

The Case for Medicaid Self-Direction:

A White Paper on Research,
Practice, and Policy Opportunities



National Council on Disability
May 22, 2013

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

***The Case for Medicaid Self-Direction: A White Paper on Research,
Practice, and Policy Opportunities***

This report is also available in alternative formats upon request and on the National Council on Disability (NCD) Web site (www.ncd.gov).

May 22, 2013

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

May 22, 2013

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit the enclosed report, "The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities." In keeping with the community living theme central to your Administration, the goal of self-directed services is to maximize an individual's opportunities to live independently in the most integrated community-based setting of his or her choice. As more states enroll people with disabilities into managed care plans, it is critical that self-directed services remain an option for enrollees.

This report:

- Traces the history of self-directed services in the United States and its emergence and subsequent growth within the Medicaid policy arena;
- Examines the fundamental concepts that under gird a self-directed approach to organizing and delivering community-based long-term services and supports;
- Reviews the basic components of self-directed services as spelled out in federal Medicaid policy;
- Summarizes the findings and conclusions from existing studies of the cost-effectiveness of self-directed services;
- Explores the ramifications of the growing use of Medicaid managed care arrangements for the future of self-directed services and supports; and
- Recommends strategies for improving the accessibility and quality of self-directed Medicaid services and supports.

We will also share this report with the Centers for Medicare and Medicaid Services, and would welcome the opportunity to work with the Administration on behalf of Medicaid beneficiaries with disabilities.

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This report was approved by the Council prior to me becoming its Chair. I fully support the report and look forward to working with the Administration on the report's recommendations.

Sincerely,

A handwritten signature in black ink, appearing to read "Jeff Rosen", with a stylized flourish at the end.

Jeff Rosen
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the House of Representatives.)

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Executive Summary

In recent years, self-direction has emerged as a game-changing strategy in organizing and delivering Medicaid funded services, a means of affording people with disabilities enhanced opportunities to live fulfilling lives of their own choice in local communities. Yet, despite the growth in self-directed services, many key questions remain to be answered about the most effective ways of promoting individual choice and control within a Medicaid funding environment.

To assess the current state of knowledge and pinpoint remaining gaps that need to be filled, in the fall of 2011 the National Council on Disability commissioned a study of Medicaid-funded self-directed services. This paper summarizes the key study findings, conclusions, and recommendations, and more specifically—

- Traces the history of self-directed services in the United States and its emergence and subsequent growth within the Medicaid policy arena;
- Examines the fundamental concepts that undergird a self-directed approach to organizing and delivering community-based long-term services and supports;
- Reviews the basic components of self-directed services as spelled out in federal Medicaid policy;
- Summarizes the findings and conclusions from existing studies of the cost-effectiveness of self-directed services;
- Explores the ramifications of the growing use of Medicaid managed care arrangements for the future of self-directed services and supports; and
- Recommends strategies for improving the accessibility and quality of self-directed Medicaid services and supports.

CHAPTER 1. **Basic Concepts**

Within the disability policy arena, self-direction refers to an approach to delivering home and community-based services (HCBS) that allows eligible individuals to directly control a range of services and supports—with the assistance of representatives of their choice—based on their own preferences and needs. The central goal of self-direction is to maximize an individual’s opportunities to live independently in the most integrated community-based setting of his or her choice. In contrast to traditional approaches that rely on the service provider to coordinate and deliver necessary supports, self-directed strategies shift control over resources and staffing to the individual, allowing each person to determine the role that the provider will play in his or her life. From the person’s point of view, it means going about one’s life and being able to incorporate services into the flow of daily activities. Depending on the program context, self-direction sometimes is referred to as “consumer-direction” or “participant-direction.”

In a self-directed program model, a considerable degree of authority is transferred to the participant and, in some instances, a family member who is selected or legally authorized to represent the participant. This approach is in sharp contrast to a traditional service delivery model where decision-making and managerial authority is assigned to professionals who may be state employees, state contractors, or service providers. In this sense, self-direction marks a major paradigm shift in the delivery of publicly funded HCBS.

Employer Authority and Budget Authority

Medicaid HCBS policy recognizes two basic types of self-direction: employer authority and budget authority, each of which can take several forms. Participants exercising employer authority are authorized to hire, fire, and supervise personal support workers (e.g., personal care attendants, homemakers). The more comprehensive form of self-direction, referred to by Centers for Medicare and Medicaid Services (CMS) as budget

authority, allows participants to purchase goods and services as well as supervise personal support workers and manage expenditures within the limits of a specified budget allocation.¹

Employer Authority

To be recognized as a form of self-direction, program participants, at a minimum, must be allowed to hire, manage, and dismiss their personal support workers. Employer control includes the following functions: recruiting job candidates, interviewing applicants and checking their references (unless the participant knows the applicant very well), deciding who to hire, setting and negotiating work schedules and determining training needs, assigning tasks to workers, supervising and evaluating the workers' job performance, and deciding when to dismiss a worker whose performance has been unsatisfactory. Participants who self-direct their services also play a role in paying workers. At a minimum, participants should approve workers' timesheets. In some programs, however, they also are responsible for co-signing the workers' paychecks.

Participants typically play no role in establishing the hourly wages of workers in self-directed programs using the employer authority only. In contrast, participants in programs with budget authority may negotiate hourly wage rates and additional fringe benefits with their workers. The only requirement is that they observe applicable federal and state laws governing minimum wage, overtime pay, workers compensation, disability insurance, and unemployment insurance. In some states, participants also must abide by collective bargaining agreements with unions representing participant-directed workers.

Budget Authority

Under the budget authority model, participants are allowed to use their funding allotment to not only hire personal support workers, but also to purchase other goods and services designed to meet disability-related needs and, in the case of people with psychiatric disabilities, recovery-related supports. Some of these goods and services may substitute

for human assistance or otherwise enhance the individual's independence (e.g., assistive technology, home modifications, transportation services, laundry services, meal services, personal care supplies, noncovered prescription and nonprescription medications). Participant-directed goods and services usually include items that would not be covered under traditional HCBS programs, and these goods and services may be purchased from nontraditional sources. Each self-direction program establishes its own ground rules governing approvable purchases, with some programs being considerably more permissive than others.

Individuals receiving support may vary in the extent to which they require or desire assistance in carrying out their responsibilities under the program. Some may rely on considerable support from friends and family members to manage their services, while others may self-direct with minimal assistance. Still others may depend on a paid support broker, a navigator, or a recovery coach to establish goals, develop budgets, and navigate their way through the service system.

Individual Budgets

An individual budget expresses in dollar terms the amount of funding deemed necessary to meet the anticipated service and support needs of an individual with a disability who is enrolled in HCBS. When services are self-directed, the individual decides how all or a defined portion of his or her individual budget is to be used. Experts in self-directed services generally agree that the methodology used in establishing individual budgets must be:²

- **Accurate** – It must be based on a valid assessment of the individual's needs and yield an amount sufficient to ensure that the participant's needs are met.
- **Consistent** – The methodology has to be applied consistently across the entire program, state, and target population.

- **Reliable** – It should produce consistent results over time and with repeated applications.
- **Equitable** – Participants with similar support needs and circumstances should receive comparable budgets that also establish a defensible relationship between the cost of participant-directed services and agency-directed services.
- **Flexible** – Individual budgets should be revised in a timely manner when the participants’ circumstances, needs, and choices change.
- **Transparent** – The budget development process should be open to public scrutiny.

The following processes are involved in developing and using individual budgets: assessing individual needs, developing an individualized spending allocation, calculating individual budget amounts, and determining a spending plan. The order in which these activities occur varies from one self-directed program to another. Some programs begin by calculating the budget amount and subsequently assessing individual needs and developing a spending plan. This approach is referred to as prospective budgeting. Other programs begin the process by first assessing the individual’s needs, then developing a service plan to address those needs, and conclude by calculating the dollar value of the plan using a specific formula (i.e., determine the amount of the individual’s budget). This latter approach is referred to as retrospective budgeting.³

- **Prospective Budget Development.** The amount of an individual’s benefit is determined before the person-centered planning process begins and is based on an objective assessment of the individual’s support needs. This information is translated into a dollar figure using a statistical modeling methodology that predicts the amount of funding required to meet the person’s service and support needs. Once the total budget amount is determined, a person-centered plan is prepared and spending allocations determined, taking into account the person’s support needs, preferences, and life goals. When an individual’s budget allocation

is established in advance, a state is able to predict systemwide expenditures more accurately and control costs while permitting participants to exercise broad control over their personal budgets.

- ***Retrospective Budget Development.*** In a retrospective approach, the amount of the benefit is determined by the individual's needs through an open, interactive process designed to identify specific needs for external support and assistance, and the costs of the services to be provided. The resulting judgments on support needs may be based on expressed and observed needs rather than on empirical data. Projected costs are typically based on current payment rates or schedules. Given the state authority's responsibility to manage both services and costs, there generally is an authorization process prior to finalizing the service plan and individual budget. Once an individual's needs are determined, the costs of meeting those needs are assessed by using either traditional fee-for-service rate schedules or alternative methods. With the budget amount in hand, self-directing participants prepare a personalized spending plan and implementation strategy.

Regardless of the methodology used by a state, the core components of an individual budget development process include (1) an assessment of individual needs, (2) a plan for meeting those needs, (3) the establishment of a personal budget amount, and (4) the preparation of a spending plan and implementation strategy. It is important to keep in mind that determining those needs and figuring out the best approach to meeting them are part of the service planning process in self- and agency-directed services.⁴

Person-Centered Planning

Person-centered planning (PCP) is an integral part of calculating individual budgets. PCP methodologies vary from state to state and population group to population group. State/local service systems for people with developmental disabilities (DD) typically employ PCP processes that focus on identifying major life goals and making related decisions regarding living arrangements, companions, training, and employment.

DD planning processes tend to be highly structured, using assessment tools, checklists, and protocols to guide decision-making. By comparison, systems serving elderly individuals and younger people with physical disabilities tend to use more informal PCP processes, focusing on identifying the services and supports necessary to allow an individual to perform essential daily living tasks (e.g., bathing and meal preparation). Regardless of the methods used, all PCP processes should adhere to the following principles:⁵

- All planning activities and decision-making are led by the participant;
- Participants receive all of the relevant information and support they need to make informed decisions; and
- Service planning decisions are built around the participant's strengths, capabilities, preferences, desires, life goals, and support needs, rather than the availability of community supports.

Need Determination

The needs assessment process takes into account an individual's (1) medical condition(s); (2) functional capabilities and restrictions, specifically the ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs); (3) living arrangements; (4) access to unpaid supports; (5) social environment; and (6) access to required behavioral supports, if required. The methods used in assessing individual needs vary significantly from state to state, from population group to population group, and sometimes even within different geographic areas of a state. For years, state DD service systems have used standardized assessment tools, such as the Individual Client Assessment Profile or the Developmental Disability Profile to assess individual needs. In programs serving elderly individuals and younger people with physical disabilities, the primary focus is on assessing ADLs and IADLs along with the person's medical condition(s), often with a lesser reliance on standardized assessment tools.

In recent years, a growing number of state DD service systems have begun to use the Supports Intensity Scale (SIS) to assess individual needs. Using the assessment results, individuals are grouped into a series of levels based on the intensity of their support needs and this information is combined with historical service cost data to generate Individual Budget Allocations (IBAs). The resulting IBAs are used to calculate payment rates for traditional community provider agencies and determine the budgets of individuals who choose to self-direct their HCBS.⁶

In HCBS programs for elders and younger people with physical disabilities, a few states use the Minimum Data Set – Home Care (MDS-HC), a comprehensive assessment tool that gathers information on multiple need-related factors. An individual's characteristics are assigned a weighed score based on their predictive relationship to utilization and costs. These weighed scores are added to reach a total score that is adjusted to account for regional economic conditions (e.g., variations in labor costs), historical expenditure patterns, and funding restrictions to arrive at an empirically derived individual budget.

Use of Representatives

Typically, self-directed service programs allow participants to use family members and friends to help them manage and direct their services and service budgets. Especially in the case of people with significant cognitive impairments, a representative can act as an intermediary in articulating the individual's needs and preferences and also perform tasks that the individual is unable to carry out without assistance. In some cases, the representative may be the person's court-appointed personal guardian or conservator, but usually representatives play a less formal, advisory, and facilitating role.

Some self-directed services programs do not require representatives to be formally designated; however, other programs mandate that potential representatives be screened to ensure that they have a strong commitment to the participant's wellbeing, are capable of carrying out their program responsibilities, and are willing to comply with program requirements. A representative may function in an individual capacity, or a

group of individuals (often referred to as a “circle of support”) may come together to ensure that a participant receives the assistance and personal support that he or she needs. In either case, one key challenge is to ensure that the views and interest of the participant remain the paramount consideration in reaching all plan-related decisions.

Employing Family Members

Most self-directed programs, including Medicaid-funded programs, now permit relatives of a program participant to act as paid caregivers. Federal Medicaid regulations prohibit legally responsible relatives from serving as paid providers of personal care/personal assistance services (PAS) (42 CFR 440.167). The meaning of legal responsibility is defined in state law and therefore varies from state to state, but generally the term refers to the parents of a minor child. Operationally, some states prohibit payments to a spouse. This prohibition is based on the presumption that legally responsible relatives should not be paid for providing supports that they ordinarily would be expected to provide to their loved ones.

Parents and other relatives (e.g., siblings, aunts, uncles, cousins, a spouse) of adults with disabilities usually are not considered under state law to be legally liable for providing care and, consequently, may receive Medicaid payments for the provision of personal care/assistance services. In addition, since the mid-2000s, CMS has permitted states to make payments to legally responsible relatives for personal care or similar HCBS when such services are deemed to be extraordinary in scope and result directly from the individual’s disability, provided that the state sets forth satisfactory criteria for authorizing such service payments.⁷ In recent years, similar policies governing payments to legally liable relatives have been applied to Section 1915(i) home and community-based state plan services and Section 1915(j) self-directed state plan PAS. An important point to keep in mind is that federal policy is permissive regarding payments to relatives and, consequently, decisions with respect to the circumstances under which relatives may serve as paid caregivers rests with the individual state.

CHAPTER 2. **Origins of Self-Directed Services**

Shortly after World War II, the Veterans Administration launched a cash-benefit program to allow veterans with disabilities to hire personal attendants. With the exception of comparatively small family support and respite care programs, however, the notion of substituting cash payments for in-kind government benefits failed to take root in civilian programs until the mid-1990s, when the U.S. Department of Health and Human Services (HHS) joined forces with the Robert Wood Johnson Foundation (RWJF) to launch demonstration programs that enabled participants to manage the funding allocated on their behalf and directly control the staff who worked with them.

The advantages of providing PAS on an outpatient basis became evident in 1953 when Rancho Los Amigos Medical Center in Los Angeles hired personal assistants at a cost of \$10 a day to care for 158 iron lung users, thus avoiding the \$37 a day cost of providing inpatient care. This Los Angeles County program eventually was expanded statewide, becoming the California In-Home Supportive Services (IHSS) program in 1973.⁸ Initially, IHSS benefits were financed through a combination of state and local revenues, plus federal Social Services Block Grant funds authorized under Title XX of the Social Security Act. In 1993, however, California amended its Medicaid state plan to make IHSS benefits an optional coverage for individuals meeting the state's income eligibility and disability standards. With more than 435,000 current participants,⁹ IHSS is the largest public program in the nation offering self-directed services to frail elders and other people with physical, developmental, and psychiatric disabilities.

Early self-directed service models were a product of the independent living movement of the 1960s and 1970s. Several pilot programs sprung up during the late 1960s. One such program was the self-directed attendant care program at the University of California at Berkeley, founded by Ed Roberts and other disability activists. In 1972, Roberts and his allies launched a similar program for nonstudents called the Center for Independent Living using a combination of federal and private grant funds. Beginning in the late 1970s,

the World Institute on Disability, in tandem with rehabilitation professionals, began to articulate the philosophical principles underlying self-directed PAS and the ways in which these principles should guide public policies toward people with disabilities.

In 1995, RWJF launched two national programs to empower people with disabilities and chronic illnesses to make their own choices regarding long-term services and supports: the Self-Determination program for people with intellectual and developmental disabilities and the Independent Choices program for seniors and nonelderly people with physical disabilities. Various program models were explored as part of RWJF's Independent Choices initiative with varying success. In general, the initiative stimulated some innovative approaches and focused attention on the technical challenges of designing and operating consumer-directed services for senior citizens and people with physical disabilities.¹⁰

Eighteen states received seed money grants from the foundation under the Self-Determination initiative to pilot self-directed service models for people with intellectual and developmental disabilities.¹¹ Most of the participating states were able to expand self-direction options by using the RWJF grant dollars to draw down federal matching funds through their Section 1915(c) Medicaid waiver programs. In several states, the RWJF grants were used in conjunction with a special, time-limited Medicaid funding authority called Community Supported Living Arrangements (CSLA), created by Congress in 1990.¹² This special Medicaid authority in combination with the foundation grants led many states to build self-determination options into their Medicaid home and community-based waiver programs over the following decade.

In 1998, RWJF joined forces with HHS to launch the Cash and Counseling Demonstration program. Three states—Arkansas, Florida, and New Jersey—were selected to pilot new approaches to financing and delivering Medicaid-funded long-term services and supports and granted statutory waivers necessary to mount their programs. A Mathematica Policy Research evaluation of the Cash and Counseling program¹³ concluded that—

- The program significantly reduced the unmet needs of Medicaid participants requiring PAS;

- Participants in the demonstration experienced positive health outcomes;
- Both participants and their caregivers experienced an improved quality of life;
- Consumer control did not lead to increased misuse of Medicaid funds;
- Personal care costs were somewhat higher for demonstration participants compared to other recipients of Medicaid-funded PAS, mainly because demonstration participants received more of the care they were authorized to receive;
- Increased Medicaid personal care outlays were partially offset by reduced institutional and other long-term care costs; and
- Cash and counseling need not cost more than traditional PAS if states carefully design and monitor their programs.

Later, the Cash and Counseling model was replicated in 12 additional states. As discussed in greater detail below, the results of the Cash and Counseling and self-determination demonstrations led Congress to establish several Medicaid self-directed funding options in recent years.

Self-direction has taken longer to gain a foothold in the mental health service sector, mainly because most self-directed support options have been funded through the Medicaid HCBS waiver program and few nonelderly adults with mental illnesses are eligible to receive waiver services. The Florida Self-Directed Care Program, founded in 2002, is one of the earliest attempts to apply person-directed support principles to serving people with mental illnesses.¹⁴ In addition to the Florida program, small programs extending budget authority to people with psychiatric disabilities are under way in several other states, including pilot programs in Pennsylvania and Texas.

CHAPTER 3. **Evolution of Self-Directed Medicaid Services**

Personal Care/Personal Assistance Services

Self-direction initially emerged as a Medicaid funding alternative under the “personal care” state plan coverage option. Although personal care was recognized as a state plan option in the mid-1970s, for years services had to be prescribed by a physician and delivered in the beneficiary’s home by a qualified provider under the supervision of a registered nurse. Because of the strong medical orientation of the service, comparatively few states elected to offer personal care services as a state plan coverage, and those that did often restricted the circumstances under which such services would be treated as Medicaid-reimbursable costs (e.g., limiting such services to a recuperative period following a period of acute hospitalization).

By the late 1980s, however, a few states (e.g., California, New York) began to broaden the scope of reimbursable personal care services offered under their state plans, permitting such services to be furnished outside the individual’s home and allowing individuals to self-direct their services and supports. Responding to the growing demand for a more flexible array of HCBS, Congress in 1993 added personal care to the list of optional services that states could cover under their Medicaid state plans.¹⁵ In adopting a new statutory definition of personal care, Congress granted states explicit authority to provide such services outside the recipient’s home. The legislation also removed a previous regulatory requirement that the delivery of personal care services be supervised by nurses, and allowed such services to be authorized by methods other than a physician prescription if a state so elected. In November 1997, the Health Care Financing Administration (HCFA); later renamed the Centers for Medicare and Medicaid Services (CMS) promulgated regulations reflecting the above statutory provisions.¹⁶

In January 1999, HCFA released a *State Medicaid Manual* transmittal that completely revised the agency's guidance on the coverage of personal care services.¹⁷ The new guidance made it clear that personal care services could include both assistance in performing essential ADLs as well as assistance in performing IADLs, such as light housework, laundry, meal preparation, transportation, grocery shopping, medication management, and money management. HCFA also indicated that relatives, except for "legally liable relatives" (e.g., parents of a minor child), could act as paid providers of personal care services.

In addition, the 1999 manual transmittal clarified the agency's policies with respect to personal care services for people with cognitive and mental disabilities by pointing out that "cueing along with supervision to ensure the individual performs the tasks properly" constitutes a reimbursable activity. Moreover, HCFA's guidance explicitly recognized for the first time that personal care services could be directed by the beneficiary. Consumer direction had been a key feature of the personal/attendant care program in several states for many years (e.g., California, Massachusetts) but had never been formally reflected in federal policy. The 1999 manual transmittal, however, officially sanctioned such practices, including consumer training and supervision of personal aides/attendants.

Since federal policy governing Medicaid-reimbursable personal care services was relaxed during the mid- to late 1990s, states' claims for such services have increased significantly. According to an analysis performed by Thomson Reuters Healthcare, total Medicaid payments for personal care services increased from \$2.9 billion in fiscal year (FY) 1996 to \$12.5 billion in FY 2008.¹⁸ However, more than three-fifths (61.9%) of FY 2008 payments were directed to two states: California and New York. The vast majority of states still prefer to include personal care services as one of several services covered under Section 1915(c) home and community-based waiver programs because of the greater flexibility it affords them in defining the scope of such services, and the protections against escalating service demands that are built into the waiver authority.

Home and Community-Based Waiver Services

As discussed earlier in this paper, states began to introduce self-directed HCBS as part of their Section 1915(c) waiver programs in the wake of the Self-Determination and Independent Choices demonstrations sponsored by RWJF. Soon, states that had not participated in these demonstrations began to ask CMS for authority to add self-directed service options to their HCBS waiver programs. Observing this development, CMS decided in 2002, as part of President Bush's New Freedom Initiative, to spell out the circumstances under which a state could offer self-directed HCBS services under Section 1915(c) waiver and Section 1115 waiver/demonstration programs by issuing a special, "Independence Plus" waiver application template.

The term self-directed services was defined in CMS' Independence Plus guidelines as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget."¹⁹ States interested in operating an Independence Plus waiver program were required to ensure that each participant would have (1) a person-centered plan developed in collaboration with the participant and, where appropriate, his/her family members and other allies; (2) an individual budget "... under the control of and direction of the program participant"; (3) access to financial management services (FMS) to assist in administering the individual budget and complying with federal and state withholding and reporting requirements; (4) access to support brokerage services to help the participant arrange and orchestrate paid, voluntary and generic community supports; and (5) a quality assurance plan designed to protect the health, safety, and wellbeing of each participant.²⁰

Between 2002 and 2004, 11 Independence Plus waiver requests were approved by CMS in 10 states. In addition, 12 states were awarded 2003 Real Choice System Change grants to assist them in developing Independence Plus waiver proposals by 2006. Furthermore, as noted above, RWJF, in partnership with the HHS Office of the Assistant Secretary for Planning and Evaluation and the Administration on Aging, awarded Cash and Counseling development grants to 11 additional states in October 2004.

The Independence Plus waiver template was folded into a new Section 1915(c) Web-based application template in late 2005. The instructions accompanying the new HCBS waiver template incorporated an expanded version of the original Independence Plus guidelines.²¹ States were given the option of requesting authority to operate a separate waiver program for people choosing to self-direct their services or establishing a self-direction component of a broader HCBS waiver program. States electing the former option (a separate self-directed waiver program) could ask that their programs be designated an “Independence Plus” waiver if all participants had the opportunity to self-direct their services and the program provided access to “a full-range of supports for participant direction.”²² Since there are no financial advantages to the Independence Plus designation, in practice most states elected to build a self-direction component into a broader waiver program, avoiding the administrative hassle and overhead cost involved in operating separate waiver programs. In 2009, 94 waiver programs in 36 states offered some form of self-direction, while 15 waiver programs required self-direction for some or all services offered under the program.²³

HCBS State Plan Options

The Deficit Reduction Act of 2005 (DRA; P.L. 109-171) established two optional Medicaid state plan coverages of HCBS: Section 2086 of the DRA added Section 1915(i) to the Social Security Act, allowing states to offer HCBS under their Medicaid state plan, rather than under Secretarial waivers only; and Section 6087 added Section 1915(j) to the Act, permitting states to provide self-directed PAS as part of their Medicaid plans.

A state must stipulate that Section 1915(j) beneficiaries otherwise would be eligible to receive agency-directed PAS under the state’s Medicaid plan. In addition, a state must ensure that beneficiaries choosing to self-direct their PAS receive choice counseling and (1) are allowed to manage their own budgets, planning and purchasing services of their own choosing; (2) have their needs, strengths, and preferences assessed before services are designed and initiated; (3) have an individual service plan developed on

their behalf; and (4) have access to FMS to assist them in paying providers, tracking costs, and filing required reports.

States may limit the number of people receiving self-directed PAS and restrict the provision of such services to certain geographic areas of the state. In addition, at the option of the state, people who enroll in Section 1915(j) may (1) hire legally liable relatives (such as spouses and parents of minors); (2) manage a cash disbursement; (3) purchase goods, services, and supplies that increase their independence or substitute for human assistance; and (4) use a discretionary portion of their individual service budgets to purchase nonlisted items or items previously reserved for permissible purchases.²⁴

The Patient Protection and Affordable Care Act of 2010 (ACA) included revisions to Section 1915(i) of the Act aimed at making the HCBS state plan option more attractive to the states.²⁵ In particular, the ACA amendments to Section 1915(i) (1) affords states enhanced flexibility in delineating the group(s) eligible to receive HCBS state plan services; (2) gives states the option of providing services to people with income up to 300 percent of the federal Supplemental Security Income (SSI) payment standard (in addition to people with income at or below 150 percent of the federal poverty level, as permitted under the original 2005 legislation); (3) permits states to design distinctive service packages for different groups of targeted beneficiaries; and (4) allows states to claim federal reimbursement for all HCBS authorized under Section 1915(c)(4)(B) of the Social Security Act, including “other services” approved by the Secretary of HHS, as well as day treatment, partial hospitalization, psychosocial rehabilitation, and clinic services for people with chronic mental illnesses.

In keeping with the requirement of the original 2005 legislation, states still may establish need-based eligibility criteria that include individuals who do not require an institutional level of care. As a result, states may qualify people with psychiatric disabilities under its Section 1915(i) coverage who otherwise would be ineligible for Medicaid-reimbursable HCBS due to the institution for mental diseases exclusion.²⁶ However, under the provisions added by the ACA, states no longer are permitted to restrict the number of

individuals eligible for Section 1915(i) state plan services or establish waiting lists for such services. In addition, under the ACA amendments, states no longer have the option of providing Section 1915(i) services on less than a statewide basis. States, however, still have the option of providing self-directed services to Section 1915(i) beneficiaries on terms similar to those applicable to recipients of Section 1915(j) services.²⁷

In addition to amending the provisions of Section 1915(i) of the Social Security Act, the ACA also added two further inducements for states to serve Medicaid-eligible people with chronic disabilities in home and community-based settings. First, the 2010 legislation added another HCBS state plan option under Section 1915(k) of the Act, called the Community First Choice Option. Under this state plan option, participating states are eligible to receive a 6 percentage point increase in their federal Medicaid matching ratio for community-based attendant and other services aimed at assisting people with ADLs and IADLs deficits and helping them acquire and maintain the skills necessary to independently perform such tasks. States must offer recipients of Section 1915(k) services the option of self-directing their services and supports.²⁸

Second, the ACA authorized an enhanced matching ratio for states choosing to participate in the State Balancing Incentive Payments Program (hereafter referred to as the Balanced Incentive Program), an initiative aimed at helping states improve their capabilities to manage and deliver HCBS to people with disabilities, thereby increasing the proportion of Medicaid beneficiaries served in home and community-based settings. Participating states that expend less than 25 percent of their long-term services dollars on HCBS are eligible to receive a five point increase in their Federal Medical Assistance Percentage FMAP rate, but must raise the proportion of long-term services expenditures devoted to HCBS to 25 percent by September 30, 2015, when the program ends. States spending between 25 percent and 50 percent of their LTS dollars on HCBSs are eligible to receive a 2 percentage point increase in their FMAP rate but must increase the proportion of long-term services expenditures devoted to HCBS to 50 percent by the end of the program. In addition, states choosing to participate in the Balanced Incentive Program must agree to (1) implement a No Wrong Door – Single Entry Point system,

(2) establish “conflict-free” case management services, and (3) develop and use a standardized assessment instrument. As of September 2012, eight states (Georgia, Indiana, Iowa, New Hampshire, Maryland, Michigan, Missouri, and Texas) had received Balanced Incentive Program grants.²⁹ Funding for the program is capped at \$3 billion over four fiscal years (October 1, 2011, through September 30, 2015).

The Section 1915(i) and Section 1915(j) coverage options became effective January 1, 2007, while the Section 1915(k) coverage option went into effect on October 1, 2011. CMS issued final regulations governing the coverage of self-directed PAS on October 3, 2008.³⁰ Revised, proposed regulations implementing HCBS under Section 1915(i), along with final regulations governing the Community First Choice Option, were issued by CMS on May 3, 2012.³¹

CHAPTER 4. **Basic Features of Self-Directed Medicaid Services**

Currently, federal Medicaid law offers the states several approaches to funding self-directed home and community-based services and supports, including the—

- Home and community-based state plan services under Section 1915(i) of the Act;
- Community First Choice Option under Section 1915(k);
- Self-directed PAS under Section 1915(j); and
- HCBS waiver program under Section 1915(c).

These statutory authorities may be employed separately or in combination. States may also link efforts to promote self-directed supports to other Medicaid funding authorities, such as the Money-Follows-the-Person Demonstration grant program and the State Balancing Incentive Payments program, to leverage desired systemic changes. These Medicaid funding authorities have slightly different operating policies, but they all share the same basic requirements, including the following:³²

Operational Components

1. ***Person-Centered Planning.*** Federal statutory and regulatory policies require states to perform individualized assessments and use person-centered planning in developing service plans for Medicaid beneficiaries who choose to self-direct their supports. The process must be directed by the person receiving assistance, with or without the assistance of a representative(s) selected by the individual. The planning process must take into account and plan for possible contingencies (such as the unavailability of a regularly scheduled support worker) and include

these back-up strategies in the individual's written service plan. In addition, the state is responsible for ensuring that a risk assessment is conducted for each program participant and the results of the assessment are taken into account in developing back-up or contingency plans for the affected individual.

2. **Individual Service Plan.** Each recipient of self-directed supports must have a written plan specifying the services and supports required to meet his or her preferences, choices, capabilities, and needs, as well as the assistance the recipient requires in order to direct those services and supports and remain in the community.
3. **Individualized Budget.** The amount of funds under the control and direction of the person is referred to as the individualized budget. A participant's budget is tied to his or her service plan and developed through a person-centered planning process that emphasizes the importance of individually tailoring the budget to the person's needs, preferences, and life goals. States are required to spell out the methods to be used in calculating the dollar value of individualized budgets based on reliable cost and service utilization data. In addition, states must specify the methods and processes to be used in adjusting a participant's budget when service plan changes occur and delineate the procedures to be used in evaluating a participant's expenditures.
4. **Information and Assistance in Support of Self-Direction.** States are required to provide or arrange for the provision of a system of supports that is responsive to each individual's needs and desires for assistance. The amount and frequency with which self-directing participants use available supports is likely to vary from person to person and change in response to situations that arise. Among the types of assistance to be made available on an as-needed basis are help in developing a person-centered service plan and individualized budget, managing personal support workers and services, and performing other employer-related and budget management tasks. The state also is responsible for ensuring that participants are informed about such matters as the operation of self-directed services, individual rights and responsibilities, available resources, counseling, personal support worker supervision and training; the use of FMS, and access to

an independent advocacy system. Some states have created a separate Medicaid-reimbursable service—referred to as support brokerage, individual counseling, or personal guide—to perform these functions and act as a liaison between the individual and program administrators. In these situations, the support broker, consultant, counselor, or guide usually acts as an agent of the program participant and takes direction from the participant.

Financial Management Services

Although individuals who self-direct their Medicaid HCB services may elect to assume personal responsibility for handling some or all financial management tasks, very few choose to do so. CMS defines the term “Financial Management Services” as follows:

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 in performing such employer responsibilities as processing payroll, withholding and filing federal, state and local taxes, and making tax payments to appropriate authorities; and (c) performing fiscal accounting and making expenditure reports to the participant and/or family and state authorities.³³

Principal FMS functions include helping Medicaid recipients to—

- Understand their billing and documentation responsibilities;
- Perform payroll and other employer-related duties on the individual’s behalf (e.g., withholding and filing required reports on federal, state, and local payroll and unemployment taxes; purchasing workers’ compensation coverage and other types of insurance; collecting and processing worker timesheets; calculating and processing employee benefits; issuing payroll checks);
- Purchase approved goods and services authorized under the individual’s service plan;

- Monitor and track expenditures against the individualized budget; and
- Identify expenditures that are over or under the budgeted amount.

A state must make FMS available to all Medicaid-eligible participants who elect to self-direct their services.

Quality Assurance and Improvement

Federal quality monitoring and reporting requirements vary according to the Medicaid home and community-based funding authority a state elects to use. However, each state must have a system for continuously monitoring and improving the quality of its Medicaid-funded HCBS. This system must be based on a cyclical process of discovery, remediation, and quality improvement. The state must have a systemic approach to monitoring the quality of HCBS. When deficiencies are identified, a state must be capable of taking prompt corrective actions to restore service quality. In addition, a state must be capable of identifying systemic weaknesses in its service delivery process and instituting quality improvement projects to rectify such weaknesses. Finally, the state Medicaid agency must exercise overall responsibility for monitoring system performance and individual outcome measures.

Managing Risk, Balancing Personal Autonomy, and Protecting from Harm

In designing self-directed support programs, one of the main challenges that public policymakers face is to determine a means of affording participants greater personal freedom and control while at the same time ensuring that they are able to live safely in the community. Achieving the appropriate balance between personal autonomy and protection from harm is especially complex in the case of people with cognitive, intellectual, and psychiatric disabilities who are able to make informed choices only when they receive direct assistance and support from another person(s).

Federal and state policies require HCBS providers to adopt an aggressive posture to protect the individuals they serve from abuse, neglect, and mistreatment. Given the consequences of failing to fulfill these fundamental responsibilities, personal choices often are constrained by actual and perceived risks to an individual's health and safety, and consequently they become the subject of negotiation between the person and the support agency rather than being viewed as an individual right. Under a self-directed program model, authority and control over a person's health, welfare, and lifestyle are shifted to the individual, along with commensurate responsibilities. The resulting realignment of authority and responsibility necessitates changes in the manner in which services and supports are managed. But it does not alter a state's obligation to ensure the health and safety of Medicaid recipients. Policies and practices reflecting this realignment of authority and responsibilities, therefore, must occur at the individual, program, systemic, and administrative levels of a state's service delivery system.³⁴

Policies must address the following concerns:

1. **Individual risk** related to the decisions a person makes with respect to her or his lifestyle, health, and general welfare. To ensure that such decisions are made in an accountable manner, a state should (1) define the role of the individual in the assessment and management of risk; (2) identify the methods to be used in determining an individual's competency to give informed consent and to describe her or his decision-making capacity; and (3) articulate a shared understanding of the meaning of risk, liability, and mitigation for self-directed services.
2. **Program risk** related to the roles and responsibilities of each individual and the agency supporting her/him in determining risk-sharing relationships. State policies should (1) describe program features designed to limit risk and mitigate the consequences when necessary, (2) outline an appropriate risk management protocol to address provider agency risks, and (3) provide mechanisms for individuals receiving support and organizations providing support to resolve differences with respect to balancing personal choice with provider responsibility.

3. **Systemic risk** related to the development of a comprehensive community infrastructure with the capacity to minimize risk and institute timely and appropriate responses to emergency situations. State policies should (1) identify the basic components and desired outcomes of a risk management system; (2) spell out criteria for distinguishing between reasonable and unreasonable risks; (3) ensure effective responses to identified hazardous situations; (4) specify how liability is to be managed with respect to health conditions, chronic disabilities, physical and mental impairments, personal actions, decisions, and the exercise of choice and inappropriate or criminal behavior; and (5) ensure effective oversight, monitoring, and follow-up.

4. **Administrative risk and liability** associated with financial management, U.S. Department of Labor and Internal Revenue Service requirements governing wages, hours, and conditions of employment, and ensuring that support staff hired and supervised by people with disabilities is appropriately trained.

The mechanisms used to assess and respond to risk vary according to the population being served and the nature, extent, and responses of each individual to her/his disabilities. Because impairments in judgment among people with psychiatric disabilities often are episodic in nature, for example, the use of proactive planning tools such as Wellness Recovery Action Plans, Advance Psychiatric Directives, and negotiated risk agreements should be viewed as critical components of a well-designed risk management system.

There is ample evidence that people with cognitive, intellectual, and mental disabilities, with appropriate support, can successfully direct their own services. But states must ensure that appropriate policies are in place to ensure that such individuals receive the support they need to make their own choices and exercise control over their lives. As Moseley points out, “[a] system that fosters self-determination must consistently reinforce the central role of the individual receiving support.”³⁵

CHAPTER 5. **Cost-Effectiveness of Self-Directed Services**

The fundamental aim of most self-direction programs is not to save money but to give people with disabilities greater control over the services and supports they receive and when, by whom, and how they are delivered. In virtually all instances, however, the increase in personal control is accompanied by requirements that total service costs are not to exceed the costs that a community provider agency would incur in delivering the same array of services and supports. In some instances, the upper limit on self-directed support plans is set at 100 percent of the cost of provider-controlled services and supports; in other programs, a discount factor is applied to self-directed support plan allocations (e.g., 90% of provider agency costs) to be held as a “risk pool” of funds that can be used by the state or provider agency to meet unanticipated cost increases over the course of the year. As a result of such policies and the variability among self-directed programs across and within states, it is difficult to draw valid comparisons between the costs of self-directed versus agency-directed services.

Head and Conroy reported a median reduction of 8 percent in the cost of serving 70 participants in a self-determination demonstration program for people with intellectual and developmental disabilities in Michigan. Comparisons of expenditures on behalf of these individuals were made before they entered self-directed programs and again three years following their enrollment in the program. The savings increased to 14 percent when expenditures were adjusted for inflation over the three-year period, with the median public cost per participant declining from \$67,322 to \$56,778 in inflation-adjusted dollars. The study also found that participants reported that they had more and better choices, less professional domination, and a higher overall quality of life. The study did not analyze control or comparison group data, and therefore the authors warn against generalizing from the findings of this small, single-state study.³⁶

When personal care cost data of participants in the Cash and Counseling demonstration program were compared with those of a control group receiving agency-directed

personal care services, researchers discovered that participants incurred higher costs primarily because program enrollees received more of the care they were authorized to receive than control group members. In addition, the increased personal care costs were partially offset by lower institutional and other long-term care outlays on behalf of Cash and Counseling participants. The evaluation team concluded that, if a state carefully designs and monitors its Cash and Counseling program, self-directed services should not cost any more than traditional, agency-provided services.³⁷ The Arkansas Cash and Counseling program saved \$5.6 million after nine years of operation, not including the additional savings associated with reduced nursing home utilization.³⁸

In examining the experiences of states operating consumer-directed support programs for people with intellectual and developmental disabilities (I/DD), Walker found that cost savings usually are built into a state's funding assumptions. Typically, a state either pays a set fraction (e.g., 90%) of the total amount allowed for traditional agency-directed services, or establishes a lower allowance for self-directed administrative/overhead costs than for agency-directed administrative/overhead costs.³⁹

Walker also points out that some states have created consumer-directed support programs with tight spending caps that are aimed at stabilizing families and preventing emergency out-of-home placements of individuals on a waiting list for full-time residential supports. By dampening demand for residential placements, this comparatively low-cost option allows a state to extend services to additional wait-listed individuals, thus reducing the gap between supply and demand. One I/DD program administrator estimated that his state was saving more than \$1 million a year by offering low-cost self-directed support options to families caring for loved ones with an I/DD in their homes.⁴⁰

In summary, studies of the cost-effectiveness of self-directed services are few in number and generally have yielded inconclusive and sometimes contradictory results. The limited utility of such studies in shaping public policy can be attributed in large part to the cost assumptions underlying most existing programs and the methodological problems involved in conducting such research (e.g., accounting for (and weighting) all of the relevant cost variables that influence outcomes).

CHAPTER 6. Implications of Managed Long-Term Services and Supports

Increasingly, states are turning to managed care in an attempt to improve the quality and cost-effectiveness of Medicaid Managed Long-Term Services and Supports (MMLTSS). According to a recent CMS-sponsored survey, the number of states operating MMLTSS programs doubled between 2004 and 2012 (from 8 to 16) and is expected to grow to 26 by 2014. A majority of states currently operating MMLTSS programs (12 of 16) have built self-directed service options into their programs.⁴¹ Generally, these program components are based on preexisting self-direction initiatives within the states' traditional fee-for-service systems. Little comparative information, however, is currently available on the nature and scope of self-directed initiatives within MMLTSS programs.

In several important ways, the basic concepts underlying managed care conflict with the principles of consumer choice and control that lie at the heart of self-directed services. Managed care attempts to achieve systemwide efficiencies by consolidating decision-making authority in a single management entity, restricting consumer choice to network-approved providers, and substituting lower-cost interventions for higher-cost interventions wherever possible. The self-direction model, in contrast, vests decision-making authority with the individual receiving supports, with or without the assistance of a designated representative(s). However, a well-designed managed care program may help to reduce some of the barriers to implementing self-direction, especially in the behavioral health arena. For example, some states are incorporating a self-direct services component in their health home initiatives on behalf of people with psychiatric disabilities.

The current interest in applying managed care principles to public long-term support systems is motivated primarily by a desire on the part of public policymakers to curb the growth in future Medicaid outlays for services to high-cost beneficiaries, primarily people with substantial, chronic disabilities. Fueled by the escalating service needs of an aging

U.S. population, federal Medicaid expenditures are projected to increase by 134 percent between FY 2012 and FY 2022 (from \$253 billion to \$592 billion) and grow as a percentage of the gross domestic product from 1.7 percent to 2.4 percent over the same period.⁴² The question is: can self-direction thrive in an environment in which the principal aim of public policy is to limit the growth in program outlays by tightly managing utilization and expenditures and standardizing interventions practices?

Managed care originated in primary and acute health care delivery systems, with an emphasis on medical treatment and recovery. Only a handful of states and health care management firms have had extensive experience in adapting managed care techniques to the long-term services sector. Many disability advocates are deeply concerned that the significant differences in the nature, duration, scope, and intent of acute care and LTSS will smother participant choice and control under a new wave of medical paternalism once managed care is introduced to MMLTSS.

Are these fears justifiable? Will self-direction play a prominent role in future MMLTSS systems? Let's examine the recent experiences of Wisconsin and New York, which have long traditions of consumer-directed HCBS and are in the process of shifting to MMLTSS systems.

Wisconsin

Participant choice and self-determination have been core precepts of Family Care since Wisconsin's managed long-term services and supports program was initially proposed in the late 1990s. As Family Care was phased in during the 2000s, however, it became clear that too few program participants were being afforded opportunities to self-direct their services and supports. When the required Secretarial waivers to operate the Family Care program came up for renewal in 2007, CMS insisted, as a condition of waiver renewal, that the state establish a separate HCBS waiver program for qualified adults who elect to self-direct their services and supports.

The IRIS (Include, Respect, I Self-Direct) Section 1915(c) waiver program was launched on July 1, 2008, to enhance opportunities for Family Care-eligible seniors and adults with physical and developmental disabilities to self-direct their Medicaid-funded services. The program is available to qualified adults only in counties participating in the Family Care program (46 of the state's 72 counties as of August 2012). The state Department of Health Services, the single state Medicaid agency, retains an IRIS Consultant Agency to assist participants in selecting a qualified individual (consultant) to help them develop and manage a person-centered plan. The Department of Health Services also contracts with a Financial Service Agency to pay the bills and handle other back-office functions for IRIS participants and, with Disability Rights Wisconsin to act as program ombudsman, assist participants to file and settle grievances and appeals.⁴³

As initially conceived, the IRIS program was to serve as an alternative for a comparatively small number of individuals who elect to self-direct their services rather than receive them through one of the nine managed care organizations (MCOs) participating in the Family Care program. Department of Health Services officials initially projected that 1,500 individuals would be enrolled in the IRIS program by 2011. In practice, almost 6,000 individuals were participating in the program by early 2012.⁴⁴

The unexpected surge in enrollment in the IRIS program led to a series of problems, including a lack of program integrity and accountability, a flawed infrastructure to support participant choice and control, and an inequitable process of establishing individual budget allocations. These and other operational issues imposed constraints on the extent to which IRIS participants were able to select where and with whom they live as well as their capacity to direct their own services and supports. Some of these problems were pointed out in a 2011 evaluation of the Family Care program conducted by the nonpartisan Legislative Audit Bureau.⁴⁵

In response to the audit bureau's findings, as well as legislative and gubernatorial concerns about the growing cost of the Family Care program (which is expected to top \$2.8 billion, or about 40% of the state's Medicaid budget, during FY 2011–12),⁴⁶ the Wisconsin Department of Health Services developed a plan to promote the long-range

sustainability of the program. The plan includes a variety of action steps to strengthen the IRIS program and improve "...the ability of consumers to choose the most integrated, community-based and cost-effective services."⁴⁷ It is not clear, at this early stage of the process, whether the planned changes will revitalize self-direction options for Family Care-eligible adults.

New York

The roots of consumer-directed Medicaid services can be traced back to the late 1970s, when a group of young adults with disabilities in New York City rebelled against having home care administrators, nurses, and social workers control their lives. They formed an organization called Concepts of Independence to administer their home care services on a self-directed basis. In late 1980, Concepts became the state's first certified provider of consumer-directed PAS, with responsibility for acting as a fiscal conduit for Medicaid beneficiaries who elected to self-direct their home care supports. Over the following decade, consumer-directed service programs sprang up in other areas of the state; and, in 1996, the state legislature converted a statewide demonstration program into the Consumer Directed Personal Assistance Program (CDPAP) with a mandate that the Department of Health give all New York State Medicaid recipients the option of self-directing their Medicaid supports through a certified fiscal intermediary.⁴⁸

One of Governor Andrew Cuomo's initial actions upon assuming office in January 2011 was to issue an executive order creating a Medicaid Redesign Team (MRT). The governor's charge to the MRT was to develop a comprehensive plan to "transform health care delivery for New Yorkers who are enrolled in both Medicaid and Medicare."⁴⁹ One of the MRT's recommendations was to mandate the enrollment of low-income seniors and adults with physical disabilities in existing managed long-term care plans. Approved by the New York General Assembly as part of the state's FY 2011–12 budget (along with many other MRT recommended actions), the plan calls for delivering MMLTSS through existing Managed Long-Term Care plans, including existing services to more than 60,000 CDPAP participants, approximately 40,000 recipients of home health state plan

services, and 24,000 participants in HCBS waiver services for seniors and adults with physical disabilities.

Disability advocates contend that the transition to MMLTSS threatens the integrity of current and future self-directed services, due both to the abbreviated transition period (i.e., all people to be enrolled in Managed Long-Term Care plans by the end of 2013) and the many key policy issues that have not yet been addressed. The concerns of disability advocates revolve around potential conflicts between the interests of the MCOs and the interests of the individual,⁵⁰ including the following:

- The inherent conflict between the medically-oriented care management model used by existing MCOs and the overarching goals of self-direction (independence, personal control, and improved quality of life);
- The possibility that MCOs will be assigned responsibility for determining whether an individual is self-directing his/her services or has designated a willing and able representative to direct the service plan on his/her behalf;
- Whether MCOs will be responsible for notifying self-directing participants of their opportunity to appeal denials of eligibility and their right to a fair hearing on such appeals; and
- Whether MLTC plans will be required to contract with independent providers of CDPAP services instead of using existing home care contractors to furnish in-plan CDPAP services.

Participants in the Comprehensive HCBS waiver program administered by the state Office of People with Developmental Disabilities (OPWDD) are exempted from mandatory enrollment in MLTC plans.⁵¹ “Due to the complexity of the OPWDD system,” the Medicaid Reform Team decided that a separate federal managed care waiver program should be established for services to people with intellectual and developmental disabilities.⁵² This waiver request, referred to as the People First demonstration, waiver

was submitted in final form to CMS in April 2012 and remained under federal agency review at the time this report was prepared.⁵³

As part of the proposed People First waiver program, OPWDD plans to build on nearly 20 years of experience in offering self-directed support options under the state's Comprehensive DD waiver program. The state's proposal treats self-directed supports as a "non-negotiable" element of planned systemic reforms, and spells out in considerable detail the steps that OPWDD is prepared to take to ensure that people with I/DD have opportunities to control their own services and supports. Although they support the state's efforts to ensure access to self-directed services, some disability advocates express concern over the proposed model. Noting the importance of conflict-free case management, advocates point out that the current proposal to allow nonprofit and public managed care entities—referred to in the state's People First waiver request as Developmental Disabilities Individual Services and Supports Coordination Organizations—to both provide and coordinate HCBS to plan enrollees would constitute an inherent conflict of interest for individuals who choose to self-direct their services. Self-direction, they argue, is not likely to flourish in such a provider-driven service delivery system.

The problems that Wisconsin and New York have encountered in attempting to ensure access to self-directed supports for enrollees in MMLTSS plans are far from unique. Various sensitive issues must be resolved if participants in MMLTSS plans are to be afforded genuine opportunities to self-direct their own services and supports.

CHAPTER 7. **Future Directions in Self-Directed Services**

The number of people with disabilities participating in Medicaid-funded self-directed services has grown rapidly over the past decade. An inventory completed last year by a survey research team at Pennsylvania State University in conjunction with the National Resource Center for Participant-Directed Services found that every state has at least one participant-directed program in which enrollees exercise employer authority and 43 states have at least one program where enrollees exercise budget authority. At the time the preliminary results of the survey were tabulated, researchers had identified 298 programs providing self-directed services nationwide at an estimated FY 2010–11 cost of \$8.0 billion. Included were 62 programs for veterans with disabilities sponsored and funded by the U.S. Department of Veterans Affairs. Approximately 810,000 individuals were participating in these programs.⁵⁴

Participation in self-directed HCBS, however, varies considerably from state to state and community to community. California, with 143 out of 1,000⁵⁵ people with disabilities participating in self-directed service programs, had the highest proportion of people with disabilities in the nation self-directing their services and supports. In contrast, the six states with the lowest enrollment levels had fewer than one adult with disabilities per 1,000 enrolled in self-directed HCBS. Indeed, nearly two-thirds of the adults using self-directed services nationwide were residents of California.⁵⁶

Clearly, the available evidence suggests that the potential for further growth in self-directed services, nationwide, is quite significant, which raises the following questions: What are the remaining barriers to expanding access to self-directed support options within the federal-state Medicaid program? And what can policymakers do to remove or minimize these barriers?

ISSUE #1: Support Worker Qualifications

Efforts to improve the quality of HCBS have, in some cases, worked at cross-purposes with self-directed services. For example, the central premise of self-direction, that participants set the required qualifications of personal support workers and use the resulting criteria to screen and select job candidates, may be abridged by state or local training and credentialing requirements for personal support workers that limit the number and types of job candidates available to people wishing to self-direct their services.

RECOMMENDED SOLUTION #1: CMS' technical guide to designing and operating Section 1915(c) waiver requests affords states considerable latitude in accommodating their HCBS quality assurance provisions to self-directed services. The guide states that:

When the participant is the common law employer, responsibility for conducting necessary background checks devolves to the participant whenever a participant-selected worker is subject to such a check under state law. However, a FMS [Financial Management Service] or other entity may arrange for the background check on behalf of the participant. Under the Agency with Choice⁵⁷ model, the agency is generally responsible for conducting necessary background checks.⁵⁸

The CMS technical guide also makes it clear that, while the provider qualifications adopted by a state are applicable to all providers within a particular service category, a state “may establish additional staff qualifications based on [a self-directing participant’s] needs and preferences.... So long as the additional participant-specific qualifications do not contravene the qualification set [established by the state], they are permissible.”⁵⁹ In others words, a state can tailor the qualifications of a personal support worker to the needs and preferences of an individual who chooses to self-direct her/his services and supports.

In planning self-direction initiatives, states should use the flexibility built into the HCBS waiver technical guide to circumvent potential quality assurance-related barriers to self-direction—whether such initiatives are pursued under Secretari ally approved waivers (Section 1915(b), Section 1915(c), or Section 1115) or under applicable Medicaid state plan amendments (e.g., Section 1915(i), (j), or (k)).

ISSUE #2: Unionization of Personal Support Workers

Personal/home care workers are unionized in some states (e.g., California, Michigan, Oregon, and Washington). Generally, unionization has led to higher wages and improved benefits (including health insurance coverage for workers in some states), as well as better retention rates and an enhanced sense of professionalism among direct care workers. Some workers (including family members of participants), however, object to joining a union and all the obligations membership entails (e.g., payment of union dues, mandatory training, criminal background checks), thus limiting the potential employee pool available to individuals desirous of self-directing their services and supports.

A second concern expressed by some individuals receiving services is that the efforts of workers to gain increasing control over their conditions of employment and scope of work through collective bargaining will conflict with the ability of people with disabilities to direct and manage the delivery of the supports that they receive through self-direction. People are concerned that people with disabilities, particularly intellectual disabilities, are at an unfair advantage when negotiating the terms of employment and duties to be performed by the worker.

RECOMMENDED SOLUTION #2: Advocates of self-direction should collaborate with employee unions in the pursuit of common objectives, such as better wages and benefits, improved working conditions, expanded access to training and skill development, and enhanced public funding of self-directed services—all of which should contribute to higher employee retention rates and a more stable and professional workforce. States and other funding entities should develop

guidelines for identifying the mutual roles and responsibilities of people with disabilities who are self-directing and the workers who support them. Such guidelines should be designed to ensure that the service delivery structure does not supersede the ability of people to manage and control the supports they receive.

Disability advocates and union representatives also should create a common framework for resolving disputes. A November 2011 agreement between several national disability organizations and a union representing more than 2 million public service workers outlined a set of principles to guide the development of such collaborative efforts. In the sensitive area of the recruitment of personal/home care workers by employee unions, the guidelines suggest that "... workers seeking to form a union and union staff who support them shall:

- Respect the privacy of the individual receiving support by not seeking information about the individual or the individual's place of residence.
- Seek to contact workers at their own home and not at their employer's home, unless that is also the worker's home.
- After initially contacting workers, keep lists of those who wish to have further contact and those who do not. When workers and [self-direction program] participants share the same home, lists shall also note when the participant and worker have asked to have meetings in other locations.
- Clearly and promptly identify their name and affiliation with the union when contacting workers.
- Provide literature during home visits on worker rights and the rights of the individuals receiving services that relate to union activities, and that includes contact information for any further questions."⁶⁰

Oregon illustrates how a state can collaborate with a public employee union to improve opportunities for both personal care workers and people with disabilities who choose to self-direct their services and supports. In 2000, the citizens of Oregon approved a constitutional amendment creating a Home Care Commission, funded by the Department of Human Services, to improve services to frail elders and people with physical disabilities. The responsibilities of the commission subsequently were expanded to include home care and personal care services to people with DD, mental illnesses, and medically fragile children.⁶¹

The Oregon Home Care Commission has four major responsibilities: (1) to define home care worker qualifications; (2) to create a statewide registry of home care workers, (3) to provide training opportunities for home care workers and consumers of services, and (4) to serve as the “employer of record” for purposes of collective bargaining with home care workers paid with public funds.⁶² In its latter capacity, the commission represents the state in collective bargaining negotiations with Local 503 of the Service Employees International Union (SEIU), a union representing more than 20,000 home care workers in the State of Oregon, including 12,500 workers who care for seniors and people with physical disabilities and 7,500 workers who care for people with DD, mental health needs, and medically fragile children.⁶³

The commission is composed of nine members appointed by the governor to three-year terms, including five consumers of home care services and one representative each from the Department of Human Services, the Governor’s Commission on Social Services, the Oregon Disabilities Commission, and the Oregon Association of Area Agencies on Aging and Disabilities. Individuals electing to self-direct their home care services are empowered to screen, hire, and set the conditions of employment of their personal care workers, including hiring, disciplining, and dismissing such workers.⁶⁴

Since the commission assumed responsibility for negotiating collective bargaining agreements with the SEIU local, home care workers have achieved higher wages

and significantly improved benefits. For example, workers logging more than 80 hours of service a month are entitled to health insurance coverage with low copayments under the current collective bargaining agreement.⁶⁵ Meanwhile, most observers agree that the quality of home care services has improved over the past decade as a result of a better-trained, fairly compensated work force.

Oregon also has an innovative Brokerage System which allows adults with Developmental and Intellectual Disabilities to have full control over their annual budgets to purchase necessary goods and support services. Under this system, individuals with disabilities have full authority to choose which services to purchase, who to hire, and how much to spend. Many of the staff providing services through the Brokerages are not covered by the Home Care Commission. In 2010, legislation was passed to allow providers through the brokerage system to be organized. Negotiations are continuing between all stakeholders to ensure that workers are able to work for fair wages and benefits and have access to appropriate training without removing any control from individuals with disabilities to make choices about their own services. One key priority for the disability community is to ensure that individuals with disabilities maintain complete control over their budget, rather than being given vouchers for particular services which would erode their ability to direct their services.

ISSUE #3: Managed Care and Self-Direction

Unless a state establishes policies that allow self-direction to flourish within a managed care environment, the opportunities of people with disabilities to self-direct their own supports could be significantly curtailed once they are enrolled in MMLTSS programs.

RECOMMENDED SOLUTION #3: States operating or planning to initiate MMLTSS programs should ensure that individuals who choose to self-direct their services and supports are able to exercise effective control over their lives and the

resources allocated on their behalf, without jeopardizing their health and safety. In particular, state MMLTSS policies should ensure that—

- ***Service eligibility determinations are made by state personnel. States may contract for evaluation and recommendations for eligibility.*** The MCO or state personnel, not the service providers, assess the service needs and develop the individual plan, and do so separately from service financing and delivery to avoid potentially serious conflicts of interests. This approach is consistent with statutory requirements governing the Balanced Incentive Program.

- ***All plan enrollees, including those who choose to self-direct their supports, should receive conflict-free support coordination services.*** In guidelines and regulations governing the Balanced Incentive Program, CMS has articulated the following core characteristics of conflict-free case management:
 - Responsibility for providing case management services is separated from responsibility for the provision of direct services and supports;
 - Case managers are not employed by an entity providing services;
 - Case managers are not responsible for determining individual funding levels; and
 - Persons performing evaluations and assessments or developing individual plans of care cannot be related by blood or marriage to the individual or any of the individual's paid caregivers.

A number of avenues are available to ensure conflict-free case management, as explained in CMS' Balanced Incentive Program Implementation Manual.⁶⁶

- ***MCOs enroll in their provider networks: individual support workers selected by the individual and/or by community support providers, and financial management entities that are experienced in assisting individuals who self-direct their LTSS, provided that such community agencies and independent support workers are willing to accept MCOs payment rates and operating requirements.*** The goals of self-direction will be thwarted if MCOs are not obligated to enroll support workers selected by self-directing individuals. Encouraging existing community providers to enroll in MCO networks, moreover, is an important step toward promoting continuity of services and maintaining critical interpersonal relationships as people with disabilities transition to MMLTSS plans.
- ***Individuals choosing to self-direct their services and supports have access to independent advocacy (ombudsman) services and retain the right to pursue grievances and appeals through established Medicaid channels, including appealing directly to the single state Medicaid agency and requesting a fair hearing.*** Given the highly individualized nature of self-directed support plans, it is particularly important that the rights of such individuals not be curtailed once they are enrolled in MMLTSS plans.
- ***Quality management policies and practices accommodate the special circumstances that apply when an individual is self-directing his or her services and supports.*** The aim of such accommodations should be to strike a reasonable balance between safeguarding the individual's health and safety and respecting the person's right to control his/her own life. Required safeguards should be based on individual circumstances rather than standardized provisions (e.g., training should be customized to the needs and aspirations of each person, rather than being applied uniformly across all program participants).

- ***Fair, equitable, and transparent methods are used in determining and adjusting individual budget allocations of people who elect to self-direct their LTSS.*** Public resources are finite and, therefore, it is important that each plan enrollee receive sufficient funding to cover the costs of his or her essential support needs and nothing more.

The safeguards outlined above must be built into state operating policies and MCO contractual requirements to ensure that self-direction opportunities are fully supported and are not curtailed once individuals are enrolled in MMLTSS plans. The recent experiences of self-advocates and their allies in Wisconsin and New York underscore the nature of the risks involved.

ISSUE #4: Risk Management

In self-directed services, risk management is a critical ingredient in striking a balance between individual safety and personal choice and control. Managing risk is a process that involves (1) objectively assessing an individual’s exposure to potentially harmful situations, (2) developing plans to prevent such exposure, and (3) ensuring the capacity to respond quickly in a dangerous situation.⁶⁷

Various standardized risk assessment tools are currently in use, but, given the highly diverse capabilities and vulnerabilities represented within the population of people with disabilities, additional studies are needed to establish the validity and reliability of risk assessment instruments for specific subgroups, and institute effective policies and procedures for identifying roles and responsibilities within the service delivery system to plan and implement individualized risk management strategies and monitor compliance with such plans.

RECOMMENDED SOLUTION #4: States offering self-directed HCBS should establish and maintain risk management systems that include—

- Policies and procedures that clearly identify the roles and responsibilities of key actors within the service delivery system, including people with disabilities, their case managers/counselors/support coordinators, state or local support agency staff, and direct support workers;
- A well-defined process of identifying circumstances that could endanger the health, safety and well-being of self-directed participants and assess the probability of such occurrences;
- A procedure for discussing the implications of potential risky situations with self-directed participants;
- A plan to reduce or eliminate the possibility of potentially harmful situations and a plan for responding promptly if they occur;
- A process for protecting the rights of self-directed participants to assume risk and honor their decisions; and
- A system for monitoring implementation of risk management provisions contained in the individual service plans of self-directed participants.

CMS, in collaboration with the HHS Administration on Community Living, should underwrite the cost of a series of longitudinal studies of the components of effective risk management planning and execution for people with disabilities who are receiving community-based long-term services and supports. Among the subjects that should be examined as part of these studies are the instruments used in assessing risk among various subgroups of people with disabilities and capacity to pinpoint potentially harmful situations. In addition, attention should be directed toward avoiding the imposition by provider agencies of unjustified restrictions on individual choice and control and ensuring that participants have appropriate avenues to appeal such restrictions.

ISSUE #5: Financial Management Services

Medicaid law prohibits direct cash payments to recipients of HCBS waiver services and most state plan services.⁶⁸ As a result, FMS have become virtually ubiquitous in Medicaid-financed self-directed services.

A state may employ various FMS models, as explained in the Handbook for Developing Self-Direction Programs and Policies.⁶⁹ A state's FMS design, operation, and oversight choices can have significant consequences for individuals who choose to self-direct their services, including potential violations of employment laws and serious disruptions in services and supports.

RECOMMENDED SOLUTION #5: States should carefully analyze alternative FMS models as they design support systems for Medicaid beneficiaries who choose to self-direct their services and supports. Such reviews should also examine the experiences of other states that have alternative approaches to organizing and delivering FMS. In addition, CMS should continue to offer states technical assistance in designing FMS programs through the National HCBS Quality Enterprise.

ISSUE #6: Costs and Outcomes

Large gaps exist in our understanding of the relationship between public expenditures and individual outcomes in both self-directed and agency-directed community services.

RECOMMENDED SOLUTION #6: The HHS ACL should spearhead a departmentwide effort to initiate a series of longitudinal studies of the costs and benefits of self-directed HCBS for people with long-term support needs. The primary purpose of these studies should be to elucidate the relationships among program design elements, service costs, and measurable outcomes for identified subgroups of LTSS users, thereby creating an empirical foundation for evidence-

based practices in formulating and financing self-direction programs for frail elders, nonelderly adults with physical disabilities, children with severe chronic disabilities and illnesses, people with I/DD, people with severe and persistent mental illnesses, and people with traumatic brain injuries. ACL should draw upon the expertise and resources of the following other department units in designing and financing these projects: CMS; the Substance Abuse and Mental Health Administration; the Health Resources and Services Administration; the Agency for Healthcare Research and Quality; the National Institutes of Health; and the Centers for Disease Control and Prevention.

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