Received Services under a Budget 90 Days after Enrollment for the Each of the Last Twelve Months, by Month
- 11. Enrollment and Disenrollment Report
 - Cumulative through the End of Month X
 - Detail on Reasons for Disenrollment
 - Enrollment in Each of the Last Twelve Months, by Month
- 12. Enrollment in the program, by Referral Program
- 13. Recipients of Services Under an Individual Budget and Dropouts, by Referral Program

Ability to Tailor the CDM to Each State's Program

The CDM was designed to allow states to configure the software to their specific program features. Some of the items that can be configured are:

- Application settings
 - User and password configuration
 - State customization

- Field configuration
 - Special fields
 - Required fields
- Financial
 - Spending plan categories
 - Spending plan columns
- Affirmations (under Application settings)
- Drop down lists
- Roles and permissions
 - Role names
 - Role permissions
- Alerts and notifications
 - Alerts (without editing recipient lists)
 - Notifications (without editing recipient lists)
- Upload forms and reports
- Edit role communications
- Define Local Program Offices
- Set FMS Agencies
- Set Support Broker Agencies
- Add users

The system administrator manual thoroughly describes all of the items that can be configured and the user manual index identifies the default settings in the CDM system for each configurable item. The CDM is delivered to states with the default configurations as a starting point.

Costs and Resources to Implement the CDM

When determining whether to use the CDM, states need to consider its cost—both initial and ongoing—as well as available training and materials, future enhancements, and technical assistance from the National Resource Center for Participant-Directed Services. Each of these items is discussed below.

Costs

The current vendor cost for assisting states to install the CDM, including 40 hours of technical phone support, is \$5000. The source code, installation manual, and user manuals are supplied at no cost in return for providing aggregate data to the Center.

In addition, an optional one-time upload of existing program data currently costs \$5,000. The one-time upload option allows states with existing program data to load it into the CDM rather than manually entering it.

Costs for creating an interface between the CDM and other state software systems are borne by the state. Based on input from the CDM steering committee, staffing requirements to maintain and support the system are estimated in the table below.

Estimated Resources to Maintain the CDM and Support Users	
Management Resources	Hours per Month
State Managerial Oversight	2
State CDM Administrator (can be a non-technical person)	12
Help Desk	12
IT Resources	
Network Administrator	4
Database Administrator*	1
Developer/Report Writer*	3
Total	32

* One person can fill both positions.

User Manuals & Training

User manuals for each role in the CDM (excluding guest roles) are provided. These manuals are also available in Word format to allow states to edit them to reflect their customization of the CDM. For example, if a state changes the term “support broker” to “counselor”, this change can be made in the support broker manual. The manuals include both text explanations and illustrations of the CDM.

Enhancements

Since the start of the CDM project, a number of enhancement requests and ideas have been generated by the CDM steering committee and users. Small enhancements have been made to the CDM and the Center maintains a list of proposed enhancements for future consideration.

An enhancement project was completed in early 2008, which will allow FMS agencies to obtain and distribute all participant spending plan and monthly statement data from the CDM at one time, rather than having to access this information through each individual participant's file. This FMSA Data Connector Project includes functionality that will decrease the amount of time FMSA users will need to retrieve spending plan information as well as reduce the data entry time for providing monthly statement information.

The steering committee continues to meet to provide oversight on CDM enhancements and requests for enhancements and to provide support for states both using and preparing to use the CDM. States interested in the CDM are encouraged to join the steering committee to obtain more information on the CDM and for support in the implementation process.

Endnotes

- 1 Angela Sutkaitis is the lead author of this Appendix. Pamela Doty is a contributing author.
- 2 The US Department of Health & Human Services, Office of the Assistant Secretary for Planning and Evaluation funded the development of the Consumer Direction Module. The Robert Wood Johnson Foundation and the Administration on Aging provided some additional funding.

Appendix III: History of Self-Direction

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Appendix III

History of Self-Direction¹

Origins, Development, and Expansion

The origins of self-directed personal assistance services (PAS) can be traced back more than 50 years. In 1953, Los Angeles County discovered that it could take care of the needs of its 158 iron lung users with polio at a cost of only \$10 per day using personal assistants rather than paying \$37 a day for inpatient care at the Rancho Los Amigos Medical Center.² The Los Angeles County program eventually grew to become, in 1973, the statewide California In-Home Supportive Services (IHSS) program. At this time, the program was not a Medicaid program and was financed through a combination of county and state revenues and federal Title XX funding.

Since 1993, IHSS has been funded with county, state, and federal funds, mainly through the Medicaid program. Whereas the original county program was only for polio survivors, IHSS has always served older persons, working age adults, and young children with a wide range of disabling physical and mental conditions. With over 300,000 participants, IHSS is the single largest public program providing the employer authority feature of self-direction.³

An early budget authority prototype was the Veteran's Administration's Attendant Care non-taxable "cash" benefit program established shortly after World War II for veterans with service connected disabilities. However, until the late 1990s, when the first Cash & Counseling Demonstration and Evaluation began, programs that allowed participants to manage a budget were rare.

The Independent Living Model and Movement

People with disabilities who benefited from early self-direction prototypes founded the Independent Living Movement in the 1960s and 1970s. One of them, Ed Roberts, started the Physically Disabled Students Program, which, among other activities, ran a self-direction attendant program at the University of California, Berkeley. In 1972, Roberts and others established a similar program for non-students with federal and private grant funding—the first Center for Independent Living (CIL).

From the late 1970s to the early 1990s, the World Institute on Disability (WID) along with rehabilitative services professionals began to articulate the Independent Living model of self-directed personal assistance services as a set of philosophical principles that should guide public policy.⁴

Social Services Programs Pre-Medicaid

On a parallel track, local and state-funded home care programs that were targeted primarily to low-income older persons with chronic disabilities, and that pre-dated the enactment of Medicaid in 1965, often paid friends, neighbors, and sometimes family members to provide care. These programs grew out of the efforts of social services program officials to prevent nursing home placements with very limited budgets. Prior to Medicare and Medicaid, few home care agencies existed.⁵

State officials also saw what are now characterized as self- or family-directed services as a way to support and sustain the traditional role of family, friends, and neighbors in providing care to low-income older persons and individuals with disabilities. They were aware that informal caregivers of low-income elderly and disabled persons often had low incomes as well. Many were unemployed or under-employed or, alternatively, worked several poorly paid part-time jobs to make ends meet. Others who provided significant amounts of informal care were unable to take jobs outside the home. Indeed, it was recognized that many family caregivers could not leave their relatives with severe disabilities alone at any time and needed some “respite.”

The desire to reduce dependency on informal caregivers and alleviate caregiver stress led to the creation of some state-funded programs that provided cash allowances to family caregivers. They could use these funds to purchase respite care or for a variety of other purposes such as reimbursement for out-of-pocket costs associated with caregiving and making home modifications.⁶

Medicaid Programs

In the late 1960s, Oklahoma’s state-funded “non-technical medical care” became the first Medicaid State Plan personal care services program. In the early 1970s, Michigan’s Home Help program established the precedent within Medicaid of allowing family members—except spouses and parents of minors—to become paid personal care attendants.

In 1975, nursing home scandals prompted New York to launch what quickly became the single largest Medicaid State Plan personal care services program. Originally, participants in New York’s program recruited individual providers, who could be friends and neighbors, but not relatives. However, as this program grew, New York officials decided that they could not effectively oversee so many individual providers. The State also came under pressure from the Health Care Financing Administration (now CMS) to ensure that providers were “qualified” by defining what made them so.

Officials decided that aide training, credentialing, and nurse supervision of aides required them to be agency-employed. However, when a small group of disability activists in New York City protested, they were allowed to create a

participant-directed agency—Concepts for Independence—to serve as a “co-employer” through which they could continue to exercise employer authority over their attendants.

In the mid-1990s, disability activists persuaded the state legislature to enact a law directing all counties to make available a self-direction alternative to agency-delivered personal care to any participants who preferred self-direction.

When the Medicaid HCBS waiver program was enacted by Congress in 1981, several HCBS programs included some form of self-direction. However, CMS (then the Health Care Financing Administration) did not formally recognize the model as a service delivery modality until 2002.

From the early 1980s through the early 1990s, federal policies did not seem to support self-direction, likely due to the widely prevalent view that professional oversight was required to protect persons with chronic illnesses and disabilities. Quality assurance was generally equated with training and credentialing requirements for both professionals and non-professionals and with physician, nurse, and social worker supervision of unlicensed caregivers. The emphasis was on encouraging the growth of a formal services system composed mainly of licensed home care agencies. With few exceptions, state officials agreed.⁷

In the 1980s, CMS issued a notice of proposed rulemaking for the Medicaid State Plan personal care services option. Based on what CMS called a “modified medical model,” the proposed regulation was incompatible with existing self-directed services programs. Although the regulation never became final, it galvanized disability activists, who, with some state support, lobbied Congress to (1) eliminate the “physician prescription” and “nurse supervision” requirements in the personal care benefit and (2) allow personal care services to be delivered outside the home. A final regulation reflecting these changes to the law (which Congress enacted in 1993) was published in 1997.

Resurgence of Interest in Self-Direction

During the 1990s, the Independent Living philosophy, disability rights activism, and the emerging self-determination movement for people with mental retardation along with research findings on positive outcomes of self-directed services began to influence advocates for older persons, federal policymakers, and program administrators. In 1993, self-direction options for HCBS were included in the President’s health care reform recommendations and proposed legislation introduced in Congress.

In the mid-1990s both the federal government and private philanthropy began to invest in promoting self-directed services options for persons of all ages with disabilities. The box below lists milestones in the history of federal and foundation-sponsored initiatives to experiment with and evaluate self-directed

Federal and Private Foundation-Funded Self-Direction Initiatives

1995–1996—The Robert Wood Johnson Foundation (RWJF) funded a Self-Determination Initiative with grants to 15 Medicaid or state-funded MR/DD programs.¹⁰

1996—The Cash & Counseling Demonstration and Evaluation (CCDE), funded by the RWJF and the Department of Health and Human Services/Assistant Secretary for Planning and Evaluation (ASPE), awarded grants to Arkansas, Florida, and New Jersey.

1996—The Independent Choices Grant Program, funded by the RWJF and administered by the National Council on Aging (NCOA) began. Grants included funding for small self-directed services experiments in Oregon (cash benefit) and Ohio (consumer-directed aide services for older persons).

1996–1998—ASPE and the Administration on Aging (AoA) funded the National Institute for Consumer-Directed Services, a partnership between the NCOA and the World Institute on Disability (WID) to disseminate information about self-direction.

1997–2001—The RWJF provided “Independent Choices” funding to the NCOA and the National Association of State Units on Aging (NASUA) to promote self-direction in aging services.

1998–2000—CMS approved Section (§) 1115 research and demonstration waivers for three CCDE states. Arkansas began Independent Choices in 1998; New Jersey began Personal Preference in 1999; and Florida began Consumer-Directed Care in May 2000.

2000—Congress enacted the first Real Choice/Systems Change Grant legislation. In 2001, states began using some of this grant funding to plan and implement self-directed services options.

2001—ASPE, the RWJF, AoA, AARP, and SAMSHA sponsor a *National Symposium on Consumer-Directed Services for the Elderly and Disabled* in Washington, D.C.

2001–2006—The RWJF provided grant funding to NASUA to work with selected states on *Mainstreaming Consumer-Direction in Aging Services*.

2002—CMS announced the Independence Plus initiative to streamline approval of states’ waiver applications for self-directed services.

2003—CMS provided Systems Change Independence Plus grants to 12 states to develop Medicaid-funded participant-directed services.

2004—A second round of Cash & Counseling grants—funded by the RWJF—were awarded to 11 states (AL, KY, IA, MI, MN, NM, PA, RI, VT, WA, WV).¹¹

2005—The Retirement Research Foundation awarded a Cash & Counseling grant to Illinois.

2004–2007—CMS revised the §1915(c) HCBS waiver application template to incorporate both employer authority and budget authority self-direction options, and implemented a web-based electronic waiver application.

2005—Deficit Reduction Act provided new statutory authority for the budget authority model of self-directed services.¹²

2007—AoA Nursing Home Diversion Modernization Grants Initiative, which included funds for technical assistance to grantees that include “self-directed services” in Older Americans Act-funded programs.

services and to disseminate information about and encourage replication of successful programs.

The three Cash & Counseling Demonstration and Evaluation states—Arkansas, Florida, and New Jersey—which operated under the Section (§) 1115 research and demonstration authority (hereafter, §1115 waiver), evaluated the budget authority feature. Colorado and Oregon also operated under a §1115 waiver to experiment with participant-directed budgets on a smaller scale. Oregon's is the only experimental program in which substantial numbers of Medicaid beneficiaries—approximately 300—received and managed funds to pay for their services without the assistance of a fiscal/employer agent. Oregon's §1115 waiver expired January 31, 2008, at which time the State transitioned to the §1915(j) self-directed PAS State Plan option.

In 2002, CMS released an Independence Plus waiver application to streamline approval for waiver programs offering self-direction. From 2004 to November 2005, CMS revised the §1915(c) HCBS waiver application to include self-direction options, which mainstreamed both employer and budget authority programs.⁸ This revised application superseded the stand-alone Independence Plus waiver application. The §1915(c) HCBS waiver application will be updated periodically to reflect changes in CMS policy and to provide additional guidance to the states. Version 3.5 is currently in use.

In late 2005, Congress passed the Deficit Reduction Act (DRA), which created several new Medicaid statutory authorities for self-direction, including one that allows states to offer budget authority to Medicaid State Plan personal care services participants without having to operate under the §1115 demonstration authority.⁹ See Chapter 2 for detailed information about all of the Medicaid authorities and the DRA's provisions.

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty is the author of this chapter.
- 2 According to Gini Laurie, a pioneer disability rights activist and historian of the Independent Living Movement (ILM), this was the start of the movement.
- 3 Also in the 1950s, the March of Dimes implemented a program that provided polio survivors \$300 per month to live at home—an early budget authority prototype. The March of Dimes stopped funding this program after the polio vaccine was invented, but California took it over and continued to provide funds to some polio survivors until this program was superseded in the 1970s by the In-Home Supportive Services Program. Levy, C.W. (1988). *A People's History of the Independent Living Movement*. Research and Training Center on Independent Living at the University of Kansas, cited in Batavia, A.I. 2003. *Independent Living: A Viable Option for Long-Term Care*. Clearwater, FL: ABI Professional Publications.

Levy also credits a small program established at the University of Illinois for students with disabilities as an early prototype of consumer-directed personal assistance services. Additional material on the early history of self-directed services in California can be found at <http://www.cicaihss.org/history.htm>.

- 4 DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, 60 (October). DeJong, G. and Wenker, T. (1979). Attendant care as a prototype independent living services. *Archives of Physical Medicine and Rehabilitation*, 60 (October). DeJong, G. (1984). *Independent Living and Disability Policy in The Netherlands: Three Models of Residential Care and Independent Living*. New York, New York: World Rehabilitation Fund, Inc., Monograph 27.

During the 1980s and the early 1990s, WID conducted several national surveys of attendant care programs and measured how well or poorly each one scored on a ten-point scale with respect to promoting Independent Living. Litvak, S. , Zukas, H. and Heumann, J.E. (1987). *Attending to America: Personal Assistance for Independent Living. A Survey of Attendant Services in the United States for People of all Ages with Disabilities*. Berkeley, CA: World Institute on Disability. WID also published descriptions of programs that exemplified best practices. Litvak, S. (1990). *New Models for the Provision of Personal Assistance Service: A Research and Demonstration Project*. Berkeley, CA: World Institute on Disability.

- 5 Subsequent Medicare and Medicaid requirements for certified home health agencies resulted in an expensive medical model that emphasized skilled nursing services and rehabilitation therapies more appropriate to post-acute than long-term care.

- 6 These programs were often targeted to particular types of caregivers such as families caring for children with severe developmental disabilities or terminally ill children, or to families caring for adults and older persons with severe cognitive impairments (e.g., those caused by dementia and traumatic brain injury).
- 7 State officials in Oregon, Wisconsin, and New Hampshire had positive views of self-direction.
- 8 Several state associations contributed to the success of the waiver application revision, including the National Association of State Medicaid Directors, the National Association of State Directors of Developmental Disabilities Services, the National Association of State Units on Aging, and the Alliance of Cash and Counseling Programs.
- 9 The State Plan personal care benefit serves twice the number of “elderly and disabled” Medicaid participants with disabilities other than MR/DD who live at home than do HCBS waiver programs.
- 10 This program was based on a small experiment in New Hampshire, funded by the RWJF in 1993. See <http://www.rwjf.org/reports/npreports/sdpdd.htm>
- 11 ASPE, the RWJF, and AoA also provided funding for a National Program Office for the 11 C&C replication states to the Boston College School of Social Work.
- 12 The DRA-2005 also provides for a new grant program to states—Money Follows the Person (MFP)—to promote transition from nursing homes to community living. The legislative language for the MFP program encourages self-directed services.



Robert Wood Johnson Foundation

www.rwjf.org



www.participantdirection.org