

Part 3

Independence Plus Grantees

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Section One. Overview

In 2002, as part of the New Freedom Initiative, the Centers for Medicare & Medicaid Services (CMS) began the Independence Plus Initiative to promote self-direction of services and supports by persons of all ages with disabilities and their families. In its description of the Initiative, CMS defined a self-directed services program as “a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget.” CMS also stated that the requirements for a comprehensive self-directed services program—or Independence Plus (IP) program—include the following:

- *Person-centered planning*—A process, directed by participants, intended to identify their strengths, capacities, preferences, needs, and desired outcomes.
- *Individual budgeting*—The total dollar value of the services and supports, as specified in the plan of care, under the control and direction of participants.
- *Services to support self-direction*—A system of activities that help participants to develop, implement, and manage the services and supports identified in their individual budget.
- *Quality assurance and quality improvement (QA/QI)*—A QA/QI model that will build on the foundation of discovery, remediation, and continuous improvement.

In FY 2003, to further encourage states to offer self-directed services options, CMS awarded \$5.4 million in IP grants to 12 states, as listed in Exhibit 3-1.

Exhibit 3-1. FY 2003 Independence Plus Grantees

Colorado	Maine
Connecticut	Massachusetts
Florida	Michigan
Georgia	Missouri
Idaho	Montana
Louisiana	Ohio

States receiving IP grants could (1) develop a new Section (§) 1115 Research and Demonstration waiver (demonstration waiver) or a §1915(c) Home and Community-Based Services waiver (HCBS waiver), or amend an existing HCBS waiver to incorporate the IP features; (2) build capacity to strengthen new or existing self-direction programs in any of the IP required areas; (3) build provider capacity under the self-directed services option; and/or (4) hire personnel to research self-direction program designs or funding

opportunities with the expectation of submitting an IP waiver application or amending an existing waiver to include IP features.

During the grant period, federal policy regarding self-direction in Medicaid HCBS changed. In 2005, CMS modified the requirements for IP programs when it revised the HCBS waiver application, developing a new template to clarify CMS policies governing HCBS waivers. States no longer need to apply for a distinct HCBS-IP waiver to offer participants the full range of self-direction options. Instead, states can offer degrees of self-direction if they are not yet ready to offer the comprehensive program required for IP designation (e.g., they may offer only the employer authority to hire/dismiss workers but not the budget authority).

As a consequence of these changes, a few IP Grantees revised their initial plans concerning which Medicaid authority to use for developing and implementing an IP program. Rather than applying for a new IP waiver, some Grantees began considering amendments to existing waiver programs in order to add or expand self-direction options.

Enduring Systems Improvements

In addition to their numerous accomplishments, all of the IP Grantees reported enduring improvements that helped to develop or expand options for individuals to direct their services and supports, as shown in Exhibit 3-2. All of the Grantees developed the infrastructure for a new self-direction program; about half did so with the intent to implement a self-direction program after the grant ended. Several states had developed infrastructure prior to receiving the IP grant and planned to use their grants to develop IP waiver applications and/or add a new IP option in a Medicaid State Plan or waiver program during the grant period, as either a pilot or a full-fledged program. This section describes the Grantees’ enduring improvements in these two areas.

Exhibit 3-2. Enduring Systems Improvements of the IP Grantees

Improvement	CO	CT	FL	GA	ID	LA	ME	MA	MI	MO	MT	OH	Total
New infrastructure for self-direction program	X	X	X	X	X	X	X	X	X	X	X	X	12
New IP option in waiver or State Plan program(s)		X		X	X			X	X	X	X		7

Section Two provides more detailed information about each state’s grant initiatives: both their accomplishments and their enduring changes. Grantees’ accomplishments were preliminary steps in the process of bringing about enduring systems improvements. For

example, developing a funding algorithm for generating individual budgets is an accomplishment, whereas implementing a new waiver program that offers participants the option to direct an individual budget is an enduring systems improvement.

New Infrastructure for Self-Direction Programs

A service delivery system that allows participants to direct their services and supports differs markedly from the traditional service system. States that want to offer participants the option to direct some or all of their services need to develop an infrastructure that will enable them to do so.

Financial Management and Counseling/Support Broker Services

Financial management services (FMS) play a crucial role in supporting participants to fulfill their employer-related payroll, tax filing, and reporting responsibilities. When designing and implementing FMS, states have to choose among different models and determine which will be available to participants; for example, will the participant be the employer of record, will the participant enter into a co-employer relationship with an FMS entity, or will there be a choice between these two options? Will the FMS be paid for as a waiver service out of a participant's individual budget, or as a Medicaid administrative expense?

Counseling or "support broker" services also play a crucial role in self-direction programs. Counselors' responsibilities include helping participants to develop spending plans and locate employees and resources. As with FMS, in addition to choosing a specific counseling model, states must also decide whether counseling will be reimbursed as a waiver service or a Medicaid administrative expense.

Ohio developed several key IP waiver infrastructure components, including specifications for a statewide FMS entity, which will be available to all state agencies in Ohio that offer or will offer a self-direction option in their waivers and other programs.

Georgia's grant and state staff designed a financial management fiscal agent service for waiver participants who choose to direct their services and established an enrollment and payment process. In addition to providing financial services, the fiscal agent facilitates a criminal records check on any potential employees in the self-direction system. Georgia's grant staff also developed a process to recruit, train, and certify support brokers. Although support broker services initially are being provided by traditional case managers, the State plans to have independent support brokers (i.e., someone other than a waiver case manager) by making case management services separate from support broker services.

Idaho's grant staff contracted with the University of Idaho to develop a training program for support brokers. One component of the training—available on the Department of Health and Welfare website—provides information about the philosophy of self-direction and extensive

program information. The curriculum offers six modules: self-direction, support broker roles and responsibilities, person-centered planning, needed skills, ethics and professionalism, and resources. By making these materials available online, the program hopes to encourage the provision of support broker services in rural communities. Grant staff also developed a training curriculum to be used in person, which addresses the program's policies, procedures, and operational features. Individuals who want to be support brokers are not required to undergo formal training but must pass an exam.

Idaho wanted to establish a cadre of support brokers from whom participants could choose but also wanted participants to be able to choose someone they knew to serve as their support broker. To achieve this goal, the State developed recruitment and training materials for both situations. In addition, the Idaho Developmental Disabilities Council, in partnership with grant staff, created a sustainable training program for providers to increase their awareness of self-determination concepts and to help them move from the traditional service model that uses Medicaid service coordinators to a self-direction model that uses support brokers and a circle of support.²

Individual Budget Methodologies

An individual budget includes the funds or resources available to participants to meet their needs. Individual budgeting allows states to better match a program's benefits to participants' needs by allowing participants to exercise choice and control over a specified amount of funds. With budget authority participants can, at a minimum, make decisions about the amount that will be paid for each service and support in accordance with the state's policies, and select providers and review and approve their invoices. Regardless of which budget methodology a state chooses, the core elements of the individual budgeting process constitute a process for determining needs and translating the information into a service plan and a methodology for setting the budget amount.

Connecticut established a valid and reliable methodology to predict level of need and compute participants' associated costs, and developed an individual budgeting process incorporating the assessment methodology and resource allocation strategy. Having a single valid statewide assessment tool and reimbursement schedule has enabled the State to distribute funding more equitably across all Developmental Disabilities Services program participants. Additionally, given that the models allocate funds precisely, they can be used

² A circle of support is a group of people who meet on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person (the "focus person") who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. The focus person is in charge, both in deciding whom to invite to be in the circle, and also in the direction that the circle's energy is employed, although a facilitator is normally chosen from within the circle to take care of the work required to keep it running.

to equitably increase or decrease funding. They also provide a method for generating an individual budget that is portable.

Georgia's grant staff developed a computerized system that incorporates data on past service use and current cost data to use with the formula for calculating individual budgets. They also designed operational procedures and policies for self-directed services, including procedures for budget reviews, modifications, and re-determinations; monitoring and audits; and use of unexpended funds.

Idaho's grant staff developed a scored assessment tool that provides an inventory of individualized needs and life goals using a person-centered planning (PCP) process. The assessment provides the foundation of each person's service plan. They also developed a methodology that translates the assessment results into costs to determine an individualized budget amount. This methodology is used to set budgets for participants who direct their own services as well as for those using traditional services.

In Maine, service providers have historically charged sometimes markedly different rates for the same service, and the State, accordingly, has reimbursed different amounts for the same service. The lack of a standardized rate reduced the ability of participants with fixed budgets to switch service providers if the provider they wanted to use had a higher rate. To address this problem, grant staff worked with staff from Maine's Systems Change Money Follows the Person grant on a state initiative to standardize reimbursement rates for service providers. In January 2008 the State published standard reimbursement rates for three services, which will allow waiver participants to select the service provider that best meets their needs.

Backup Plans and Critical Incident Management

Some features of a quality management (QM) system are unique to self-direction, but many are relevant for all service delivery models. A feature that is relevant to both traditional and self-direction service models is an individual backup plan for situations in which providers of services and supports essential to participants' health and welfare become unavailable. An individual's service plan should identify issues or situations that can jeopardize health and welfare and specify actions to prevent and/or correct them, and all participants should be educated about the availability of backup resources.

Several Grantees developed components of QM systems for new self-direction programs; most focused on backup plans and/or critical incident management, but others focused on the larger QM process. For example, Montana's grant staff developed a quality assurance database that incorporates the incident management system, quality assurance reviews, and quality assurance communications into one system. As a result, the State has moved from a paper-based reporting system to one that allows data entry at the provider and field

staff level. The system enables tracking, analyzing, and trending of quality assurance data and reports across the new IP waiver developed through the grant, the Elderly and Physically Disabled waiver, and the Medicaid State Plan Personal Assistance Services (PAS) program. The database also provides evidentiary review data to enable the State to respond to requirements for federal waiver assurances.

Montana also developed an individual risk assessment tool to guide participants through a process of identifying and developing plans to prevent and reduce risk, and to address problems when they arise. Participants and support brokers are trained to use the tool, which is unique to the new IP waiver, as part of the PCP process. The State plans to incorporate the tool into the care planning process for the Elderly and Physically Disabled waiver and the State Plan self-direction PAS program as well.

The Massachusetts grant staff established a quality work group, which designed and created the infrastructure for the necessary components of a QM system for the new IP program, as well as methods to ensure a consumer focus in quality management. The system includes procedures for emergency backup, critical incident management, grievances, and reporting abuse and neglect.

Idaho grant staff developed a comprehensive quality management and improvement system that monitors quality in every component of the self-direction model. Procedures are in place to ensure that planning is person centered and that backup plans are in place to ensure health and safety. In addition to addressing individual risks, backup plans may also address community-wide emergencies, such as threatening weather, electrical outages, and other situations that can create safety issues. In addition, grant staff developed a statewide critical incident reporting system, and the State offers training for participants on how to file complaints.

Although Colorado's self-direction programs already had mechanisms for participant safeguards that had demonstrated a high level of participant satisfaction, grant staff determined that some improvements were needed to better support participants in meeting emergency backup needs and preventing and dealing with critical incidents. Acting on recommendations from participants and other stakeholders, grant staff developed tools for individual backup worker plans and critical incident management in both print and electronic versions. The tools are available for single entry point agencies, Independent Living Centers, consumer advocates, and all Medicaid waiver participants who use personal care services. Although the tools were initially designed for self-directing participants, slight wording changes have enabled waiver participants receiving services through agencies to also use these tools.

Missouri developed a statewide Quality Management Plan for individuals who direct their services that was used for the IP pilot project. After evaluating the pilot, the IP Task Force reviewed the quality management plan and recommended that the Division of Mental Retardation and Developmental Disabilities expand the plan beyond health and safety compliance concerns to include quality of life outcomes for individuals directing their services. Other elements identified for further consideration include the need for a stronger emphasis in backup plans on strategies to address natural disasters, community pools of backup support staff, contracting with an agency to provide backup staff, and developing an online list of backup workers.

Georgia's grant staff—with considerable input from stakeholders—developed a list of critical incidents specific to self-direction and worked with the Department of Human Resources Information Technology Division to incorporate the information into the Department's current incident management program.

Louisiana's grant staff and partners developed an emergency backup preparedness system for every individual receiving Medicaid waiver or State Plan long-term services and supports—not just those in self-direction programs. The Resident Emergency Alert and Locator (REAL) system, which includes a preloaded database and fingerprint recording system, enables Department of Health and Hospitals staff and emergency shelter staff to identify Medicaid beneficiaries who have been evacuated in an emergency. Once identified, their emergency information can be obtained, including—but not limited to—their residence, next of kin, primary care physician, and medications. The REAL system also allows staff to link Medicaid beneficiaries to needed services in a timely and efficient manner.

Other Infrastructure

When implementing a new self-direction program or a new self-direction option in an existing program, it is essential to have a communication plan for outreach and education. 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 whatever information they need to decide whether it is right for them. Educational materials are needed not only for program participants but for everyone who will work with a new program.

Maine's grant staff worked with their Advisory Committee's work groups to develop a participant and family training package on several topics, including person-centered planning, managing personal budgets, being an effective employer, and selecting and working with support brokers and fiscal employer agents. They also started developing training curricula for support brokers that specifically address distinctions between support broker and case management services. These materials are still in draft format and will be finalized when funding is available to implement self-direction in a waiver program.

New IP Option in Waiver or State Plan Program(s)

As shown in Exhibit 3-2, 7 of the 10 states that planned to implement a new IP option accomplished their goal. Louisiana, Maine, and Ohio were unable to implement for reasons discussed in the individual state summaries in Section Two. (It was not a goal for Colorado and Florida.)

Connecticut grant staff wrote the application for an Independence Plus waiver called the Individual and Family Support (IFS) waiver, which introduced in-home, flexible services for children and adults with mental retardation. The State also received approval to replace its MR waiver in order to add individual budgeting and flexible supports under a Comprehensive Supports waiver. Within about 2 years of implementation, about 600 participants had enrolled in the IFS waiver's self-direction option, and approximately 300 had enrolled in the Comprehensive Supports waiver. Interim individual budgeting methods are in place to support self-direction in both new waiver programs while the State moves from capitated funding for limited service options to a fee-for-service system that allows participants to choose from a larger service array.

Prior to receiving its IP grant, Georgia did not have a self-directed services option in any waiver programs. The State amended three waiver programs to add self-direction of personal care services: (1) the Community Care Services Program for elderly persons and/or those of any age who are functionally impaired/disabled, (2) the Independent Care Waiver Program for adults aged 21 to 64 with physical disabilities and/or traumatic brain injury, and (3) the Mental Retardation Waiver Program (MRWP) for persons with developmental disabilities. Participants electing to use the new self-direction option are able to hire their own workers, receive both case management and support broker services from a case manager, and use financial management services. In addition, MRWP participants may choose to have an individual budget for services other than personal care.

Georgia's experience in implementing self-direction in the three waivers also informed the development of its renewal application for the Mental Retardation Waiver Program, which includes a request for IP designation and renaming as the New Options Waiver. The application was approved effective October 1, 2007. In addition, the State is amending the Community Habilitation/Support Services waiver program for persons with developmental disabilities who have intensive and comprehensive supports needs, to provide an option for them to self-direct most of their waiver services. The amended waiver program will be renamed the Comprehensive Supports Waiver.

Idaho used its grant to help implement a self-directed services option under an existing DD waiver program, which includes the IP design features of person-centered planning, individual budgeting, financial management services, support broker services, and participant protections. As a result, the infrastructure for future self-direction programs in

Idaho has been established, including a rule authority for self-direction programs; an individual budget methodology that is cost neutral and is used to set budgets for participants who select the self-direction option, as well as for those who continue to use traditional services; a contracted fiscal employer agent; and a web-based training curriculum for support brokers.

Idaho's new self-directed services option (My Voice, My Choice) was piloted in three regions and then expanded statewide to adults served through the developmental disabilities waiver, which allows participants to choose between traditional waiver services and self-direction. The State's target is for 25 percent of the nearly 3,000 developmental disabilities waiver participants to choose self-direction over the next 5 years. The State is also considering expanding and enhancing self-direction in other programs, such as the Aged and Disabled waiver.

Although the goal of the Massachusetts grant was to develop a new IP waiver, the State decided that its policy goals would be better served by including an IP option in the new demonstration waiver it was developing rather than having a separate IP waiver. The infrastructure developed for the new IP waiver was included in the State's demonstration waiver application. The new waiver covers individuals formerly served in the Elderly and Traumatic Brain Injury waivers as well as adults under age 65 with disabilities, who formerly were not served under any waivers. (Some individuals under 65 are served in the State's MR/DD waiver.) The State submitted the application to CMS in December 2006 and, as of January 2009, was still in negotiations about the waiver's terms. The anticipated start date is July 2009. The IP option will allow waiver participants to have greater control over the services they receive and the individuals who provide them.

Michigan amended its MI Choice waiver—for elderly persons and working-age adults with physical disabilities—to include a self-direction option (called self-determination) that was made available statewide in October 2007. Grant funds were used for training the Area Agency on Aging waiver staff as they prepared to initiate the new option; and for regional training events and statewide meetings, which provided awareness, information, and skill-building activities for program managers, social workers, and nursing staff in the areas of person-centered planning, quality assurance, developing a plan of service, and individual budgets. As of November 2008, 550 individuals had elected to use the new option.

Prior to receipt of the IP grant, Missouri's Department of Mental Health (DMH) offered the option to self-direct personal assistant services in three DMH waiver programs serving persons with mental retardation and other developmental disabilities: the Community Support waiver for children and adults, the Comprehensive waiver for children and adults, and a model waiver serving up to 200 children from birth through age 18. Participants and

families were the employer of record, and a fiscal intermediary provided payroll services for participant-employed workers.

As a result of the success of Missouri's grant pilot project, when applying for renewal of the Comprehensive and the Community Support waivers, the State expanded financial management services and added support broker services and PCP facilitator services as options for participants wishing to self-direct. The two waivers were renewed July 1, 2006, and a contract for FMS providers was awarded in spring 2008. The State is working on the renewal of a third §1915(c) waiver, the Missouri Children with Developmental Disabilities waiver, to which it plans to add the same components. The State is committed to improving self-direction options in all waiver programs.

Montana used its grant to develop an Independence Plus §1915(c) waiver program, known as the Big Sky Bonanza waiver, which incorporates the self-direction features of an individual budget, financial management services, support broker services, and person-centered planning. The individual budget gives waiver participants both employer authority and budget authority over a range of goods and services. The new program was initially implemented as a pilot, and as a result of its success and the overall satisfaction of the initial group of IP waiver participants, the State decided to amend its Elderly and Physically Disabled waiver to include the IP components as a distinct self-direction option. The amendment submission was targeted for January 1, 2009. The pilot areas will be expanded gradually until the IP option can be incorporated statewide into the Elderly and Physically Disabled waiver.

Currently, Elderly and Physically Disabled waiver participants can choose to enroll in the new IP waiver (Big Sky Bonanza) if they want to use the expanded self-direction option. Individuals who are currently receiving State Plan personal assistance services can also choose to enroll in the new IP waiver program—if they meet the waiver's eligibility criteria—and receive a comparable resource allocation for services they were receiving through the State Plan in their waiver individual budget. Montana uses the PAS cost information and historical waiver service costs to determine individual budget amounts.

The IP waiver allows for payment of legally responsible individuals under certain circumstances, which has increased the availability of services to individuals and their families in remote areas and in other situations where qualified caregivers cannot be found. When the IP option is incorporated into the Elderly and Physically Disabled waiver, payment for legally responsible individuals will also be allowed.

Continuing Challenges to Systems Improvements

Grantees successfully addressed many challenges throughout the grant period but reported several that remain.

Several Grantees experienced slow enrollment in their new self-direction programs, likely due to the availability of other self-direction programs in the state that allow participants to choose and employ their workers even if they do not provide the option to direct an individual budget. One Grantee stated that resistance from traditional service providers to the new self-direction program may also have slowed enrollment as well as a “wait and see attitude” among potential participants, who wanted the “bugs” to be worked out of the new program before enrolling. To increase enrollment, program staff are developing creative marketing approaches.

One Grantee noted that obtaining secure workers’ compensation coverage for participant-directed workers remains a challenge, and another said that it was difficult to find an independent organization to manage a registry of attendants who would be available 24 hours per day, 7 days per week, for short-term backup care. One Grantee noted that it is challenging to combine the flexibility of self-direction programs with state and federal requirements for accurate accounting of waiver expenditures.

One Grantee reported difficulty in securing the agreement of its Medicaid agency to changes needed to offer self-direction as proposed in the IP waiver. Although discussions about the changes are ongoing, reaching consensus has been a struggle. Another, who planned to combine funding from multiple programs for which participants were eligible into a single individual budget, said that working with state agencies to combine funding continues to be a challenge. Although the response from some agencies has been positive, others are only willing to contribute funding based on the prior year’s service utilization rather than the amount currently authorized.

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained extensive experience in developing and operating self-direction programs. They reported several lessons learned and made recommendations that may be helpful to states that are working on developing self-direction programs, specifically those with a budget authority.

Lessons Learned

Two Grantees reported lessons learned in bringing about systems change generally. One noted that it was unrealistic to try to introduce changes in multiple agencies at the local, regional, and state level in a very large state in a short time period. Rather, a more practical

approach would be to pilot a new initiative at the local or regional level. The other said that building on existing systems change efforts can help to ensure success, noting that a self-direction pilot implemented with an earlier Systems Change grant had provided valuable information for developing the IP program infrastructure. The Grantee also stressed that although a detailed sustainability plan may not be developed until later in a project, stakeholders need to plan for sustainability from the beginning.

Recommendations

Grantees made both general and specific recommendations for developing and implementing self-direction programs and for changes in federal and state policy.

Involving Participants and Other Stakeholders

Virtually all of the Grantees agreed that it is essential to involve participants and other stakeholders in the development of a new program in order to obtain their support and commitment. In particular, it is critical to ensure consistent and continual communication with all program stakeholders.

One Grantee pointed out that participant involvement provides a valuable “reality check” for policy initiatives. Most importantly, creating a strong and active stakeholder advisory board that is involved in every step of the development of a new program can create a vested interest in the program and a strong desire to see it grow and improve among both service users and providers. One noted that consumer involvement in grant activities had helped to ensure that the new IP option was designed to meet participants’ needs within state and federal parameters. Another said that consumer involvement can discourage the spread of inaccurate information about a new program, reduce the apprehension of some stakeholder groups, and help to ensure the development of a user-friendly program.

Grantees recommended several successful approaches for obtaining consumer and other stakeholder support and buy-in.

- Design systems change initiatives using a collaborative approach that involves all people with a stake in the outcome. Involve service users in planning, staff training, and policy development through advisory groups to ensure that consumer issues are identified and that consumer support for actions is likely. It is beneficial to provide a forum in which service users and providers can hear about one another’s concerns and obtain an understanding of the limitations of the long-term services and supports system.
- Contract with a knowledgeable outside entity to facilitate stakeholder meetings, and convey a national perspective on self-direction. Because stakeholders may disagree, this is a highly effective approach for reaching consensus.

- Use an independent research group to inform the discussion when stakeholders cannot agree on a particular approach to designing new program components, such as methods for assessing need and determining the amount of an individual budget. This approach can be very effective, but if the research group is unfamiliar with developmental disabilities services, for example, they may have difficulty understanding the complexities of the DD system.
- Use consumer surveys to identify individuals who are interested in serving on a committee, thus providing a pool of service users who can be contacted as needed, because it can be difficult to recruit service users to work for an extended period of time on an advisory committee.
- Develop a meaningful method for involving service users and stakeholders early and consistently in all phases of a systems change initiative in order to strengthen and facilitate systems change efforts. Provide supports such as transportation, stipends, and information in accessible formats to ensure ongoing participation. Focus groups and key informant interviews are excellent methods for obtaining input from diverse service users and families, not just from those able to participate on advisory committees and work groups.
- Give work groups sufficient time and staff support to consider information in a timely manner that allows for real input into the process. Provide meeting agendas 1 to 2 weeks prior to an event to allow individuals time to read about and understand the topics to be discussed.
- Commit to program staff spending considerable time and resources to involve self-advocates in a meaningful way. Three years was insufficient for the targeted population. Ensuring the involvement of self-advocates may initially require meeting in a less “professional” environment so they can feel comfortable expressing themselves. Once a comfort level is established, self-advocates may need assistance to learn how to participate in a professional environment.

Therefore, it is important to plan up front for more time to complete activities and to budget for stipends to enable self-advocates to be involved. Also, it is useful to work directly with self-advocates rather than with their direct care workers. When workers’ attendance at meetings was discouraged, many self-advocates were able to be more open and to share their thoughts—not because their workers prevented them from doing so, but because many workers were in the habit of speaking for the individuals for whom they worked.

The state staff who develop and will operate a new program are also stakeholders, and one Grantee emphasized the importance of a collaborative approach when developing self-direction policies and procedures that will cross systems serving different populations. Such an approach will result in a comprehensive design that minimizes duplication while allowing for differences as needed.

Implementing Self-Direction Programs

Half of the Grantees made recommendations specific to implementing their self-direction programs. Three noted that ongoing outreach, education, and training are required to help stakeholders—particularly long-term services and supports professionals—make the paradigm shift from a traditional service delivery model to a self-direction model. Traditional service providers may be unfamiliar with the self-direction model or may have long-held negative views regarding the ability of people with disabilities to direct their services.

Participants and their families also need education to understand the new program, and many may need training to succeed in directing their services and supports. Participant education and training materials should be developed with participant input to ensure that materials are effective, useful, and meet participants' needs.

One program initially had a "cumbersome and complicated person-centered planning process" that limited support brokers' effectiveness in working with participants and hindered program enrollment. Grant staff simplified the process and recommend that other states not "person-center the process to death like we did"; they suggest that Grantees test the service planning and development process prior to implementation, with the goal of simplifying it to the extent possible.

State and Federal Policy

Some Grantees made recommendations aimed specifically at their state or specifically related to self-direction programs and policies, whereas others addressed a wide range of issues that impede full community integration for people with disabilities.

- Michigan needs to allocate additional funding for increased waiver slots to reduce the number on the waiting list for the MI Choice waiver.
- All states without a Medicaid Buy-in policy should adopt one to reduce work disincentives for persons with disabilities.
- The state-federal Vocational Rehabilitation program should be given incentives to work with more difficult-to-place job seekers, such as individuals with severe disabilities.
- State and federal requirements for accurate accounting of waiver expenditures must be adjusted to ensure the flexibility required for self-direction, such as moving funds across budget line items to address participants' needs.
- State and federal policies are needed to address the negative impact of workforce shortages and rising transportation costs on access to home and community-based services.

- The Deficit Reduction Act, which created the §1915(j) authority, requires that financial management services be paid as an administrative expense, with a federal match of 50 percent. For states with higher service match rates (e.g., 70 percent in Montana), a 50 percent match rate for FMS limits the State's ability to expand the IP model to State Plan services. A statutory change is needed to allow FMS to be reimbursed at the service rate.
- Asset rules for Medicaid eligibility should be liberalized for individuals with permanent and significant disabilities who want to work and become independent. Florida needs to obtain a waiver from CMS that will permit participants with Individual Development Accounts (IDA) who transition to Disabled Adult Child/Title II eligibility to have IDA assets disregarded when determining eligibility for Medicaid. Such an approach is used for accounts established under the federal Assets for Independence Act (AIA). Eligibility for public benefits is not affected by AIA accounts and should not be affected by IDAs. (More information about AIA accounts can be found at the following site: <http://www.acf.hhs.gov/programs/ocs/afi/assets.html>.)

CMS

Several recommendations were addressed to CMS specifically.

- CMS should recognize that an individualized process to address emergency backup needs and critical incidents is the most appropriate method for ensuring health and welfare in self-direction programs.
- CMS should have a process to ensure that changes in HCBS policy—as communicated in Olmstead Updates to State Medicaid Directors—are integrated into the §1915(c) HCBS waiver application template and instructions.
- CMS should continue to provide grants to states to help improve the HCBS system for people of all ages with disabilities. Without the IP grant, the state would never have developed the IP waiver program.

Section Two. Individual IP Grant Summaries

Colorado

Primary Purpose and Major Goals

The grant's primary purpose was to improve Colorado's emergency backup and critical incident management systems to better support self-direction in Medicaid programs. The grant had two major goals: (1) to strengthen and build upon existing capacity to establish statewide emergency backup and critical incident management systems for all current and future self-direction programs, and (2) to develop training mechanisms for critical incident management and emergency backup systems.

The grant was awarded to the Department of Health Care Policy and Financing, the state Medicaid agency.

Role of Key Partners

Service users and stakeholders reviewed grant products and outreach materials; participated in planning meetings, focus groups, and committees; responded to surveys; served as peer mentors; developed outreach materials and evaluations; pilot tested outreach materials; and attended grantee-sponsored conferences.

Major Accomplishments and Outcomes

- Grant staff conducted research to determine how other states operate statewide systems for emergency backup and critical incident management in self-direction programs. In addition, a consultant was contracted to conduct six focus groups statewide with participants in Medicaid waiver programs—including some who are self-directing services—their family members, and representatives when appropriate.

Grant staff also conducted key informant interviews with other stakeholders within Colorado's current systems for emergency backup and critical incident management, including current and former staff at the Medicaid agency, the Department of Public Health and Environment, the Board of Nursing, single entry point agencies, service provider agencies, Adult Protective Services, the Division of Developmental Disabilities, the Division of Child Welfare, and Community Centered Boards, as well as advocates.

Based on the findings from these activities, grant staff submitted a report to CMS recommending that rather than a statewide system, an individualized approach to emergency backup and critical incident management is the most appropriate way to ensure participant safeguards in self-direction programs. They also recommended creating a registry of attendants who would be available to provide backup services, and conducting outreach activities to educate police officers and firefighters on how to support people with disabilities during emergencies. Such efforts would significantly support participants in self-direction programs while maintaining their independence, choice, and control.

- Although Colorado's self-direction programs already have mechanisms for participant safeguards that have demonstrated a high level of participant satisfaction, grant staff determined that some improvements were needed to better support participants in meeting emergency backup needs and preventing and dealing with critical incidents. Acting on recommendations from participants and other stakeholders, grant staff developed individual backup worker plan and critical incident management tools in print and electronic versions. The tools are available for single entry point agencies, Independent Living Centers, consumer advocates, and all Medicaid waiver participants who use personal care services.

Peer trainers piloted the tools with new Consumer Directed Attendant Support (CDAS) program applicants during the training conducted prior to enrollment. The tools were then incorporated into the CDAS training manual and enhanced training modules were developed, including those on preventing critical incidents; minimizing risk of identity theft, personal property theft, and legal exploitation; planning emergency backup; preparing for community-wide disasters; and preparing a health care emergency guide in case of unconsciousness.

- Grant staff conducted five statewide regional conferences to inform service users and other stakeholders about the availability of self-direction options and to provide training in workshops that incorporated the new tools developed by the grant. The conferences generated calls from potential In-Home Services and Supports³ providers and participants, an increase in case manager referrals to the CDAS program, and a 25 percent increase in CDAS applications.

Enduring Systems Change

Because of the successful implementation of the CDAS program (prior to the grant) and the support of the Independence Plus (IP) grant and other Systems Change grants, the State enacted legislation in 2005 directing the state Medicaid agency to add a self-direction option to all Colorado HCBS Medicaid waiver programs. The backup worker plans and critical incident management protocols developed through the IP grant will be part of the training for the self-direction option. In addition, although the tools were initially designed for participants in self-direction programs, slight wording changes have enabled waiver participants receiving services through agencies to also use these tools.

Key Challenges

Grant staff found that the lack of accessible transportation, particularly in rural areas, made it impossible for some service users to participate in focus groups, meetings, and conferences. Although scholarships were available to cover transportation, attendant costs, and lodging, fewer service users requested them than expected. Teleconferencing alleviated but did not solve the problem completely, because it is more difficult to communicate information and to identify who is speaking in teleconferences. Video-conferencing is

³ In-Home Support Services is an agency-with-choice model available to clients enrolled in either the Elderly, Blind, and Disabled waiver program or the Children's waiver program.

another alternative, but equipment may not be in an area that service users can reach easily.

Continuing Challenges

- It has been difficult to find an independent organization to manage a registry of attendants who are available 24 hours per day, 7 days per week, for short-term backup care. After two organizations reviewed the systems requirements for managing and maintaining an online registry of attendants, both declined. A grassroots community group offered to develop and support an attendant registry website to provide information and referral services for persons with disabilities, but it has not yet done so.
- Lack of accessible transport presents a continuing barrier to independent living in the community.

Lessons Learned and Recommendations

- An individualized process to address emergency backup needs and critical incidents is the most appropriate method for ensuring health and welfare in self-direction programs.
- Use a collaborative approach when designing systems change initiatives to involve all people with a stake in the outcome.
- Ensure that the resources participants need to succeed in self-direction are provided through training, and incorporate participant and peer trainer input to ensure that training materials and presentations are effective, useful, and meet participants' needs.
- Educate long-term services and supports professionals in the community, some of whom are unfamiliar with the self-direction model or may have long-held negative views regarding the ability of people with disabilities to direct their services.

Key Products

Educational Materials

A brochure was created using feedback from consumer focus groups, peer trainers, and other stakeholders: *Emergency Backup & Safety and Prevention Strategies: Resources for People Who Use Attendant Services and Manage Their Own Care*. It provides strategies such as planning for backup care, preparing for attendant support during a community-wide disaster, how to minimize risk of theft, and provides a form for emergency health care instructions. The brochure is available on the HCBS website at <http://www.hcbs.org/moreInfo.php/doc/1654>.

Reports

- The focus group consultant produced a report, *Improving Infrastructure: Voices of Attendant Services Users*, that identified the strengths and weaknesses of the Colorado long-term care system from the service user's point of view. The report also specified what to include when defining a critical incident and developing an emergency backup

system, and recommended ways to improve the self-direction infrastructure. The report is available on the HCBS website at <http://www.hcbs.org/moreInfo.php/doc/1561>.

- Grant staff produced a report, *Improving Emergency Backup and Critical Incident Management for Consumer Direction*, summarizing information gathered from the key informant interviews and consumer focus groups, as well as research on other states' initiatives. The report provides recommendations for the Department and outlines an implementation plan for the recommendations. The report is available on the HCBS website at <http://www.hcbs.org/moreInfo.php/doc/1560>.

Connecticut

Primary Purpose and Major Goals

The grant's primary purpose was to enhance the ability of individuals and families to self-direct their supports by developing new individual budgeting mechanisms and resource allocation strategies. The grant had four major goals: (1) to establish a valid and reliable methodology to determine participants' level of need (LON) and to compute associated costs; (2) to initiate an individual budgeting process that incorporates the new LON assessment methodology and resource allocation strategies; (3) to prepare an application for a new Independence Plus (IP) waiver and an amendment to the State's existing Mental Retardation (MR) waiver program that includes the new assessment methodology and individual budgeting mechanisms; and (4) to disseminate information about the project's findings, methodologies, and outcomes in order to enhance self-direction options in other Connecticut waiver programs, and to facilitate knowledge sharing and reduce duplication of efforts across state entities.

The grant was awarded to the Department of Mental Retardation, later renamed the Department of Developmental Services (DDS).

Role of Key Partners

- A grant Steering Committee—comprising family members and service users, and representatives from DDS, state agencies, provider associations, and self-advocacy groups—guided the research, design, and implementation of the new instrument to determine level of need for supports for all DDS participants.
- The Department contracted with an independent research team, the University of Connecticut Health Center, to assist in the development of the methodology to determine level of need.

Major Accomplishments and Outcomes

- Grant staff developed a LON assessment and risk screening tool and completed validity and reliability studies on the tool. The tool is used to evaluate a person's level of need for eight different support categories, to establish funding levels for annual individual budgets, to determine acuity-based rates for providers based on the person's level of need in day and vocational services, and to identify potential individual risk factors for care planning. The tool also has an automated report function that provides a summary for the team developing the individual service plan. The State requires that the assessment and risk screening be reviewed and updated annually by the case manager, if needed.

As part of the LON tool development, the University of Connecticut Health Center examined other states' assessment and funding methods, reviewed relevant literature, and conducted focus groups and key informant interviews with people selected for their

first-hand knowledge about DDS: service users, family members, policy makers, providers, case managers, direct care staff, and specialists such as medical staff, psychiatrists, and behavioral specialists. Draft surveys followed by field tests and statistical analysis led to modifications and changes in the tool and its administration. This process was repeated multiple times in a 2-year period.

- Grant staff produced a funding algorithm for generating individual budgets, using historical cost data, and analyzed the impact of the algorithm on day and vocational services. The algorithm generates an individual budget allocation based on statistical analyses of data representing all the people in the DDS system who are receiving services. All individuals receiving DDS services or on its waiting list have had an LON assessment for fiscal analysis and planning purposes; funding estimates have been provided for fiscal forecasting.
- Grant staff made presentations on the LON tool during National State Directors of Developmental Disabilities Services conference calls, and the tool has been adopted by a Connecticut DDS pilot program to serve adults with autism spectrum disorder.

Enduring Systems Change

- The State began using the grant-produced LON assessment/risk screening tool and associated individual budgeting mechanisms in 2006. An interim electronic LON database is operational, and a new web-based data application deployment was anticipated by the end of 2008. The amount of departmental funding available for services and supports is a political/legislative decision, therefore the budget methods developed through the grant cannot ensure an adequate overall supply of funding.

However, having one valid statewide assessment tool and reimbursement schedule has enabled the State to distribute funding more equitably across all DDS program participants. Additionally, because the models allocate funds precisely, they can be used to equitably increase or decrease funding. They also provide a method to generate an individual budget that is portable.

- Grant staff wrote the application for an Independence Plus waiver called the Individual and Family Support (IFS) waiver, which introduced in-home, flexible services for children and adults with mental retardation. In January 2005, the State received approval both for the IFS waiver and to replace its MR waiver in order to add individual budgeting and flexible supports under a Comprehensive Supports waiver. The LON assessment tool and budget methodologies are used in both waiver programs.

As of spring 2007, approximately 600 participants had enrolled in the self-direction option of the IFS waiver, and approximately 300 had enrolled in the self-direction option of the Comprehensive Supports waiver. Interim individual budgeting methods are in place to support self-direction in both new waiver programs while the State moves from capitated funding for limited service options to a fee-for-service system that allows participants to choose from a larger service array. The revised and updated LON and

budget methodologies were incorporated into the IFS waiver renewal submitted in September 2007.

Key Challenges

- Changing the traditional service delivery system—particularly moving from capitated program-based MR services to individual budgets—represented a major paradigm shift, which has made it difficult for participants, families, and providers to understand the new system. Some providers became concerned about the impact of the LON assessment on their reimbursement, and some families were concerned about its impact on the type of service options that would be available to them.

Grant staff worked with the provider community to engender trust and confidence in both the support needs determination and the funding methodologies by offering information sessions and ongoing communication about systems implementation issues and by including providers in a work group to address rate modifications. Provider input was also sought for modifications to be included in the renewal applications for both new waivers.

Grant staff also worked to adequately support participants and families who choose self-direction and to educate them about the benefits of more flexible supports in the new self-direction paradigm.

- Developing an assessment protocol that all stakeholders considered to be valid and to accurately reflect all of the factors influencing support needs required extensive testing and modification to gain the confidence of the majority of the stakeholders.
- Developing the web-based application required more time and staff resources than anticipated, delaying rollout of the final version of the LON tool and algorithm.

Continuing Challenges

A recent lawsuit settlement requires the State to serve 150 individuals on the waiting list each year with an average expenditure of \$50,000. Given the State's fixed budget for DD services, it is challenging to serve new individuals as well as current waiver participants, some of whom are aging and need additional services. The increased demand combined with the funding limit requires the State to continually forecast expenditures because they can have an impact on the resource allocation methodology and the resulting amount of individual budgets.

Lessons Learned and Recommendations

- Extensive inclusion of all stakeholders at the outset is critical and can be achieved through focus groups and key informant interviews. Input from participants and families enabled grant staff to understand the factors that influenced the level of support needed, and, at the same time, it was beneficial for participants to hear about provider concerns and the limitations of the DD system.

- The use of an independent research group is very effective when systems change efforts are contentious (e.g., when stakeholders disagree on the factors that influence support needs), but researchers who are unfamiliar with developmental disabilities services may have difficulty understanding the complexities of the DD system.

Key Products

Educational and Outreach Materials

Grant staff presented information to legislators, participants, and stakeholders about the opportunities and challenges of self-direction options in Medicaid waivers. They also produced and distributed guides for participants and families: *Understanding Connecticut's Department of Mental Retardation HCBS Waivers* and *Understanding Your Hiring Choices*.

Technical Materials

The grant project produced a LON assessment and risk screening tool, an electronic data application, funding methodology and algorithms, and the *Connecticut Level of Need Assessment and Screening Tool Manual*. The manual was developed to assist the case manager in completing the LON assessment and to help program participants and members of the care planning team to understand the LON process. The tool and the manual were updated based on findings of an analysis of the first 12 months of service use during the grant project.

Reports

Final reports by the University of Connecticut Health Center include *Connecticut Level of Need and Resource Allocation: Development of Funding Mechanisms*, and *Connecticut Level of Need and Resource Allocation: Development of an Assessment Tool*.

Florida

Primary Purpose and Major Goals

The grant's primary purpose was to enable individuals with developmental disabilities who were currently enrolled in Consumer-Directed Care Plus (CDC+)—a cash and counseling demonstration program—to become more independent through an asset development and self-determination project. The grant project, called Florida Freedom Initiative (FFI), had three major goals: (1) to secure a waiver from the Social Security Administration (SSA) that would allow CDC+ participants to have increased levels of income and assets without jeopardizing their Medicaid or Social Security benefits; (2) to train relevant state agency staff and consultants statewide to have a working knowledge of FFI program features, and to provide specialized knowledge in this area to six staff members working directly with FFI participants; and (3) to evaluate the effects of the SSA waiver, including the cost-effectiveness of increased flexibility and the reduction in work disincentives.

The grant was awarded to the Florida Agency for Persons with Disabilities (the Agency), formerly the Department of Children and Families. The project was undertaken as a cooperative effort with the Florida Developmental Disabilities Council and the Agency for Health Care Administration, with additional support from the Agency for Vocational Rehabilitation, the Advocacy Center for Persons with Disabilities, and the Center for Self-Determination.

Role of Key Partners

- The Center for Self-Determination was contracted to conduct an independent evaluation of the grant project and was involved in training, curriculum development, and outreach.
- The SSA provided training, technical assistance, and consultation on work incentives.

Major Accomplishments and Outcomes

- The grant project secured a waiver from the Social Security Administration under Section 1902(a)(10)(c)(i) to allow CDC+ participants who receive SSI and are enrolled in the Florida Freedom Initiative to keep more of their earned income if they work. The waiver also allows them to save earned income (up to \$10,000 per year) in special Individual Development Accounts (IDAs) without affecting their eligibility for SSI and SSI-linked Medicaid. The funds in IDAs can be used to increase independence, for example, by purchasing assistive technology, innovative employment supports, workplace supports, and transportation. They may also be used to develop a small business, pay for post-secondary education—including college or trade school—or to purchase or lease a home.

The SSA waiver was granted for only 3 years, which ended February 28, 2007. The SSA did not renew the waiver to allow enrollment of new participants in FFI but continued limited benefits to the 35 participants already enrolled, permitting them to continue

saving in an established IDA for 5 years without confronting the barrier of asset limitations; additionally, earned income deposited into these accounts would be overlooked as income for the purposes of calculating the SSI check. However, the ability to save has been reduced because the participants have a lower net income due to the cutback of the income disregard.

- Grant staff worked closely with the state Medicaid agency to develop rules allowing increased flexibility in CDC+ budgets for FFI participants. For example, one rule allows participants to use up to \$1,500 of their budget to develop a microenterprise (a small business with fewer than five employees and an initial investment of less than \$25,000). Another rule permits the purchase of a vehicle using CDC+ budgets. FFI participants can save this money from their CDC+ budget through service efficiencies or the use of natural supports. Savings from individual budgets cannot be commingled with savings from earnings in IDA accounts. However, purchases may be made combining funds from the two accounts.
- Six employment coordinators were hired as FFI program staff. The use of employment coordinators was a key innovation of the FFI program, and the job requirements were high. The coordinators received intensive training on a wide range of public and private programs that could improve the lives of people with disabilities, and they established working relationships with these programs in order to guide FFI participants through the decision-making process required to (1) expand their control over their personal budgets, (2) build assets, and (3) make choices that improve their quality of life. The coordinators also developed a variety of outreach and educational approaches to recruit FFI participants and identified 35 suitable CDC+ participants to enroll in the program.

All of the current FFI participants have IDAs, and several are working toward asset development goals. Examples of microenterprise business plans that participants have developed are (1) a plan to provide recycling services to local businesses, agencies, and organizations; and (2) a plan to offer bulk vending of high-quality snacks to local businesses. A period of 4 to 5 years is anticipated for participants to reach their goals. However, some participants have already achieved their goals. For example, one employment coordinator reported working with 12 participants, 2 of whom found better jobs, 1 bought a house, 1 started college, and 1 was developing a microenterprise.

- Grant staff educated support brokers, advocacy groups, providers, and policy makers about consumer direction, self-determination, and the broad authority provided under research and demonstration waivers, with a specific focus on the SSA waiver of the income and asset rule. In addition, the State used general revenues and funds from a Medicaid Infrastructure Grant (MIG) to provide intensive training to FFI and other agency staff about work incentives, supported employment, and public benefits. The MIG grant funded five of the six employment coordinators who were hired to work with FFI participants, and the Independence Plus (IP) grant funded the other.
- The grant provided the impetus to develop a work group that is advocating for the adoption of Medicaid Buy-in legislation in Florida.

Enduring Systems Change

- The FFI project increased awareness among multiple state agencies of employment barriers, how they can be addressed through Medicaid Buy-in legislation, and the importance of widespread dissemination of Social Security Work Incentive information to all professionals serving individuals with disabilities.
- The State now has a network of trained state staff and consultants available to supplement the information provided by SSA benefits planners about work incentives and public benefits. This network is continuing outreach, training, and education activities related to benefits planning. The network includes staff in the Agency for Persons with Disabilities, in the Division of Vocational Rehabilitation, the state Department of Children and Families, and independent professionals throughout the State who have contact with Medicaid participants with disabilities who work.
- The State is funding the project coordinator and five employment coordinators to continue working with the FFI participants who are currently enrolled and grandfathered for 5 years.

Key Challenges

- The expiration of the SSA waiver effectively terminated the initiative before the State could measure the individual outcomes and benefits of the system reform. Although it is unclear why the SSA declined to renew the waiver in Florida, one factor may have been the small number of individuals enrolled in what was expected to be a major breakthrough in the employment of persons with significant disabilities. Nonetheless, the problems that FFI sought to address continue and undoubtedly will lead to demonstrations with similar goals in the future. Key challenges encountered during the project include the following:
 - difficulty securing multi-agency buy-in to the project’s vision and goals;
 - lack of Medicaid Buy-in legislation in Florida;
 - lack of sufficient interagency collaboration; and
 - lack of high-quality benefits planning assistance for individuals with significant disabilities who can earn moderate incomes but need Medicaid coverage.
- Because SSI eligibility automatically confers Medicaid eligibility, the SSI “overlook” of the FFI Individual Development Account ensured that SSI-related Medicaid would continue regardless of the amount of funds in the FFI account. However, FFI participants could become ineligible for Medicaid if a parent died and the participant became eligible for Adult Disabled Child Social Security survivor benefits and the Individual Development Accounts funds were not expended immediately. Medicaid coverage is not automatic for Title II/Disabled Adult Child (DAC) and individuals must apply for eligibility and meet the State’s financial eligibility criteria for income and asset limits, which do *not* exempt the FFI account.

In fact, a parent of an FFI participant did die during the course of the project, and the participant became eligible for Adult Disabled Child Social Security survivor benefits, effectively ending this individual's participation in the FFI program. As a Title II/DAC Medicaid participant, the individual was no longer exempt from the State's \$2,000 asset limit for Medicaid, and the Individual Development Account was counted as an asset. This problem was recognized too late in the project to pursue a waiver from CMS so that the affected participant's IDA funds would not count toward Medicaid asset limit for non-SSI participants.

Continuing Challenges

Social Security disability programs are based on the assumption that an individual is unable to earn income. Although SSI has relatively generous earned income limits once eligibility is established initially, several unavoidable types of life events—such as the death of a parent—can lead to a sudden change from SSI eligibility to Title II/DAC eligibility. Earned income limits are much lower for Title II/DAC beneficiaries, and exceeding these limits leads to loss of cash benefits, Medicare, and Medicaid. Therefore, even current SSI participants who have generous earning limits must include in their career planning the likelihood that they will at some time face sharply reduced earnings limits. Employer-based health care coverage is typically inadequate to provide the level of care and personal assistance needed by individuals with severe and chronic disabilities, so steps to ensure continued Medicaid eligibility is critical in long-term planning.

Lessons Learned and Recommendations

- When seeking to bring about comprehensive systems change, it is best to pilot initiatives first at the local or regional level. Working with the multiple systems that serve individuals with disabilities who choose to earn income is a daunting task. In retrospect, the grant's goal was unrealistic: bringing about systems change in multiple agencies at the local, regional, and state level in a very large state.
- To obtain buy-in for a program such as FFI, policy makers need to be convinced that asset building has the potential to reduce the demand for public resources by making individuals with disabilities more independent.
- Florida needs to enact a Medicaid Buy-in policy to reduce work disincentives for persons with disabilities. All states without a Buy-in policy should adopt one.
- Asset rules for Medicaid eligibility should be liberalized for individuals with permanent and significant disabilities. The State needs to obtain a waiver from CMS that will permit participants with IDAs who transition to Title II/DAC eligibility to have IDA assets disregarded when determining eligibility for Medicaid. Such an approach is used for accounts established under the federal Assets for Independence Act (AIA). Eligibility for public benefits is not affected by AIA accounts and should not be affected by IDAs. More information about AIA accounts can be found at the following site:
<http://www.acf.hhs.gov/programs/ocs/afi/assets.html>.

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- The state-federal Vocational Rehabilitation program should be given incentives to work with more difficult-to-place job seekers, such as individuals with severe disabilities.

Key Products

Outreach and Educational Materials

- Grant staff produced multiple recruitment materials.
- Grant staff produced a variety of educational materials, primarily related to earned income and SSI, SSDI, and Medicaid benefits. These resources continue to be widely distributed.

Reports

- Grant staff collaborated with the Center for Self-Determination to produce a project evaluation report, titled *The Florida Freedom Initiative: Lessons Learned From an Innovative Experiment*. The report describes the program and discusses the many factors that influence employment of individuals with disabilities. It also discusses how these factors affected the grant initiative.
- Grant staff produced (1) informal analyses (e.g., for the Agency's legislative affairs unit) of the need for a Medicaid Buy-in policy to eliminate work disincentives for individuals with disabilities, and (2) informal as well as formal analyses of the work disincentive posed by Medicaid's financial eligibility criteria.

Georgia

Primary Purpose and Major Goals

The grant's primary purpose was to bring about systems change that supports self-directed community-integrated living for people of all ages with disabilities, with a particular focus on four HCBS waiver programs in Georgia.⁴ The grant had five major goals: (1) to develop a uniform methodology to calculate all individual budgets in the State, (2) to adapt the State's Quality Assurance/Quality Improvement (QA/QI) system for the various waiver programs to ensure necessary safeguards for the health and welfare of participants in self-direction programs, (3) to design a self-determination pilot for adults with serious mental illness that builds on peer supports, (4) to design key operational functions of the self-directed services delivery system, and (5) to develop a self-determination master plan that incorporates the components of the self-directed services system and procedures for accessing the system. The master plan was intended to assist the State in the transition to a self-directed services system and includes specific recommendations for completing CMS's Section (§) 1915(c) waiver application (Version 3.3, October 2005) in regard to participant direction of services.

The grant was awarded to the Department of Human Resources (DHR), which contracted with APS Healthcare to provide technical assistance to DHR during the grant period, and to produce several reports for the Division of Mental Health, Developmental Disabilities, and Addictive Diseases/Office of Developmental Disabilities.

Role of Key Partners

- Stakeholder committees were formed for each grant initiative—the QA/QI system, individual budgeting, and the key operations master plan—to provide input into the design of the self-directed services system and to produce reports on each initiative. The committees included representatives from the DHR Division of Mental Health, Developmental Disabilities, and Addictive Diseases; the DHR Division of Aging Services; the Department of Community Health; and self-advocates and family members of waiver participants.
- Grant staff partnered with the Medical College of Georgia to train psychiatric residents in Augusta, Georgia, to utilize Certified Peer Specialists to facilitate self-directed recovery.
- Grant staff collaborated with Georgia's QA/QI grant staff to enhance the State's existing HCBS QA/QI system to incorporate the Independence Plus (IP) program's QA/QI principles and standards.

⁴ The Independent Care Waiver Program, for persons with physical disabilities and/or traumatic brain injury; the Community Care Services Program, for elderly persons and/or those who are functionally impaired/disabled; and the Mental Retardation Waiver Program and Community Habilitation/Support Services, for persons with developmental disabilities.

- Grant staff collaborated with Georgia's Real Choice grant staff on initiatives regarding direct care staff and peer support development as they relate to the self-directed services delivery system.

Major Accomplishments and Outcomes

- Grant staff developed a model of collaboration that included multiple state government and private agencies, community-based agencies and organizations, persons with disabilities and their families, and advocates to plan and develop self-direction policies and procedures across systems serving different disability populations. This collaborative approach resulted in a comprehensive design that minimized duplication while allowing for design differences when needed.

For example, grant staff and stakeholders found that addressing the needs of specific populations required different approaches to training. For elderly persons and adults with physical disabilities, training was conducted for case managers who work one-on-one with waiver participants. For persons with developmental disabilities, the many people who provide their services and supports—families, intake workers, peer support—all received training.

- Grant staff coordinated with agencies developing a Direct Support Professional Certification program in association with community colleges to ensure that it included information about the self-directed services delivery system. In addition, grant staff conducted statewide training that provided information on how peers can help waiver participants and their families to assume self-direction responsibilities.
- Grant staff designed a pilot self-determination program under the Medicaid rehabilitation option for adults with serious mental illness, which includes peer support to help clients articulate their personal recovery goals. Grant staff obtained additional funding to implement and evaluate the pilot. The pilot bills peer specialist services under the Medicaid Rehabilitation Option, which covers Peer Support Service.

Enduring Systems Change

- The State amended three waiver programs to add self-direction of personal care services: (1) the Community Care Services Program for elderly persons and/or those of any age who are functionally impaired/disabled, (2) the Independent Care Waiver Program for persons (adults 21–64) with physical disabilities and/or traumatic brain injury, and (3) the Mental Retardation Waiver Program (MRWP) for persons with developmental disabilities.

Participants who elect to use the new self-direction option will be able to hire their own workers, receive both case management and support broker services from a case manager, and use financial management services. In addition, MRWP participants may choose to have an individual budget for services other than personal care.

The State's experience in implementing self-direction in the three waivers informed the development of a renewal application for the MRWP, which included a request for IP designation and renaming as the New Options waiver. The application was submitted to CMS on July 5, 2007, and approved effective October 1, 2007.

In addition, the State is amending the Community Habilitation/Support Services waiver program for persons with developmental disabilities who have intensive and comprehensive supports needs to provide an option for them to self-direct most of their waiver services. The amended waiver program will be renamed the Comprehensive Supports waiver.

Prior to receiving the IP grant, Georgia did not have a self-directed services option in any of its waiver programs.

- Following recommendations from grant staff and stakeholders, the State decided that person-centered planning would be used in all waiver programs, whether participants choose a traditional service model or a self-directed services model.
- Grant staff developed a computerized system that incorporates data on past service use and current cost data to use with the formula for calculating individual budgets. They also designed operational procedures and policies for self-directed services, including procedures for budget reviews, modifications, and redeterminations; monitoring, public inspection, and audits; backup plans; and use of unexpended funds.
- Grant and agency staff designed a financial management waiver service for participants who choose to self-direct allowable waiver services, and established an enrollment and payment process. In addition to providing the financial services, the fiscal agent facilitates a criminal records check on potential employees before they are hired in the self-direction system.
- Grant staff developed a process to recruit, train, and certify support brokers. Although support broker services initially are being provided by traditional case managers, the State plans to have a system of independent support brokers (i.e., someone other than a waiver case manager) by separating case management services from support broker services. Initially covered as an administrative expense, support broker services will be covered as a waiver service when they are provided independently from case management. When support brokerage becomes an independent waiver service, participants will pay for this service out of their individual budget allocation.
- Grant staff conducted stakeholder meetings and focus groups throughout the State to obtain input on modifications needed in the State's QA/QI system to enhance the safety of participants in the new self-directed services delivery system. They addressed the issues of critical incident management, emergency backup plans, and hiring practices, as well as the need for education and training for both participants and direct care workers.

As a result, grant staff developed a list of critical incidents specific to self-direction and worked with the DHR Information Technology Division to incorporate the information

into DHR's current incident management program. Grant staff also recommended policies and procedures for developing individual worker backup plans to address needs specific to each waiver participant; these have been implemented.

Key Challenges

A specific implementation challenge was transitioning current waiver participants from the traditional service systems to an individual budget without disrupting services or funding, because in some instances implementing the individual budget formula led to a decrease in the amount of the individuals' budgets. This issue is being addressed through a transition process in which historical funding initially contributes more to determining the amount of the individual budget but decreases over time. This process ensures that current waiver participants will not experience a disruption in services when they switch to an individual budget.

Continuing Challenges

- Workforce shortages and rising transportation costs reduce access to home and community services.
- Combining flexibility in self-direction programs with state and federal requirements for accurate accounting of waiver expenditures is challenging.

Lessons Learned and Recommendations

- Consistent and continual communication with all waiver program stakeholders is critical in creating a comprehensive and successful self-directed services option. A collaborative approach to planning and developing self-determination policies and procedures across systems serving different populations results in a comprehensive design that minimizes duplication while allowing for design differences as needed.
- The availability of grant funding targeted for technical assistance (TA)—in particular, state-specific TA—is vital for implementing policy and procedural changes.
- The success of a self-determination program depends on the availability of trained workers.
- CMS should have a process to ensure that changes in HCBS policy—as communicated in Olmstead Updates to State Medicaid Directors—are integrated into the §1915(c) Home and Community-Based waiver application template and instructions.
- State and federal requirements for accurate accounting of waiver expenditures must be adjusted to ensure the flexibility required for self-direction, such as the movement of funding across budget line items to address participants' needs.
- State and federal policies are needed to address the negative impact of workforce shortages and rising transportation costs on access to home and community services.

Key Products

Educational Materials

- APS Healthcare produced the *Consumer and Family Guide to Consumer Self-Direction in the State of Georgia Medicaid Waivers*, a user-friendly booklet that provides basic information about self-directed services options and enrollment in the State. The Guide also covers information about individual budgets: the methodology used to calculate them, and processes and procedures for their use.
- A grant-funded TA contractor produced a flow chart describing the process for participants to direct their waiver services.
- Grant staff produced presentations on the self-directed services delivery system for service users, families, support coordinators/brokers, regional and state office staff, and providers.

Technical Materials

The grant TA contractor produced the Independence Plus Initiative–Individual Budget Software Program, a CD containing the formula, algorithm, and software program for calculating individual budget allocations based on service use and cost data. The CD also contains a user guide for individual use in formulating and calculating budgets.

Reports

- APS Healthcare produced *The Master Plan for Self-Directed Care through Georgia's HCBS Waivers*, a comprehensive overview and design of the key operational functions of a self-directed services delivery system for Georgia's HCBS waivers.
- APS Healthcare produced *Quality Assurance and Quality Improvement (QA/QI) for the State of Georgia's Self-Directed System of Care*, a report on Georgia's QA/QI system at the time of the IP grant project, which recommends adaptations and modifications for various HCBS programs to ensure necessary safeguards for the health, welfare, and safety of participants in the self-directed services delivery system.

Idaho

Primary Purpose and Major Goals

The grant's primary purpose was to enable individuals with developmental disabilities (DD) to exercise personal choice and control by directing their supports. The grant had four major goals: (1) to amend an existing Medicaid DD waiver to incorporate Independence Plus (IP) components in a new self-directed services option; (2) to develop an infrastructure to support participant direction of Medicaid services, including more flexible provider options; (3) to conduct statewide public education and training about self-determination for service users and providers; and (4) to develop a system of quality management and improvement employing the CMS HCBS Quality Framework.

The grant was awarded to the Department of Health and Welfare, Division of Medicaid.

Role of Key Partners

- The Idaho Task Force on Self-Determination was created in 2001 to develop the guiding principles for self-determination in the State. Its membership was expanded in order to serve as the advisory body for the IP grant and to develop the components of the new self-directed services program. The Task Force included self-advocates and family members; two state legislators; private service providers; staff from the Governor's office, Independent Living Centers, and the University Center on Disabilities; and representatives from the Departments of Health and Welfare, Education, and Vocational Rehabilitation, and the Idaho State School and Hospital.
- The Idaho Council on Developmental Disabilities (hereafter, the DD Council) coordinated and supported the Task Force on Self-Determination and also had responsibility for the public awareness and consumer education activities.
- The Idaho Self-Advocate Leadership Network, a group that is closely aligned with and trained by the DD Council, partnered with the Division of Medicaid to develop training and outreach materials, to review drafts of these materials (e.g., support broker training manuals), and to help orient and train individuals interested in directing their care. The self-advocates played a major role in training sessions across the State.

Major Accomplishments and Outcomes

- Grant staff developed a person-centered planning (PCP) process that identifies participants' needs and life goals and serves as the foundation of each person's service plan. Support brokers and a self-directed circle of support (i.e., informal caregivers such as family and friends who volunteer to share responsibility in providing support to the individual) take part in the PCP process and work with the participant to create a support and spending plan.

- Grant staff developed a scored assessment tool that provides an inventory of individualized needs and a methodology that translates these needs into costs to determine an individualized budget amount. This methodology is used to set budgets for participants who select the self-direction option as well as those who continue to use traditional services.
- The grant's financial management services (FMS) work group struggled with the tax and legal complexities in developing this IP component. After a long and arduous process, the State secured a provider—one with previous experience in providing financial management services in other states—to handle billing, accounting, and quality assurance responsibilities, and arranged for the service to be implemented on a fee-for-service basis.
- Grant staff developed a comprehensive quality management and improvement system that monitors quality in every component of the self-direction model. Procedures are in place to ensure that planning is person centered and based on choice, and that there is a backup plan for supports needed to ensure health and safety as well as methods to identify risks. Backup plans may also address community-wide emergencies, such as threatening weather, electrical outages, and other situations that raise safety issues; and participants' training emphasizes the value of a criminal background check for workers as a method to help ensure safety. In addition, grant staff developed a statewide critical incident reporting system, which includes training for participants on how to file complaints.
- The Grantee contracted with the University of Idaho to develop a training program for support brokers. One component of the training—available on the Department of Health and Welfare website—provides information about the philosophy of self-direction and extensive program information. The curriculum offers six modules: self-direction, support broker roles and responsibilities, person-centered planning, needed skills, ethics and professionalism, and resources. By making these materials available online, the program hopes to encourage the provision of support broker services in rural communities.

The contractor also developed a training curriculum that is presented face-to-face and addresses the program's policies, procedures, and operational features, which was provided in each of the State's regions. Individuals who want to be support brokers are required to pass an exam, but they are not required to take either of the training opportunities.

- The State wanted to establish a cadre of support brokers from which participants could choose but also wanted participants to be able to choose someone they knew to serve as their support broker. To achieve this goal, the State developed recruitment and training materials for both situations.
- The grant's training activities included regional teams of self-advocates using a train-the-trainer approach to deliver the curriculum to individuals choosing to direct their services. An unanticipated positive outcome was the formation of the Idaho Self-

Advocate Leadership Network. The network's original purpose was to provide a forum for the regional teams of self-advocates involved in the grant project. As the teams became active, they decided that they wanted their own organization and established the network. The network is continuing its training activities and is beginning to play a stronger role in policy development.

- Using grant funds, the DD Council designed and conducted a 10-day statewide bus tour of 35 communities, using self-advocates, agency staff, DD Council members, and others to raise awareness about the new self-direction option in the DD waiver and to obtain feedback about what is important in a self-directed services delivery system. In addition, the DD Council, in partnership with grant staff, created a sustainable training program for providers to increase their awareness of self-determination concepts and to help them move from the traditional service model that uses Medicaid service coordinators to a self-direction model that uses support brokers and a circle of support.

Enduring Systems Change

The grant enabled the State to implement a self-directed services option under the existing DD waiver program, which includes the IP design features of person-centered planning, individual budgeting, financial management services, support broker services, and participant protections. As a result, the infrastructure for future self-direction programs in Idaho has been established, including a rule authority for self-direction programs; an individual budget methodology that is cost neutral and used to set budgets for participants who select the self-direction option, as well as for those who continue to use traditional services; a contracted fiscal employer agent; and a web-based training curriculum for support brokers.

The new self-directed services option, called My Voice, My Choice, was piloted in three regions and then expanded statewide to adults served through the DD waiver, which allows participants to choose between traditional waiver services and self-direction. Participants may transition back to the traditional waiver service model if they want. At the end of the grant reporting period, 19 participants were directing their services under the My Voice, My Choice option. The State's target is for 25 percent of the nearly 3,000 DD waiver participants to choose self-direction over the next 5 years.

The My Voice, My Choice program will be evaluated every 6 months with a major focus on quality assurance, participant safety, and participant satisfaction. Evaluation results will be used to improve the program and to inform needed program revisions as the State considers expanding and enhancing self-direction in other programs, such as the Aged and Disabled waiver.

Key Challenges

- The major implementation challenge was to move from a provider-driven system to a self-direction approach. Some providers had difficulty accepting self-direction concepts, and, in particular, questioned the viability of a circle of support for certain clients. Also, ensuring participant safety while allowing flexibility proved difficult. For example, the

state legislature approved self-direction rules and regulations that allow participants to waive criminal background checks under certain circumstances (e.g., for chore services and outdoor work or for services provided by known relatives), which raised much concern among stakeholder groups. These issues were addressed through outreach, training, and stakeholder orientation.

- Developing a statistically valid model to determine individual budgets was challenging because the DD Council and other advocacy organizations demonstrated that an assessment score did not necessarily correlate with a participant's needs. In response, the State developed an individual budget tool that assigns a specific budget amount based on an individual's assessed needs.
- Getting companies interested in providing financial management services was a slow process. One reason for the difficulty was that the State wanted the FMS entity to be established so it could start providing services immediately, whereas some entities that were interested in providing services were new and needed funds for start-up and overhead costs, which Medicaid does not provide.
- Despite advertising through state venues, colleges, and the Medicaid agency, and providing training for families and legal guardians, the State initially certified only 2 individuals as support brokers, although eventually 19 support brokers were trained and certified.

Continuing Challenges

- Enrollment in the program has slowed. Many potential participants are taking a wait-and-see attitude before enrolling. Grant staff have heard that some are waiting for the "bugs" to be worked out of the various processes and want to see whether the program is successful for the initial participants. Program staff are working to develop creative marketing approaches to increase interest in the program.
- The State is facing some resistance to the program from traditional service providers and does not know whether this is slowing enrollment.
- Recognizing that Idaho is a rural state and resources and supports may be unavailable in some areas, the State anticipates that only a small proportion of waiver participants will shift to self-direction initially. Given this situation, support brokers might be unable to work full-time until the caseload grows, further hampering recruitment.

Lessons Learned and Recommendations

- Ongoing outreach and training is required to help stakeholders make the paradigm shift from a traditional service model to a self-direction service model.
- The value of involving self-advocates in the design and development of a program from the outset cannot be overstated. Supporting service users to be meaningfully involved discourages the spread of inaccurate information about a new program, reduces the

Key Products

Outreach Materials

- Grant staff developed flyers, brochures, and flow charts about the self-determination philosophy and the self-direction process to provide at open house informational meetings. They also developed a job description for support brokers that was posted in the Medicaid newsletter, in newspaper ads, in the DD Council newsletter, and in local universities.
- The DD Council developed outreach materials, including a 20-minute video documentary about self-direction in Idaho and two public service announcements promoting the new self-direction option in the DD waiver.

Educational Materials

- The DD Council developed training materials, including a manual entitled *The Guide to a Self-Directed Life*. The manual contains information about the tasks participants will need to perform to direct their services and supports in the My Voice, My Choice program, including how to manage their budget, choose services, hire and manage workers, and fill out required paperwork.
- Grant and University staff jointly developed a manual entitled *How to Be a Support Broker*, focused on program policies and procedures.
- Grant staff produced additional training materials that are available to both providers and participants and have been widely distributed across the State. These materials have helped to raise community awareness of self-direction as a concept. In addition to general exposure, participants are targeted and provided with self-direction materials during their annual redetermination for services.

Technical Materials

A variety of technical materials were produced through the grant project: (1) employment agreements for use with support brokers and community support workers; (2) a risk identification tool, a workbook, and a support and spending plan for use in the PCP process; (3) a Fiscal Employer Agent start-up packet for participants; (4) an evaluation form for community support workers; and (5) a Complaint Report form.

Louisiana

Primary Purpose and Major Goals

The grant's primary purpose was to incorporate the self-determination philosophy into all of the State's long-term services and supports programs. The grant had five major goals: (1) to create an Independence Plus Advisory Committee, (2) to amend policies and procedures within the long-term services and supports system based on the principles of self-determination, (3) to create an individualized backup and emergency preparedness system for the State's three existing Medicaid waivers and in the Long Term Personal Care Services (LT-PCS) Medicaid State Plan program, (4) to expand opportunities for home and community-based services (HCBS) program participants to earn income and own businesses in order to address unmet income needs, and (5) to develop a model for self-direction in the LT-PCS program in the Baton Rouge area based on the system developed under a prior Systems Change grant.

The grant was awarded to the Department of Health and Hospitals, Office of Aging and Adult Services (OAAS), formerly the Bureau of Community Supports and Services.

Role of Key Partners

- The Independence Plus Advisory Committee—comprising service users, families, and representatives from self-advocacy groups, state agencies, and provider associations—oversaw the grant project and assisted the project director with grant implementation. Representatives from the private business sector also served as Advisory Committee members and provided guidance and resources for the employment and microenterprise initiative.

The Advisory Committee formed three subcommittees to each work on specific grant goals: amend policies and procedures to conform to self-determination principles, develop an emergency backup system, and microenterprise development. The OAAS will continue to invite Advisory Committee members to serve on current and future committees for input on new and existing program development.

- The Arc of Louisiana was instrumental in developing a Microenterprise Revolving Loan Program and assumed the role of fiscal agent for the funds.

Major Accomplishments and Outcomes

- Policies and procedures in the New Opportunities waiver, the Elderly and Disabled Adults waiver, the Children's Choice waiver, the Program for All-Inclusive Care for the Elderly, and the LT-PCS State Plan program were revised to incorporate the self-determination philosophy. Although the New Opportunities waiver, which serves individuals with mental retardation and other developmental disabilities, had already offered a self-direction option, the waiver manuals needed to be updated to incorporate self-determination principles.

- Grant staff and subcommittee members of the grant's Advisory Committee developed participant satisfaction surveys to obtain feedback regarding the State's HCBS programs. Of the 500 surveys sent to 20 support coordination agencies, 433 were completed and returned to grant staff, who summarized the results in an Excel spreadsheet.
- Grant staff conducted statewide training for all Bureau of Community Supports and Services staff and support coordination agencies to incorporate the self-determination philosophy in program implementation and service delivery. In addition, members of the grant's Advisory Committee provided self-determination training related to fiscal procedures for all support coordinators and regional offices involved in the self-direction option that is available to New Opportunities waiver participants. The OAAS anticipates that some of the training materials will be used in future trainings with support coordination agencies and regional office staff when the new self-direction option in the Medicaid State Plan is implemented in 2009.
- The grant administrator conducted an evaluation of current emergency preparedness and backup worker plans, which included a review of 135 Comprehensive Plans of Care for Elderly/Disabled waiver participants throughout the State. The results of the evaluation demonstrated that although all participants had backup worker and emergency preparedness plans, the process for developing these plans differed from region to region. The OAAS is working to develop a new electronic version of the Comprehensive Plan of Care, which incorporates a section on personalized emergency preparedness and evacuation planning for all participants in HCBS waiver programs and the State Plan LT-PCS program. Once developed and implemented, its use will be mandated for all support coordination agencies.
- The grant administrator and consultants established a microenterprise revolving loan fund, including policies and safeguards for the use of those funds, and conducted three 2-day workshops on defining, developing, and implementing microenterprises. A total of 50 persons, 6 of whom were individuals with disabilities, attended the trainings. The microenterprise program provides an opportunity for persons receiving Medicaid waiver and/or State Plan services to apply for a small business loan of up \$1,000 to assist in opening up a new business or to assist with operational expenses for an existing small business.

By the end of the grant, no loans had been disbursed, mainly because of the State's inability to secure a fiscal agent to oversee and manage the disbursement of the loans. Recently, the Arc of Louisiana assumed the role of fiscal agent, and the Louisiana Small Business Development Center is working with it as a business partner to help implement the program. Grant staff are marketing the program to the support coordination agencies in Region 2 and have received the names of three persons interested in starting a business. The Arc of Louisiana is looking into alternative funding sources to sustain and expand the microenterprise program to eventually serve a larger geographic area and possibly offer loans greater than \$1,000.

- The OAAS contracted with consultants to assist in the design and development of a self-direction option to be implemented in the Medicaid State Plan LT-PCS program. A draft

of the Section (§) 1915(j) State Plan Amendment (SPA) was submitted to CMS for review in October 2007. CMS suggestions were incorporated and the final SPA was circulated for comments within the OAAS offices. The consultants completed drafts of the RFP for the fiscal agent, as well as draft program policies and forms. Grant staff worked with the consultants and Medicaid staff to finalize the SPA and all of these documents and forms. The OAAS intended to offer this program as an option in January 2009.

Enduring Systems Change

- Using the §1915(j) option authorized by the Deficit Reduction Act of 2005, the OAAS submitted the final draft of the application for the new self-direction option—LA Personal Options Program (LA-POP)—to CMS in November 2008. By amending the existing State Plan program, the State can ensure that if a participant voluntarily disenrolls from LA-POP, he or she will be able to transition smoothly back into the LT-PCS program. In spite of delays caused by Hurricane Gustav in September 2008, at the time the grant ended, the State was still hoping to implement LA-POP in January 2009.
- The grant project helped to create the infrastructure for the new self-directed services option for participants in the LT-PCS State Plan program for elderly persons and adults with physical disabilities, to be offered in 2009. This will be the second self-direction program within the State’s long-term services and supports system, the first being self-direction in the New Opportunities waiver. Members of the grant’s Advisory Committee reviewed and edited the draft policies that will guide the implementation of the self-direction option in the waiver and the self-direction option in the State Plan. The OAAS continues to modify all programs to include the self-determination philosophy by updating policies and manuals.
- The OAAS, in conjunction with the Department of Health and Hospitals Medicaid Management and Information Systems, developed an emergency backup preparedness system—the Resident Emergency Alert and Locator (REAL)—for every individual receiving Medicaid waiver or State Plan long-term services and supports. It began registering Medicaid beneficiaries residing in the coastal lying parishes of Louisiana in early spring 2008.

The REAL system includes a preloaded database and fingerprint recording system to identify Medicaid beneficiaries who may evacuate to area shelters in the event of a statewide or other emergency. By scanning the Medicaid beneficiary’s thumb or entering his or her social security number into the database, Department of Health and Hospitals staff and emergency shelter staff will be able to access the person’s emergency information, including his or her residency, next of kin, primary care physician, and medications. This will enable beneficiaries to obtain medical services in a timely manner during emergencies.

The REAL implementation plan also includes customized GEO-Tracking Software, which will allow staff to map available Medicaid and community resources and services by simply typing the Medicaid beneficiary’s ZIP code into the system. The identification of

available resources and services using this software will allow emergency personnel and staff to connect beneficiaries to needed services in a timely, more efficient manner. Through the grant project's purchase of 80 laptop computers, 80 fingerprint scanners, fingerprint scanning software development, and software licenses, the REAL system was ready for implementation for the 2008 hurricane season.

- Although the grant has ended, OAAS staff continue to work on implementing all of the grant initiatives and programs.

Key Challenges

- The reorganization of the Bureau of Community Supports and Services—which divided aging and developmental disabilities programs formerly housed in the same unit and led to the creation of the Office of Aging and Adult Services—called for numerous personnel changes resulting in the assignment of five different project managers during the grant period. The most recent hire (in April 2007) was delayed because grant funds were erroneously sent back to CMS, and contracts could not be secured until paperwork was submitted and money restored (July 2007).
- Hurricanes Katrina and Rita—and, more recently, Gustav—necessitated a shift in the grant staff's and the OAAS staff's focus to meet the immediate needs of persons receiving or in need of long-term services and supports, making it difficult to achieve the grant's goals and timelines.
- The State has faced considerable difficulty in obtaining workers' compensation coverage for participant-directed workers. The Louisiana Workers' Compensation Corporation stated that it would insure only the fiscal agent providing financial management services because it believed that the fiscal agent should be the statutory employer (i.e., the employer of record). In addition, the state Department of Labor declared that participant-directed workers fall under an exemption to the workers' compensation law.

Continuing Challenges

Obtaining secure workers' compensation coverage for all participant-directed workers remains a challenge that the State has continued to address.

Lessons Learned and Recommendations

Recruiting service users to participate in the grant's Advisory Committee meetings, even by conference call, proved difficult; those who did become members had difficulty finding time in their schedule to devote to Committee tasks. Grant staff addressed this problem by incorporating in the self-determination surveys an area for participants to complete if they would be interested in serving on a committee, and that information was catalogued for future use.

Key Products

Outreach Materials

- Grant staff and Advisory Committee members created brochures and flyers about the self-direction option in the New Opportunities waiver.
- Grant staff, with the input of stakeholders and community partnership agencies, created brochures, flyers, and program folders to market the microenterprise program in one region of the State, which will continue to be used as the program expands.

Educational Materials

A contractor developed self-determination training modules for state agency staff and support coordination agencies and also for the Advisory Committee self-direction work group. Grant staff and members of the Committee used the modules to conduct statewide trainings on how to incorporate the philosophy of self-determination into programs and service delivery.

Maine

Primary Purpose and Major Goals

The grant's primary purpose was to ensure that individuals and their families have sufficient information, training, and support to manage their own services as participants in a new Independence Plus (IP) waiver program. The grant had five major goals: (1) to implement an IP waiver program for adults with autism or mental retardation, in order to offer a broad range of flexible supports in keeping with the self-determination philosophy; (2) to develop materials that will help participants and their families understand their responsibilities and options within the IP waiver program; (3) to develop training materials to help participants make choices and participate actively in planning and managing their services; (4) to help support brokers to understand and perform their role in accordance with the philosophy of self-determination; and (5) to adopt policies regarding the use of representatives in self-direction programs.

The grant was awarded to the Department of Behavioral and Developmental Services (hereafter, the Department), which is now the Office of Adults with Cognitive and Physical Disabilities Services. The Department contracted with the Edmund S. Muskie School of Public Service, University of Southern Maine, to implement the grant.

Role of Key Partners

- The IP Advisory Committee—comprising service users, families, service providers, and Department of Human Services staff—worked with the Department and the Muskie School on all aspects of the grant project. Several work groups were formed to concentrate on the following specific areas: communications, training, financial management services, guardianship, and the waiver application. The work groups included people with mental retardation or other developmental disabilities, people with physical disabilities who currently self-direct their services, parents, and direct support professionals.
- The Office of MaineCare Services (Medicaid Agency) participated in the grant's Advisory Committee, helping the members to develop a vision to guide all initiatives and efforts to increase options for self-direction, including a self-direction waiver program.
- The Center for Community Inclusion (CCI) at the University of Maine consulted with grant staff on the development of a co-instruction model and training materials. Grant staff met regularly with CCI staff and local self-advocates to develop a self-direction training curriculum and related materials.
- Members of the Developmental Disabilities Council and staff from the Disability Rights Center served on the grant's Advisory Committee and helped develop training materials.

- The National Association of State Directors of Developmental Disabilities Services provided expert consultation on a number of topics, including personal budgeting, employer-employee agreements, and surrogate/representative policy.

Major Accomplishments and Outcomes

- The grant's overarching goal was the implementation of an IP waiver program for adults with autism and/or mental retardation. However, because the State was in the midst of an ongoing budget shortfall, it was not possible to implement an IP waiver during the grant period. Consequently, many of the planned grant activities relating to the development of the waiver program were not completed. The State is now considering amending a recently approved Support waiver to incorporate IP components.
- Grant staff worked with the Advisory Committee's work groups to develop a participant and family training package on several topics, including person-centered planning, managing personal budgets, being an effective employer, and selecting and working with support brokers and fiscal employer agents. They also worked to develop training curricula for support brokers that specifically address distinctions between support broker and case management services. These materials are still in draft format; when funding is available to implement self-direction in a waiver, the materials will be finalized.

Training materials and brochures about self-determination have had an impact beyond the grant. The process for developing them has been used to develop approaches for educating self-advocates about other topics—for example, how to deal with emergency situations. Also, they will serve as a model for developing training and forums under the Medicaid Infrastructure grant to educate people with developmental disabilities about employment changes in the State. The materials will also be used in various activities, including agency staff training and guardianship training under the Systems Transformation grant. Self-advocates will play a major role in all training activities to ensure that the consumer perspective is presented.

- Using a co-instruction model that includes service users in all phases of training—from developing to presenting—grant staff made presentations and conducted trainings and information sessions statewide about self-determination and self-directed services.

The co-instruction model was instrumental in educating department staff and service providers about the *abilities* of persons with mental retardation or other developmental disabilities and physical disabilities to take charge of their lives and direct their services. As a result, agencies and organizations—from the DHHS Office of Cognitive and Physical Disability Services to service provider agencies—are more receptive to initiatives to increase self-direction options.

- Self-advocates and grant staff recognized that the co-instruction model demonstrated during the grant period was extremely successful in engaging and informing service users. Prior to this grant, most trainings were conducted by professionals with *assistance* from self-advocates. The co-instruction model differs in that self-advocates

“co-train” with a professional trainer, often leading a large section of the training themselves. This training approach led to the creation of outreach materials that are understandable to all target audiences, using universal design principles that include plain language and age-appropriate pictures. This format has been and will continue to be modeled for all other outreach materials created by Developmental Services. Advocacy organizations and other grant projects also use this format.

- Grant staff worked to develop policies for individuals who need to have representatives assist them in order to participate in a self-direction program. Because this is a fairly new issue for the State, grant staff formed a work group that included individuals with disabilities, family members who are guardians, key disability-related organizations that frequently deal with guardians and guardianship issues, legal staff, and key state representatives.

After carefully reviewing the State’s guardianship policies and procedures for adults with developmental disabilities, the work group concluded that many guardianship issues are too complex for them to resolve. This feedback led the State to pursue and obtain a Systems Transformation grant in 2005 with one goal focused totally on educating various audiences about alternatives to guardianship in order to increase participant choice and control over services.

With a full guardianship, individuals lose all their rights and are unable to direct their own services. The goal of identifying alternatives to guardianship is to enable individuals with disabilities to make decisions and assume responsibilities. One alternative to *full* guardianship is *limited* guardianship, which preserves certain individual rights—such as the right to direct certain services—while limiting decision making in other areas.

Enduring Systems Change

- Grant staff initiated a new way to engage people with developmental disabilities in project development and are in the process of documenting this process in order to involve service users and other stakeholders in additional grant activities and policy developments. As a result, stronger relations with consumer and family advocate groups have been achieved, and their ongoing participation is more meaningful and collaborative.
- Even though the State is not submitting the IP waiver application at this time, grant activities related to developing a vision to guide the advancement of self-direction initiatives informed, in part, the development of a new Support waiver, which was implemented in January 2008. This new waiver offers participants more service options and more control over services, and, as noted above, the State is considering amending the waiver to incorporate IP components.
- Grant staff worked with the State’s Systems Change Money Follows the Person grant staff on a state initiative to standardize reimbursement rates for service providers. Historically, providers have charged sometimes markedly different rates for the same service and, accordingly, the State has reimbursed providers different amounts for the

same service. The lack of a standardized rate reduced the ability of participants with fixed budgets to switch service providers if the provider they wanted to use had a higher rate.

In January 2008 the State published standard reimbursement rates for specific services. Thus providers will now have to compete on quality and not cost. Three of the services in the new Support waiver (Community Support, Work Support, and Employment Specialist Services) will be reimbursed according to the standardized published rates. The standardization of reimbursement rates allows waiver participants to select the service provider that best meets their needs.

- The IP grant project increased statewide awareness of self-determination ideas and access to self-determination activities.

Key Challenges

Reaching consensus was difficult when attempting to develop policy for using guardians and/or representatives to help individuals who are unable to self-direct their services. Grant staff expanded the group working on this issue to include key individuals who work with adults other than those with mental retardation; for example, elderly persons with dementia or individuals with serious mental illness. The State's Systems Transformation grant will continue to address this issue.

Continuing Challenges

The State continues to experience deep budget cuts that affect the Department's ability to create a self-direction waiver program.

Lessons Learned and Recommendations

- Giving self-advocates much of the responsibility for developing the training curriculum, developing concepts for a guiding philosophy, and planning specific self-direction responsibilities (e.g., hiring workers) required significantly more time, coordination, and logistical support than initially planned. However, the results were worth the extra effort. This approach has empowered people with mental retardation or other developmental disabilities and physical disabilities and has demonstrated to state staff and service providers that they have the ability not just to learn but to teach and to provide input on program policies and procedures that affect them.
- Grant staff learned the value of meaningfully engaging stakeholders in grant and public policy activities. The stakeholders pushed to create a less professional environment (e.g., meeting outside of the office at a restaurant, library, or picnic table near the ocean), which resulted in greater comfort for the stakeholders and more open and honest feedback. Once comfort was established, each stakeholder was taught how to work and participate in a professional environment. By the end of the grant, the stakeholders actively participated in meetings like everyone else.

- Grant staff also learned that engaging stakeholders in a meaningful way took a lot more time than anticipated. Three years was insufficient for the targeted population. Therefore, it is important to plan up front for more time to complete activities and to budget for paying self-advocates to be involved. Also, it is useful to work directly with self-advocates instead of their direct care workers. Grant staff found that when workers did not attend meetings, many self-advocates were more open and better able to share their thoughts. This was not because their workers prevented them from speaking but because many workers were in the habit of speaking for and answering questions for the person with a disability.

Key Products

Outreach and Educational Materials

- Grant staff and the Advisory Committee members produced flyers and brochures describing the IP grant project and the proposed IP waiver.
- Grant staff and the Advisory Committee work groups developed materials to be used in training about self-determination and self-directed services.

Massachusetts

Primary Purpose and Major Goals

The grant's primary purpose was to develop a program structure to allow individuals with disabilities to direct individual budgets and choose the services and supports that best meet their needs in the community. The grant had three major goals: (1) to develop an Independence Plus (IP) waiver program that builds on the current self-directed services program infrastructure; (2) to ensure meaningful involvement of people with disabilities and other stakeholders in the planning, design, and evaluation of grant activities; and (3) to develop and submit an IP waiver application no later than the third year of the grant.

The grant was awarded to the Center for Health Policy and Research, University of Massachusetts Medical School.

Role of Key Partners

- The State used the Consumer Planning and Implementation Group (CPIG) established under its 2001 Real Choice grant to involve service users in the design of the IP program. CPIG members also participated in an integrated work group on quality management and served on the Collaborative Team: the decision-making entity for the grant. Half of the members of this team were service users and the other half state partners, including representatives from the Office of Elder Affairs/Long-Term Care, the Office of Disability and Community Services, the Department of Mental Retardation, the Massachusetts Rehabilitation Commission, and the Department of Mental Health.
- Consumer Quality Initiatives, Inc., a consumer-driven participatory action research group, was involved in designing the IP quality management system as part of an integrated quality work group, which included members from the CPIG and other community and state partners.

Major Accomplishments and Outcomes

- Grant staff worked with state, consumer, and community partners to build a decision-making cross-disability collaborative team with a strong person-centered planning focus. The model was recognized nationally as an effective process for including people with disabilities in the design and implementation of community services. Members from both the Collaborative Team and the CPIG have presented their process in several venues, including the CMS New Freedom Conference and the National HCBS Waiver Conference.
- The grant sponsored statewide forums with local officials, disability advocates, and community partners to provide updates on the progress of the self-direction design activities. Grant staff also collaborated with the staff of other Massachusetts Systems Change grants to coordinate annual forums to inform and involve the larger stakeholder community of all systems change activities.

- Ongoing outreach to diverse disability and community organizations led to a greater understanding of the IP model and how it can be implemented across disability groups. The disability community now better understands the specific challenges that different disability populations may face when using the IP model.
- Grant staff worked with the fiscal intermediary from the Real Choice grant's self-direction pilot to identify forms and tools that could be used in the IP initiative; for example, time sheets, invoices, and spending plans. In addition, an IP grant consultant analyzed findings from the Real Choice pilot on uniform assessment principles, processes, and tools to ensure that the assessment process in the new IP option identifies both functional and medically related needs. Another consultant reported the challenges that traditional case managers may face as they move into a support broker role and produced a recommended training curriculum for support brokers.
- The grant's quality work group designed and created the infrastructure for the necessary components of a quality management system for the new IP program, as well as the methods to ensure a participant focus in quality management. The system includes procedures for emergency backup, critical incident management, grievance procedures, and reporting abuse and neglect.

Enduring Systems Change

- The infrastructure developed for the new IP waiver was included in the State's research and demonstration (R&D) waiver application. Although the grant was intended to develop a new IP waiver, the State decided that its policy goals would be better served by including an IP option in the new R&D waiver rather than having a separate IP waiver. The new R&D waiver will subsume the Elderly and Traumatic Brain Injury waivers and also serve adults under age 65 with disabilities, who are not currently served under any waivers, apart from some individuals under 65 who are served in the State's MR/DD waiver. The State submitted the application to CMS in December 2006 and, as of January 2009, was still in negotiations about the waiver's terms. The anticipated start date is July 2009.

The R&D waiver, called the Community First waiver, will (1) expand eligibility for waiver services by allowing higher asset levels, and (2) provide services to individuals who do not meet nursing home level-of-care criteria but who are determined to have needs that, if not met, could place them at risk for institutionalization. Through the IP option, waiver participants will have greater control over the services they receive and the individuals who provide them.

- Consumer involvement in grant activities helped to ensure that the new IP option was designed to meet participants' needs within state and federal parameters. Although the CPIG has not been sustained since the IP grant ended, the Collaborative Team, which includes some former CPIG members, continues to meet. Members of the Collaborative Team and former CPIG members are also serving on the Systems Transformation grant steering committee and subcommittees.

Key Challenges

The major challenge was ensuring that grant activities were coordinated with the development of the Community First R&D waiver, which made it difficult to meet IP grant timelines because they had different time tables. Grant staff also had to ensure that the IP model developed with this grant was compatible with the operational features of the R&D waiver. State staff designated to design the larger waiver were less familiar with the IP grant and its purpose, making integration of IP concepts more challenging.

Continuing Challenges

- Ensuring that people with significant mental health disabilities have access to community services (including self-directed services) is a continuing challenge because of the Institutions for Mental Disease exclusion in Medicaid law.
- Ensuring an adequate supply of support brokers and providers of fiscal intermediary services will be a challenge when the new IP option is implemented. Experience implementing the Real Choice pilot self-direction program demonstrated that some traditional case managers may be unable to easily assume the support broker role and training will be needed. The Office of Elder Affairs recently piloted case manager training on self-direction concepts, which built on the work of the Cash and Counseling model. Statewide training was scheduled to take place in spring 2008.

Lessons Learned and Recommendations

- The Real Choice grant's self-direction pilot program provided valuable information for developing the IP program infrastructure. Designing a grant to build on existing systems change efforts can help to bring about systems change.
- A meaningful method for involving service users and other stakeholders early and consistently in all phases of a systems change initiative will strengthen and facilitate systems change efforts. Supports such as transportation, stipends, and accessible formats for information are needed to ensure ongoing participation. Also, meeting agendas should be provided 1 to 2 weeks prior to an event to allow individuals time to read about and understand the topics to be discussed.
- Although a detailed sustainability plan may not be developed until later in a project, stakeholders need to plan for sustainability from the beginning. Sustainability plans need to address policy, service provision, and processes for ensuring systems change.

Key Products

Outreach Materials

Grant staff produced PowerPoint presentations to provide an overview of the Real Choice and Independence Plus grants and the collaborative decision-making process.

Technical Materials

- Grant staff researched other states' methods for determining the amount of individual budgets and reviewed relevant publications. Based on this research, they produced a summary report and at-a-glance charts of various individual budgeting models and other states' costs for fiscal and support broker services.
- Grant staff produced a draft document on fiscal intermediary roles and responsibilities, and a sample spending plan, monthly statement, time sheet, and other tools based on those originally developed under the RC grant.
- Grant staff produced a comparison chart of IP components and requirements as specified under the Section 1915(c) Waiver Authority, the Section 1115 Demonstration Authority, and the Deficit Reduction Act Cash and Counseling State Plan.
- The grant's quality work group developed a proposed *Framework for Designing and Measuring Quality: Massachusetts Independence Plus*, which incorporates the CMS quality domains with outcomes and indicators; design features that include how the outcomes are assigned to the major roles within the IP model (i.e., support broker, fiscal intermediary, participant/representative, participant's worker); and quality measures with potential data sources.
- The grant's quality work group developed draft forms for critical incident reports and created a comparison chart of selected states' grievance procedures. The work group also produced a document entitled *Potential Back-Up System for Independence Plus Model*, which describes two levels of contingency backup for the IP model: level I, which is created by the participant and is customized to the participant's unique needs and preferences; and level II, which provides additional infrastructure support.

Reports

- The IP grant-funded report *Support Brokerage in the Real Choice Pilot: An Analysis of Experiences and Perceptions of Consumer-Directed Agencies' Staff* described the experiences of the community liaisons and agency managers in the Real Choice grant's self-direction pilot, and provided information to inform the development of support broker services in the IP option in the Community First waiver. The report includes recommendations for support broker training and for promoting respectful discussions about service users in staff meetings (e.g., not defining people by their diagnosis).
- The IP grant funded the development of a DVD documenting the involvement of the CPIG, titled *When CPIGs Fly: Consumer Involvement in Systems Transformation*, and a companion report, *CPIGs Fly: Stakeholder Involvement within the Massachusetts Real Choice and Independence Plus Grants*.

Michigan

Primary Purpose and Major Goals

The grant's primary purpose was to develop within the long-term care, mental health, and developmental disabilities services systems the capacity to offer participants a high level of choice and control over planning, selecting, directing, and purchasing needed services and supports. The grant had four major goals: (1) to strengthen knowledge, networking, and advocacy for participants, families, and their supporters concerning the tools and techniques inherent in the Independence Plus (IP) components; (2) to introduce IP principles and practices in the MI Choice waiver program for elderly persons and working-age adults with physical disabilities; (3) to develop a quality of life assessment methodology to evaluate participant satisfaction with self-determined service arrangements;⁵ and (4) to increase participant involvement in program policy decision making.

The grant was awarded to the Department of Community Health, Office of Long-Term Care Supports and Services.

Role of Key Partners

- A Project Work Group—comprising service users, advocates, service providers, and state agency staff—oversaw all grant activities and product development with guidance from participants and advocates experienced in IP design features. Additional work groups were formed to develop specific IP components.
- The Michigan Association of Community Mental Health Boards partnered with grant staff in organizing training, hosting planning meetings, and arranging communications.
- The Michigan Partners for Freedom (MPF), a grassroots advocacy group organization, was subcontracted by the Grantee to conduct statewide awareness and leadership training for service users, and also training for peer mentors to assist individuals beginning the transition to self-determination.
- The Arc of Michigan was a member of the Project Work Group and also provided technical consultation for writing technical reports about participant direction.
- The Michigan Disability Rights Coalition was a member of the Project Work Group, and also provided staffing services for the grant project coordinator, some consultants and

⁵ For participant-controlled arrangements utilizing the person-centered planning process, individual budgets, fiscal intermediary services, direct hiring of staff or an agency-with-choice model, Michigan prefers to use the term *self-determination*. The use of this term is intended to include and embrace a constellation of values regarding the participant's right to understand and control basic features of their life, such as where and with whom do they live? what services do they feel they need? what do they want to do with their time? The term "self-directed" may not imply these features.

support staff, as well as web hosting and support for service users' participation in grant activities. It also hosted the grant project's website.

- The Michigan Developmental Disabilities Council was a member of the Project Work Group and also funded the Michigan Partners for Freedom organization.
- The Paraprofessional Healthcare Institute (PHI) conducted training workshops to support participants who wish to hire their own staff.

Major Accomplishments and Outcomes

- Grant staff developed a standardized model for participant-controlled services in Michigan's mental health and developmental disabilities service system, which includes fiscal intermediary services and methods for determining individual budgets. Staff also refined and implemented models for participant-controlled long-term services and supports in the MI Choice waiver. In both service systems, these models include independent facilitators for person-centered planning (PCP) and the option to use independent support brokers.
- To support all the target populations, grant staff drafted new technical assistance materials on the following topics: working with fiscal intermediaries, introduction to self-determination for service users and allies, hiring staff, and guidelines on PCP policy and practice. The guidelines' purpose was to define how person-centered planning should be used in home and community-based long-term services and supports—specifically the MI Choice waiver—and to establish the State's expectations for provider agencies' policies and practices. The materials are also providing direction for self-directed services in the State's Section (§) 1915(b)(c) Managed Care Specialty Supports waiver, and §1915(c) Children's waiver.
- Grant staff partnered with the Michigan Partners for Freedom, which is a coalition of people with disabilities, family members, advocates, organizations, and other allies working together to build statewide demand for self-determination. During the grant period, MPF conducted 14 community training events and 3 local leader training events in 16 communities throughout Michigan, to empower people with disabilities and to develop their advocacy skills and awareness of state and local issues. In addition, MPF presented at six statewide and three county conferences.

The day-long community training sessions included an overview of self-determination and how to employ the self-determination tools (person-centered planning, individual budgets, independent facilitation, and fiscal intermediary services). A total of 1,118 people attended both the trainings and conferences, far exceeding expectations; of these, 576 were service users, 363 were direct care workers and local field staff, and 179 were family members or other allies (e.g., friends, community members, co-workers, or fellow students).

In part through IP grant funding, MPF developed effective training and advocacy materials and a website (<http://www.mifreedom.org/>) that includes many resources.

The organization has secured funding beyond the grant time frame and will continue to provide advocacy, training, and support for people with disabilities, their families, and their allies.

- Grant staff worked with the Paraprofessional Healthcare Institute to create and conduct a train-the-trainer program for participants in self-determination arrangements who wish to learn how to hire and manage their own staff. This initiative developed seven teams of participant and staff trainers, and adapted the PHI curriculum “Employing, Supporting and Retaining Your Personal Assistant: A Workshop Series for People with Disabilities” to the needs of Michigan participants with developmental disabilities.
- Grant funds were used to develop a participant quality of life assessment, and the University of Michigan Gerontology Institute has been working on validation studies for the draft survey tool: Participant Outcomes and Status Measures. The tool currently has 59 items in nine categories, and pilot studies indicate that the number of items could be reduced without compromising the measure.
- Grant staff developed a bimonthly Self-Determination Implementation Leadership Seminar as a forum for sharing information and strategies as well as for clarifying technical requirements. Communities that had already implemented self-determination arrangements shared policy documents with communities that had been slower to implement. As part of these forums, participants who had made the transition to self-determination explained to developmental disabilities and mental health agency staff—in person and through video interviews—the specific outcomes of person-centered planning, individual plans of services, individual budgets, how to code services for reimbursement, working with fiscal intermediaries, developing quality of life measurement and evaluation systems, and supported employment options.
- The grant funded the participation of service users in annual self-determination conferences that were held each year of the grant project, with a typical attendance of more than 500 people, half of whom were people with disabilities and family members. These conferences have served to showcase progress and as learning laboratories for others interested in self-determination.
- The grant’s activities led to other developments that have built on the IP initiative. For example, two of the goals for Michigan’s Systems Transformation grant (dealing with person-centered planning and self-determination for long-term services and supports) grew out of the success and acceptance of these policy initiatives within mental health services; also, the PCP and other self-determination materials will be used to implement a single point of entry approach through an Aging and Disability Resource Center grant.

Enduring Systems Change

A self-determination option became available statewide on October 1, 2007, for participants in the MI Choice waiver. Grant funds were used to provide training for the Area Agency on Aging waiver staff as they prepared to initiate self-determination in long-term services and supports. Regional training events and statewide meetings provided awareness,

information, and skill-building activities to program managers, social workers, and nursing staff in the areas of person-centered planning, quality assurance, developing a plan of service, and individual budgets. As of November 2008, 550 individuals had elected to use the new option.

Key Challenges

- One of the grant goals was to plan and develop the infrastructure for a research and demonstration waiver to offer individuals with disabilities the option to receive and direct a cash allotment in lieu of receiving services and supports through traditional methods. The goal was dropped because of a lack of state resources to do the technical work required for the waiver.
- There have been no state General Fund increases for local mental health services in Michigan in more than 12 years. Implementing new services in this type of budget environment has posed challenges.
- Implementing self-determination policy and practice in the mental health services delivery system has been a major challenge. Resistance and misunderstanding among local service delivery agencies have delayed the development of a series of documents to define and describe recommended practices for self-determination implementation. Local agencies' adoption of these practices has varied from one part of the State to another, depending partly on local leadership; some areas have not adopted them at all.
- The State has found that the nature of services and supports for persons with mental illness has posed a challenge to the development of individual budgets. Many supportive services for persons with mental illness are combined and billed at a combined rate, making it difficult to determine the amount that would be available for one individual budget. This issue arises most often when states offer rehabilitative services in their Medicaid State Plans or in an HCBS waiver program, because they have used reimbursement methodologies that combine payment for multiple rehabilitative services performed by multiple practitioners within a single combined rate. The challenge is to develop a method to cost-out the amount of funds available to an individual who wishes to self-direct his or her mental health services in an individual budget.
- Another challenge is that the "unbundled" individual cost for certain services, such as group therapy, can be very low. A potential approach to addressing this problem is the development of consumer cooperatives that pool individual funds for several service users who are working together to directly manage their services. Michigan developed such a cooperative model with an FY 2001 Real Choice Systems Change grant, and one cooperative is currently operating.

Continuing Challenges

- Funding for self-determination for people with serious mental illness continues to be insufficient, and increases in the foreseeable future are unlikely.

- A focus on person-centered planning as the basis for initiating self-determination has posed an interesting challenge for training staff, many of whom believe that their approach is already person centered even though they do not practice some of the basic features of the PCP approach (i.e., identifying values, open-ended questions, predetermined universe of services, living arrangements, or employment options).

Lessons Learned and Recommendations

- Participant involvement in planning, staff training, and policy development through advisory groups is a way to ensure that participant issues are identified and that participant support for actions is likely. Without such involvement, a valuable reality check to policy initiatives is overlooked.
- Presenting success stories from participants in initial implementation efforts was an effective means for teaching others how to implement self-direction.
- Michigan needs to allocate additional funding for increased waiver slots to reduce the number on the waiting list for the MI Choice waiver.
- New program approaches—such as self-determination—are more likely to be successfully implemented when they are mandated.

Key Products

Outreach Materials

Michigan Partners for Freedom developed two DVDs and handouts describing self-determination options for service users seeking information through local Community Mental Health Boards. In addition, grant staff produced self-determination brochures, flyers, and presentations for the annual self-determination conferences and for the self-determination implementation leadership seminars.

Educational Materials

Hiring and Managing Personal Assistants was developed under contract with The Arc of Michigan. The book addresses the issues common to service users moving into the role of managing their own staff in self-determined arrangements. It also includes sample documents to support job descriptions, advertising, interview questions, an employment application, a background check release form, and an employment agreement.

Technical Materials

Grant staff developed many technical advisory documents to provide information about self-determination to local program staff working in the mental health system and in the MI Choice waiver system.

Reports

Grant staff wrote a training needs analysis for community mental health staff involved in self-determination efforts in August 2006. The data for the analysis were collected during

the bimonthly Self-Determination Implementation Leadership Seminars, in which participants identified training topics needed to support their job performance in regard to person-centered planning, individual plan of service, individual budget, and working with fiscal intermediaries.

Missouri

Primary Purpose and Major Goals

The grant's primary purpose was to develop and implement a self-direction system to enhance choice and control of services and supports for people with disabilities and their families. The grant had four major goals: (1) to establish a statewide task force to assist with the planning, implementation, and evaluation of grant activities; (2) to develop the components of the self-direction system; (3) to implement and evaluate a self-direction pilot program; and (4) to ensure the sustainability of the self-direction system by identifying components that the pilot has demonstrated to be fiscally neutral or cost effective and by obtaining additional funding.

The grant was awarded to the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities (DMRDD), in partnership with the Missouri Planning Council for Developmental Disabilities (MPCDD), and the Institute for Human Development (IHD), Missouri's University Center for Excellence.

Role of Key Partners

The Independence Plus (IP) Task Force consisted of 22 members—13 of whom were self-advocates or family members, with the remainder representing disability stakeholder groups, state agencies, and other professionals working in the field of disability services. The Task Force guided the development of the grant's pilot initiative, and during pilot implementation they reviewed resource materials and training materials and recommended ways to recruit pilot participants and support brokers. When the pilot was completed, the Task Force reviewed pilot evaluation results and developed a set of recommendations for expanding self-directed services in Missouri.

Major Accomplishments and Outcomes

- Grant staff implemented a pilot program to test the use of individual budgeting, new financial management services (FMS) models, and support broker services for persons with mental retardation and other developmental disabilities. Twenty-eight waiver participants (aged 8 to 60) from rural and urban areas enrolled in the pilot program, and grant staff developed workbooks to orient participants to the program and assist them with service planning. Grant staff also trained 18 person-centered planning (PCP) facilitators and 28 support brokers.

The pilot was funded with the participants' current budget allocation for services through either the Comprehensive or the Community Support waiver programs, whereas grant funds paid for independent planning facilitators, independent support brokers, and fiscal management services that were not in the existing DMRDD waiver contract. The pilot ended in September 2006, and all of its participants continued using the self-direction option in one of the two waiver programs.

- As part of the pilot, a worker call-in system that documents and verifies a worker's time and the type of service being provided was explored. By using the call-in system, pilot participants were relieved from having to process timesheets to get their workers paid. Although the use of this service by pilot participants was voluntary and limited, the Task Force recommended that the DMRDD continue to explore the use of a call-in system for people self-directing services and that the use of such a system be mandatory. The Task Force also recommended that whatever call-in system might be used, it should include a way for those directing their own services to access information about the status of their individual budget.

The DMRDD issued a Request for Proposals (RFP) for FMS providers to offer more services than are currently provided, including assisting participants and families with completing tax forms, verifying citizenship, conducting criminal background checks, monitoring workers' hours, and providing workers' compensation insurance. In response to the Task Force recommendations, the RFP included the requirement that the FMS provider(s) have a phone call-in system. The contract was awarded in spring 2008.

- Grant staff developed a training curriculum that covers support broker services, PCP facilitation, and other self-direction topics. The training was targeted to participants, families, regional offices, service providers, persons interested in becoming support brokers and/or PCP facilitators, and other stakeholders. The Missouri Planning Council for Developmental Disabilities authorized funds to facilitate this training process statewide.

Participants (or their parent/guardian if under age 18) may choose to employ a support broker and/or use an independent PCP facilitator, both of which are waiver services paid from the individual budget. They may hire the individuals providing services themselves and negotiate a pay rate or they can obtain these services through an agency and pay the agency rate. Individuals may complete both PCP and support broker training and fulfill both roles for a participant if they qualify as a provider of each service.

The two positions have different training requirements. Because PCP facilitators have a higher-level skill set than support brokers—who primarily assist participants in arranging for, directing, and managing services—they are required to have a 4-year degree and be credentialed as a qualified mental retardation professional, which is not required for support brokers. PCP facilitators perform services that include professional observation and assessment, individualized program design and implementation, training of participants and family members, consultation with caregivers and other agencies, and monitoring and evaluating service outcomes.

- Grant staff produced a pilot project recruitment brochure targeted to current waiver participants and their families, and produced PCP facilitator and support broker recruitment announcements. They also created a project website with information and resources that include a description of the IP grant and the pilot project, a definition of self-determination, a listing and discussion of the supports available, and educational materials such as workbooks designed to orient participants to the self-determination philosophy and the individual budgeting process (<http://www.ihd.umkc.edu/>).

- The IP Task Force recommended that a work group be formed and empowered to assist the DMRDD in its efforts to sustain and expand self-directed services options. Members from the original Task Force as well as other participants and family members became the Self-Directed Supports and Services Advisory Work Group. The group consists of 12 members: self-advocates, parents, DMRDD staff, and MPCDD staff. Supported in part by funds from the MPCDD, the group has met on numerous occasions and plans to continue meeting in the future to discuss issues and needs regarding self-direction.

Enduring Systems Change

- Prior to receipt of the IP grant, the Department of Mental Health (DMH) offered the option to self-direct personal assistant services in three DMH waiver programs serving persons with mental retardation and other developmental disabilities: the Community Support waiver for children and adults; the Comprehensive waiver for children and adults; and the Sara Lopez waiver, a model waiver serving up to 200 children from birth through age 18. Participants and families are the employer of record, and a fiscal intermediary provided payroll services for participant-employed workers.

As a result of the success of the grant pilot project, when applying for renewal of the Community Support and Comprehensive waivers, the State expanded financial management services and added support broker services and PCP facilitator services as options for participants wishing to self-direct. The two waivers were renewed July 1, 2006, and a contract for FMS provider(s) was awarded in spring 2008. The State is working on the renewal of a third Section 1915(c) waiver, the Missouri Children with Developmental Disabilities (Sara Lopez) waiver, and plans to add the same components. The State is committed to improving self-direction options in all waiver programs.

- DMRDD staff, in conjunction with the IP Task Force, developed a *Statewide Quality Management Plan for Individuals Who Self-Direct Their Services* that was used for the IP pilot project. After evaluating the pilot, the Task Force reviewed the quality management plan and recommended that the DMRDD expand the plan beyond health and safety compliance concerns to include quality of life outcomes for people self-directing services. Other elements identified for further consideration included the need for a stronger emphasis in backup plans on strategies to address natural disasters (after Hurricane Katrina), revisiting the idea of community pools of backup support staff, contracting with agency of choice to provide backup staff, and developing an online listing of backup workers.
- The MPCDD has committed funds to support ongoing efforts associated with self-direction outreach and training; for example, by helping DMRDD to provide information statewide about self-direction options and to provide multiple modules of support broker training statewide to build support broker capacity.

Key Challenges

- Recruiting support brokers and PCP facilitators was difficult in sparsely populated areas. If only one person in a remote area was interested in participating, it was not possible to

include that person in the pilot. In this instance, the person was referred to the self-direction option in the waiver program (unless he or she was already enrolled).

- Delays in developing the training workbook and curriculum delayed training activities.
- It was challenging to integrate data systems for the new pilot services with data systems for current waiver services.
- It was sometimes difficult for stakeholders to reach consensus on systems change priorities.
- Grant staff explored the possibility of combining funds from programs administered by different agencies in the individual budgets for pilot participants eligible for more than one state or Medicaid program; they were unable to do so during the pilot because of numerous staffing changes at several agencies.

Continuing Challenges

Working with State agencies to combine funding continues to be a challenge. Meetings have been held with staff from the Departments of Elementary and Secondary Education, Health and Senior Services, Social Services, and Mental Health to discuss combining funding. Although the response from some agencies has been positive, other agencies are willing only to contribute funding based on the prior year's service utilization rather than the amount authorized.

Lessons Learned and Recommendations

States should give work groups enough time and staff support to consider information in a timely manner that allows for real input into the process.

Key Products

Outreach Materials

Grant staff developed numerous outreach materials to increase community awareness of self-directed services, including IP pilot project brochures and recruitment materials, PowerPoint presentations on person-centered planning, a success story booklet, and DVDs of parent and participant testimonials about self-direction. Some of these materials are available at <http://www.ihd.umkc.edu/>.

Educational Materials

- Grant partners developed training and technical assistance materials to assist participants in directing their services and supports. For example, the *Designing and Selecting Supports Workbook* includes job descriptions, interview questions, employer/employee agreements, and other tools that will assist participants in designing, developing, and managing their supports and quality assurance processes. Other workbook topics include financial management, individualized budgets, person-

centered planning, self-determination, and orientation overview. Some of these materials are available at <http://www.ihd.umkc.edu/>.

- Grant partners developed training materials to increase community capacity for support broker and PCP facilitator services. These include *Person-Centered Planning: A Guide for Training Facilitators*, and six modules of a support broker curriculum entitled *The Role and Functions of Support Brokers*. In addition, the modules provide training about the IP pilot program; self-determination values, beliefs, and assumptions; navigating service systems; managing support personnel; and accessing community resources.

Reports

- An IP Summit was convened near the end of the pilot to (1) obtain feedback on how people's lives were affected, what worked well, and what could have been improved; (2) explore ways to sustain and enhance self-direction efforts in Missouri; and (3) begin planning the process to transition participants from grant-funded services available during the pilot to comparable waiver services. The Summit was attended by 60 people, including individuals with disabilities and their families, service coordinators, support brokers, personal care assistance staff, IP Task Force members and grant staff, and speakers. A report (the *Independence Plus Pilot Summit Outcome Report*) was produced and is available at <http://www.ihd.umkc.edu/>.
- Two surveys were developed to evaluate the impact of self-direction on the lives of pilot participants. The first survey examined their level of autonomy prior to participating in the pilot. The second examined the impact of self-direction on their lives after being served for 12 to 18 months in the pilot. The *Pilot Participant Survey Report* summarizes the results of these two surveys; 26 pilot participants and their families returned the surveys.
- The *Independence Plus Pilot Process Evaluation Report* summarizes the findings from interviews conducted with 29 pilot participants or their representatives, 15 DMRDD service coordinators, and 6 support brokers who worked for the pilot participants. The survey solicited information on their perceptions of some of the pilot's components and processes.
- The *Independence Plus Statewide Task Force Final Report and Recommendations* summarizes the work of the IP Task Force during the grant period and includes recommendations for support brokerage services, expanding fiscal management services, and quality assurance.

Montana

Primary Purpose and Major Goals

The grant's primary purpose was to enhance self-direction in the Medicaid State Plan personal assistant services (PAS) program and in the home and community-based services (HCBS) waiver program. The grant had three major goals: (1) to develop an Independence Plus (IP) waiver for elderly persons and persons of all ages with physical disabilities that includes person-centered planning (PCP), individual budgeting, financial management services (FMS), and support broker services; (2) to implement and evaluate an Independence Plus (IP) pilot program; and (3) to implement an emergency backup system, incident management plan, and quality assurance process.

The grant was awarded to the Department of Public Health and Human Services, Senior and Long-Term Care Division, Community Services Bureau.

Role of Key Partners

- The grant's Advisory Board—comprising service users, state staff, legislators, regional program officers, independent living centers (ILCs), case management teams, and self-direction personal assistance agencies—oversaw grant activities and created subcommittees to develop the support services spending plan, and develop the roles of independence advisors and fiscal managers.
- Summit Independent Living Center developed participant and provider training materials and conducted training in pilot areas.
- The Native American coordinator at the Center on Disabilities, Montana State University, conducted outreach to the Indian nations to ensure cultural sensitivity in all phases of program development and implementation.

Major Accomplishments and Outcomes

- Grant staff obtained ongoing input on the design of the new IP waiver program from service users—particularly, current waiver participants and their families—advocates, tribes, community service providers, personal assistants, case managers, and ILCs. Focus groups were conducted in urban and rural locations, as well as on Indian Reservations, and surveys were mailed to collect data from those who did not attend group meetings.

The input helped to improve the support services spending plan, making it more user friendly. Similarly, the reporting requirements for FMS agencies were streamlined, and a new standard utilization quarterly report form was developed for use by all FMS agencies. As a result of participant feedback, the State is also simplifying the training and the assessment and enrollment process.

- The Department contracted with Summit Independent Living Center to develop and provide the initial orientation and training for participants and providers. In the future, regional state staff will be responsible for this activity. The ILC developed an orientation presentation and guide to educate service users, providers, and the public about participants' roles and responsibilities in the IP waiver, and conducted two orientation sessions in two pilot areas, which was attended by both service users and providers. The ILC also developed participant, support broker, and financial manager training curricula and manuals and conducted training sessions in the pilot areas.

Enduring Systems Change

- The Senior and Long-Term Care Division received approval from CMS in January 2006 for an Independence Plus Section (§) 1915(c) waiver, called the Big Sky Bonanza waiver, which incorporates the self-direction features of an individual budget, financial management services, support broker services, and person-centered planning. The individual budget gives waiver participants employer authority and budget authority over a range of goods and services, including Native American healing services.

The grant facilitated the submission and approval of the IP waiver application, and grant staff implemented the IP waiver in six pilot areas, enrolling nine individuals. In response to the success of the pilot and the overall satisfaction of the initial group of participants, the State decided to amend its Elderly and Physically Disabled waiver to include the IP components as a distinct self-direction option. The pilot areas will be expanded gradually until the IP option can be incorporated statewide into the Elderly and Physically Disabled waiver. After the grant ended, the amendment submission was targeted for January 1, 2009.

Currently, Elderly and Physically Disabled waiver participants can choose to enroll in the new IP waiver if they want to use the expanded self-direction option. Individuals who are currently receiving State Plan personal assistance services can also choose to be in the new IP waiver program—if they meet the waiver's eligibility criteria—and receive a comparable resource allocation for services they were receiving through the State Plan in their waiver individual budget. The State uses the PAS cost information and historical waiver service costs to determine individual budget amounts.

The IP waiver allows for payment of legally responsible individuals under certain circumstances, which has increased the availability of services to individuals and their families in remote areas and where other qualified caregivers cannot be found. When the IP option is incorporated into the Elderly and Physically Disabled waiver, payment for legally responsible individuals will also be allowed.

- Grant staff developed an individual risk assessment tool to guide participants through a process of identifying and developing plans to prevent and reduce risk, and to address problems when they arise. Participants and support brokers are trained to use the tool, which is unique to the IP waiver, as part of the PCP process. The State plans to incorporate the tool into the care planning process for the Elderly and Physically Disabled waiver and the State Plan self-direction PAS programs.

- The grant enabled the development of a quality assurance database that incorporates the incident management system, quality assurance reviews, and quality assurance communications into one system. As a result, the State has moved from a paper-based reporting system to one that allows data entry at the provider and field staff level and enables tracking, analyzing, and trending of quality assurance data and reports across the IP waiver, the Elderly and Physically Disabled waiver, and the PAS programs. The database also provides evidentiary review data to enable the State to respond to requirements for federal waiver assurances.

Key Challenges

- The biggest challenge in implementing the pilot waiver program was that the State already offered a limited self-direction option to HCBS waiver participants and has a State Plan self-direction PAS program. Additionally, participants in these programs are very satisfied and comfortable with their current service arrangements and highly value their case management services. Thus, they had little motivation to enroll in a new program, and only a few people in the designated pilot areas were interested in the IP program. As it has become better known, interest has increased. When the State expands the pilot, it will conduct another educational campaign about the program.
- The complexity of the new waiver made it challenging to assure some stakeholders that the new features were a “value added” and would not reduce services and supports. For example, some stakeholders did not understand why State Plan personal assistance resources were included in the waiver program’s individual budget and thought the State was taking away services and supports.

Also, the report outlining the individual budget determination was perceived as too complex because it included the budget calculation formula, leading to concerns that participants would have fewer resources under the new waiver program. In addition, grant staff mistakenly thought that FMS agents already serving State Plan participants using the self-direction option would easily be able to provide services under the new waiver. More hands-on training about individual budgeting and the PCP process was required.

- Steep increases in workers’ compensation rates were a major challenge for providers. Nevertheless, several providers became certified support brokers and financial managers.
- In spite of outreach efforts to include Indian Nations, Native Americans did not participate in the pilot, largely because of issues related to tribal relations with the federal government; generally, Tribes wanted Medicaid funding to come to the Tribes directly from the federal government.

Continuing Challenges

None at this time.

Lessons Learned and Recommendations

- The grant project developed a very strong and active Advisory Board, which was involved in every step of the development of the IP waiver pilot. Involving the Advisory Board to this extent created a vested interest in the program among both service users and providers and a strong desire to see the program grow and improve.
- A cumbersome and complicated planning process limits support brokers' effectiveness in working with participants and hinders program enrollment. Grant staff recommend that other states not "person-center the process to death like we did" and that they test the planning process with just a few participants and providers with the goal of simplifying it before implementation.
- The Deficit Reduction Act, which created the §1915(j) authority requires that financial management services be paid as an administrative expense, with a federal match of 50 percent. Because Montana's federal match rate is 70 percent, a 50 percent rate limits the State's ability to expand the IP model to State Plan services. A statutory change is needed to allow financial management services to be reimbursed at the service rate.
- The State would never have developed the IP waiver without the IP grant. CMS should continue to provide grants to states to help improve the HCBS system for people of all ages with disabilities.

Key Products

Outreach and Educational Materials

Summit Independent Living Center produced an overview brochure for the Big Sky Bonanza program (the IP waiver pilot) to inform potential participants about the program. This brochure will continue to be used on an ongoing basis for the IP waiver.

Educational Materials

- Summit Independent Living Center produced an orientation video and a booklet to educate service users, providers, and the public about participants' roles and responsibilities in the IP waiver.
- The ILC also developed participant, support broker, and financial manager training curricula and manuals. The participant and provider training materials have been reproduced as training packets and have been incorporated into the IP waiver policy manual, which provides the basic information needed to manage services. When information in this manual changes, the Department will send updated material through the post or via e-mail. A waiver orientation manual is available on the HCBS website at <http://www.hcbs.org/moreInfo.php/doc/1655>.

Technical Materials

- In response to participant feedback and input, grant staff developed a culturally sensitive and user-friendly support services spending plan. They also developed a risk

prevention assessment form to be used during the planning process. The support services spending plan is available on the HCBS website at <http://www.hcbs.org/moreInfo.php/doc/1655>.

- Grant staff developed a standard reporting form to be used by all FMS agencies for submitting quarterly financial information to the State.

Reports

- Summit Independent Living Center completed in-person interviews and satisfaction surveys with each enrolled participant and submitted a final report to the State—*Big Sky Bonanza Pilot Program: Consumer Evaluation and Final Interview Report*.
- Grant staff produced a summary of information gathered from the focus groups conducted in August 2004—*Big Sky Bonanza Grant, Focus Group Report: Improving Consumer Direction in Personal Assistant and Home and Community Based Services Programs*. The summary identified certain common themes regarding self-direction, self-directed services programs, types of services, supports, and training. The report also includes recommendations for enhancing self-direction.

Ohio

Primary Purpose and Major Goals

The grant's primary purpose was to expand self-direction options for individuals with mental retardation and other developmental disabilities (MR/DD) by developing an Independence Plus (IP) waiver program to be implemented in at least five demonstration counties. The grant had three major goals: (1) to develop and submit an IP waiver application; (2) to help participants, families, and all other stakeholders within the demonstration counties to understand the alternatives available under the IP waiver and the processes related to its implementation; and (3) to evaluate the implementation of the IP waiver, including assessments of participants' quality of life and satisfaction with services.

The grant was awarded to the Ohio Department of Mental Retardation and Developmental Disabilities (hereafter ODMRDD).

Role of Key Partners

The grant's Advisory Committee consisted of individuals with mental retardation and other developmental disabilities and their families, and representatives from the Ohio Department of Jobs and Family Services, the Ohio Association of County Boards of MR/DD, the Arc of Ohio, People First of Ohio, the Ohio Developmental Disabilities Council, the Ohio Provider Resource Association, the Ohio Olmstead Task Force, the Ohio Self-Determination Association, Ohio Legal Rights, and United Cerebral Palsy.

The Advisory Committee, which included persons with the expertise or authority to help eliminate barriers and establish the infrastructure needed to support implementation of the IP waiver, reviewed and provided feedback on the waiver's initial design and on the draft waiver application. They also identified instances in which the draft waiver application conflicted with current statute and helped to develop statutory language to address those conflicts.

Major Accomplishments and Outcomes

- Of the State's 88 county boards of MR/DD, 15 agreed to participate in the design and implementation of the IP waiver. The demonstration counties created local work teams to identify any barriers to implementing the IP waiver and ways to address them. The counties prepared reports, which were compiled and distributed to all stakeholders to inform development of the IP waiver program.
- Grant staff worked with stakeholder groups on several provisions in the IP waiver program, including those related to financial management services (FMS) and quality assurance.
- The new IP waiver application was submitted to CMS in draft form, and CMS provided both verbal and written feedback to be incorporated into the final application. Grant and

other staff in ODMRDD worked to develop a transition policy to enable IP waiver participants to transfer to the Department's Individual Options waiver if they cannot or choose not to continue in the IP waiver (e.g., Individual Options waiver slots will be reserved for this purpose).

- Grant staff developed a draft strategy for obtaining baseline data for individuals prior to enrollment in the IP waiver; however, additional work on data collection has been postponed until ODMRDD is closer to submitting the formal waiver application.
- In preparation for implementing the support broker service in the new IP waiver, grant staff conducted statewide trainings for state and county staff on the support broker's role and responsibilities.
- Grant and other ODMRDD staff helped to establish a family information network to help individuals with mental retardation and other developmental disabilities and their families to acquire the knowledge and skills needed to use a wide range of MR/DD services, including those in the IP waiver.

Enduring Systems Change

- ODMRDD was unable to realize the goal of having an approved IP waiver by the end of the grant period for the reasons mentioned in Key Challenges, below. Instead, ODMRDD planned to submit a self-direction waiver application in 2009 as one of the department's primary strategic goals for the future.

However, in the last budget bill, legislative language requesting that ODMRDD concentrate on developing a waiver for children with intensive behavioral needs was incorporated. To that end, ODMRDD has committed resources to designing this waiver, which will contain elements of participant direction, including both employer and budget authority. The time frame for this new waiver to be operational is 2009.

- Key IP waiver infrastructure components have been developed, including specifications for a statewide FMS entity, which will be available to all agencies in Ohio that have or will have a self-direction option in their waivers and other programs. The contract was awarded in October 2008 by the Ohio Department of Jobs and Family Services, the single state Medicaid agency, to Jewish Employment Vocational Services and currently covers Ohio's Money Follows the Person grant; ODMRDD will look to be added to the FMS contract when it comes up for renewal in 2009.
- As a result of the stakeholder involvement in the development of the IP waiver application, a number of county boards of MR/DD have taken steps to implement more elements of self-direction into their current programs.

Key Challenges

- When the grant was awarded, ODMRDD allowed MR/DD county board participation in the IP waiver to be voluntary, and 23 counties joined at the outset. As components of the waiver infrastructure were being formalized, however, several county boards opted out

for a variety of reasons, including opposition to the mandatory use of an independent support broker service because of their concerns about potential duplication with county board functions.

- The grant initiative received a setback when some stakeholders objected to the statutory language needed to implement an IP waiver in Ohio. The language attempted to treat the IP waiver differently from other waivers so that the State would not have to contend with numerous issues currently affecting other waiver programs. As a result of their lobbying, the authorization was removed from the Budget Bill in 2006. Grant staff worked with a small stakeholder group, whose members included those with concerns about the statutory language, to reach consensus on the legislative language.
- The elimination of Ohio's Community Alternative Funding Source program in 2005 required that ODMRDD design and implement a new waiver reimbursement system, which has taken considerable time, effort, and resources. As a result, work on the IP waiver was placed on hold. The transition to the new reimbursement system was completed in June 2008.

Continuing Challenges

Ohio's Medicaid agency has had difficulty agreeing to the systemic changes needed to incorporate self-direction as proposed in the IP waiver. Discussions about the needed changes are ongoing, but finding a middle ground between ODMRDD and the Medicaid agency has been a struggle.

Lessons Learned and Recommendations

- Contracting with an outside entity (the Center for Self-Determination) to facilitate stakeholder meetings and to convey a national perspective on self-determination was a highly effective approach to constructing a self-direction waiver.
- The State should provide its agencies that administer HCBS waivers with incentives to either submit an application for a new self-direction waiver, or amend one or more of their existing waivers to include services that support self-direction (e.g., financial management services and support brokers). The agencies need to amend the waivers to increase opportunities for self-direction by mandating person-centered planning and allowing participants to exercise employer and budget authority over a comprehensive range of goods and services.

Key Products

Outreach and Educational Materials

- A draft brochure describing the IP waiver was created by one of the county boards of MR/DD that agreed to participate in the development of the waiver. However, since the original brochure was created, modifications have been made to the IP waiver application, so the brochure needs to be modified to conform to these changes prior to distribution. Another participating county developed a self-direction guidebook.

- A PowerPoint presentation entitled *Self-Determination: Principles for Evaluating your System* was created for ODMRDD by the Center for Self-Determination. The presentation has been used as an educational tool at statewide conferences and is currently posted on ODMRDD's website.