

Chapter 4: Enrollment

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Chapter 4

Enrollment¹

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

A. Choosing an Overall Enrollment Strategy

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

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

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

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

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

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

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

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

B. Outreach

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

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

Planned Outreach

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

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

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

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

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

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

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

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

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

Unplanned Outreach

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

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

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

C. Establishing Enrollment Policies and Procedures

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

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

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

Staffing

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

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

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

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

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

Timeliness of the Enrollment Process

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

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

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

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

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

Policies Regarding Representatives

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

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

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

Assigning Responsibility for Conducting Enrollment

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

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

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

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

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

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

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

Providing Program Information to Interested Individuals

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

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

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

When to Provide Information.

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

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

Conducting Home Visits

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

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

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

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

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

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

D. Tracking Enrollment

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

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

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

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

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

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

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

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

E. Factors That Influence Enrollment

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

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

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

Program Design Features

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

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

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

Perceived Fairness of the Individual Budget Amount

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

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

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

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

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

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

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

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

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

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

Characteristics of Potential Participants

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

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

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

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

Satisfaction with the Current System

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

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

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

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

Perceived Difficulty of Recruiting Workers

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

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

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

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

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

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

Stakeholders’ Views

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

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

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

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

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

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

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

Resources

Publications

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

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

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

Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. (2003). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey*. Washington, DC: Department of Health and Human Services, Assistant Secretary for Planning and Evaluation.

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

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

Web-Accessible Resources

Cash & Counseling National Program Office

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

This website contains extensive, wide-ranging resources concerning self-direction, including state initiatives to incorporate self-direction into the delivery of Medicaid HCBS. In particular, on the interactive map site, each state has provided a wealth of materials, including enrollment forms and other marketing materials. For example, <http://www.cashandcounseling.org/resources/browse?SourceIndex=Arkansas>

Also, the following toolkits are available:

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

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

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

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

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

Citations, Additional Information, and Web Addresses

- 1 Pamela Doty and Janet O’Keeffe co-authored this chapter. Kevin Mahoney is a contributing author.
- 2 While some new self-direction options are not separate programs (i.e., they are an addition to an existing program), for ease of reference, this Handbook will use the term program, unless a distinction between an option and a program is needed.
- 3 In addition to the waiver populations, Mi Via also serves a population not covered by a waiver program—people with acquired brain injuries. O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). *Real Choice Systems Change Grant Program - FY 2002 Real Choice Grantees and Community-Integrated Personal Assistance Services and Supports Grantees: Final Report*. Baltimore, MD: Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/2172>
- 4 Dale, S.B. & Brown, R. (2006). Reducing nursing home use through consumer-directed personal care services. *Medical Care*. 44(8):760–767.
- 5 Focus group research in Florida indicated that the opinions of case managers about the new self-direction program carried a lot of weight with their clients. However, clients and case managers both reported that participants and family members were less trusting of and reliant on their case managers’ advice when they had experienced significant case manager turnover and believed they knew more than recently hired case managers.
- 6 The percentage of participants who designated a representative varied by state and target population—from 40 to 60 percent. Schore, J., Foster, L. & Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research*, 42(1p2):446–466. Available at: <http://dx.doi.org/10.1111/j.1475-6773.2006.00679.x>
- 7 McInnis-Dittrich, K., Simone, K., Mahoney, K. (2006). *Consultant Training Program*. Baltimore, MD: Centers for Medicare & Medicaid Services, Disabled & Elderly Health Programs Group. Available at: <http://www.cashandcounseling.org/resources/20060602-113610/>
- 8 O’Keeffe, J., Wiener, J., Greene, A. (2005). *Real Choice Systems Change Grant Programs. Consumer Direction Initiatives of the FY 2001 and 2002 Grantees: Progress and Challenges*. Baltimore, MD: USDHHS, Centers for Medicare & Medicaid Services. Available at: <http://www.hcbs.org/moreInfo.php/doc/1601>.
- 9 O’Keeffe, J., Anderson, W., O’Keeffe, C., Coleman, B., Greene, A.M., & Brown, D. (2008). Op.cit.

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

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

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

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