April 2009

FY 2003 Grantees: Final Report

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RTI Project Number 0209359.004.004

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Report Overview

In fiscal year (FY) 2001, Congress began funding the Real Choice Systems Change Grants for Community Living program (hereafter Systems Change grants) to help states make enduring improvements in their long-term services and supports system infrastructure. The grants' purpose, as stated in the invitation to apply, was "to enable children and adults of any age who have a disability or long-term illness to (1) live in the most integrated community setting appropriate to their individual support requirements and preferences; (2) exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use, and the manner in which services are provided; and (3) obtain quality services in a manner as consistent as possible with their community-living preferences and priorities."

The Centers for Medicare & Medicaid Services (CMS) awarded the third round of 3-year grants on September 30, 2003. Three categories of grants were awarded: Research and Demonstration grants (48), Feasibility Study and Development grants (16), and Technical Assistance grants (9).

The number and type of Research and Demonstration grants awarded were as follows:

- 8 Community-Integrated Personal Assistance Services and Supports (CPASS) grants
- 9 Money Follows the Person Rebalancing Initiative (MFP) grants
- 12 Independence Plus (IP) grants
- 19 Quality Assurance and Quality Improvement in Home and Community-Based Services (QA/QI) grants

The number and type of Feasibility Study and Development grants awarded were as follows:

- 6 Community-Based Treatment Alternatives for Children (CTAC) grants
- 4 Respite for Adults (RFA) grants
- 6 Respite for Children (RFC) grants

Nine states were awarded Family-to-Family Health Care Information and Education Center (FTF) Technical Assistance grants. The total number of grants awarded was 73.

Virtually all of the FY 2003 Grantees received 1-year or longer no-cost extensions to complete their grants, and they submitted their final reports 90 days after the grants ended, most by December 31, 2007. RTI is preparing a series of final reports to document the outcomes of the Systems Change grants. This report documents the outcomes of the FY 2003 Grantees.

Methods

The principal sources of data for this report were (1) Grantees' semi-annual, annual, and final reports; (2) Grantee-prepared project reports; (3) topic papers prepared by RTI on activities and accomplishments of the FTF Grantees, increasing options for self-direction under the IP Grantees, improving quality management systems under the QA/QI Grantees, and initiatives of the MFP Grantees; and (4) materials developed under the grants. RTI used these reports and materials to prepare final report summaries for each grant, which were then reviewed by key grant staff. The RTI Project Director conducted in-depth interviews to obtain additional information and to clarify information with each Grantee; the revised summary was sent to grant staff for their final review and approval.

Organization of This Report

This report is divided into six parts. The first four parts each provide an overview of the enduring improvements, continuing challenges, lessons learned, and recommendations of the 48 Research and Demonstration Grantees, organized by the four types of grants: CPASS, MFP, IP, and QA/QI. Following the overview in each part is a section containing a detailed summary of each Grantee's initiative.

Part 5 provides an overview of the FTF Grants, followed by brief summaries of each grant initiative. Part 6 contains an overview, followed by brief summaries of the Respite for Adults and Children, and Community-Based Treatment Alternatives for Children grants.

The individual grant summaries describe the Grantees' major accomplishments resulting from numerous activities to address key long-term services and supports issues. In most cases, these accomplishments were essential preliminary steps in the systems change process. In addition to their many accomplishments, virtually all Grantees reported a wide range of enduring improvements that directly or indirectly helped to create a better and/or more balanced service delivery system. In some states, grant activities have acted as a catalyst for additional systems change activities since the grants ended.

Enduring Systems Improvements

Grantees made enduring systems improvements in several areas—many states in more than one area:

Personal Assistance Services and Supports (PASS)

- New policies to enable and support PASS and self-directed PASS
- Increased options for self-directed PASS
- Increased access to self-directed PASS
- Improved quality of PASS for persons with serious and persistent mental illness
- New methods to recruit and retain workers

Money Follows the Person Policies (MFP)

- New assessment and budgeting process for individualized portable budgets
- New MFP funding mechanism
- New infrastructure/funding to support transition services and MFP policy
- Increased access to and funding for home and community-based services (HCBS)
- Increased access to and funding for supported housing
- New process to involve consumers in policy development

Self-Directed Services

- New infrastructure for self-direction program
- New Independence Plus self-direction option in waiver or State Plan program(s)

Quality Assurance and Improvement

- New provider standards or monitoring tools
- New or improved system to collect, analyze, and report quality data
- New or improved methods to measure participant satisfaction and other participant outcomes, and new processes to involve participants in policy development
- New/improved critical incident reporting and/or remediation process or system
- New methods to involve participants in QA/QI processes and policy development

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained expertise in developing and implementing policies and programs to achieve their goal to establish a more balanced long-term services and supports system and to ensure that improvements would be sustained. They reported numerous lessons learned that can guide other states that are pursuing similar systems change efforts.

Involving Participants and Stakeholders

Virtually all of the FY 2003 Grantees agreed that it is essential to involve consumers and other stakeholders in systems change initiatives to obtain stakeholder buy-in and commitment. Stakeholders include individuals or entities that will have authority over or be affected by planned changes: most importantly, the individuals who use services, their families and advocates; community and institutional service providers; Medicaid and other state agency staff; policy makers; and housing authorities.

Involving stakeholders in the development of new policies and programs can help to reduce the apprehension of some stakeholder groups and to ensure that new programs and policies are designed to meet participants' needs within federal parameters.

The involvement of service users, in particular, provides a valuable reality check for program and policy initiatives and can help drive systems change in ways that state staff cannot. It is also essential to ensure broad, strategic participation of stakeholders with the authority and responsibility to bring about change. Enlisting the support of top administrators and securing the commitment of relevant leaders can help to ensure that resources will be committed to a new initiative and that information about systems changes will be communicated to those whose work will be affected.

Both time and resources are needed to achieve buy-in from key stakeholders and to convince them to adopt new ideas and approaches. Stakeholders need to be involved in many activities: from advisory groups to work groups to focus groups. It is also beneficial to provide a forum in which service users and providers can hear about one another's concerns and gain an understanding of the limitations of the long-term services and supports system. Project staff need to clarify what is expected of stakeholders, and, if their input is solicited, be prepared to respond to it.

Sufficient time must be allocated to promote and sustain teamwork and stakeholder collaboration and networking to create the momentum needed to reach consensus on priorities and strategies. Additionally, comprehensive systems change efforts need an effective strategy for communicating with all stakeholders on an ongoing basis. Successful strategies generally require multiple communication methods, such as meetings, e-mail, postings on state department websites, and teleconferences.

Internal communication among state decision makers is crucial to obtain buy-in by management and to ensure ongoing success. State agencies should report progress transparently, encourage stakeholders to review and provide comments on early product drafts, and celebrate milestones achieved. Having a full-time project manager can help states to develop a comprehensive and coordinated communication strategy, and executing Memoranda of Understanding can help to ensure that key stakeholders provide promised support, such as collecting data.

The state staff who develop and will operate new programs are also stakeholders. One Grantee emphasized the importance of a collaborative approach when developing self-direction policies and procedures that will cross systems serving different populations. Doing so will result in a comprehensive design that minimizes duplication while allowing for differences as needed. Another noted that states seeking to implement a single Quality Management System for multiple service delivery systems serving different populations are well advised to spend the time needed to engage all stakeholders in establishing priorities for the project *prior* to submitting a request for funding. When representatives of different service populations could not agree about design and implementation features, grant staff in one state found it helpful to get them back on track by reminding them of their initial agreement about priorities.

Other recommendations include the following:

- 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 (DD) 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 on an advisory committee.

- Provide supports such as transportation, stipends, and information in accessible formats to ensure ongoing participation. Focus groups and key informant interviews are excellent ways to obtain input from diverse service users and families, not just those able to serve on advisory committees and work groups.

- When developing a quality management system, states should base their analysis of the system's performance on what program participants consider to be most relevant to them. Focus groups can be useful in identifying what is important to participants, and obtaining their input validates and provides credibility for the performance measures.

Specific Recommendations

Grantees also had lessons learned and made recommendations specific to the focus of their grants. For example, Wisconsin MFP grant staff conducted transition training for county staff, judges, guardians, and guardians ad litem and advised that states not underestimate the time and resources needed to successfully educate these stakeholders. They further noted that talent and commitment are also critical components; without them, transitions will be compliance driven and could have a negative impact on the quality of supports, as well as the health, safety, and personal growth of individuals being transitioned. Guardians and guardians ad litem need to be informed and involved, and mediation occasionally is needed when a lack of trust at any point in the process or among any of the parties jeopardizes transitions that are critical to an individual's best interest.

Other MFP Grantees stressed that each transition is unique; many factors determine whether a transition will occur, and nursing facility transition programs cannot anticipate every possible transition barrier. Thus, nursing facility transition programs and policies should have maximum flexibility to cover transition-related services and expenses, which is particularly important when transitioning individuals with extensive and/or complex needs. Another MFP Grantee noted that nursing facility transition program staff should not limit their efforts to individuals who are easy to transition, thus putting those who face challenges at the bottom of the transition list. With additional time and effort, even individuals who face many transition challenges can move to the community. States also should provide the flexibility to allow the development of customized transition teams to accommodate time, travel, and resource constraints in rural areas.

Many CPASS and IP Grantees made recommendations specific to implementing self-direction programs, including the need for states to conduct ongoing outreach, education, and training to help stakeholders—particularly long-term services and supports professionals such as case managers—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.

To assist case managers in making the shift from working in the traditional service delivery system to one that allows individuals to direct their services, states first need to understand case managers' fears and concerns and then address them systematically by using research findings and lessons learned from other states' experiences. To reduce the potential for provider resistance to a new self-direction option, it is important that the state frame the new option as one service delivery model in a continuum of options for managing services, including the traditional agency service option. This approach can help to defuse provider opposition as well as to promote informed choice by service users. In addition, to increase professional staff's knowledge of self-direction options, states should provide continuing education or licensing credits for completing training about self-direction.

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." Instead, they recommend that states staff the service planning and development process prior to implementation, with the goal of simplifying it to the extent possible.

Finally, successful outreach efforts for a new service delivery option, such as self-direction, require that individuals and families be informed about the full range of service options available to them early in the referral process. Additionally, participants and their families 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 and meet participants' needs.

QA/QI Grantees made numerous recommendations for implementing new QA/QI initiatives, including the following:

- States should determine where additional funding might be needed to finish work begun under a grant, and/or to supplement grant funds, because technology development often costs more and takes longer than anticipated, especially when integrating new systems with existing ones. This is particularly true when information about the existing system is unavailable and must be researched during the project.
- Whenever possible, states should combine any data system development projects in the quality area with other data systems and projects related to financial systems or other mandated reporting systems. Doing so will help to ensure ongoing financial and technical support for the quality data systems.
- Before designing new data management systems, it is essential to carefully consider how the data will be used and who is the target audience for particular data (e.g.,

CMS or the state legislature). Doing so will help to ensure that the new system provides the needed data. Systems should be designed to provide sound information when needed and to have the capability to quickly and easily identify trends, key issues, and patterns, to enable rapid resolution of program participants' problems.

- States may need to educate the audience for quality data about how to interpret such data. If the data are misinterpreted and used against providers, the providers will be reluctant to provide data in the future.
- States should find ways to identify high performers and provide incentives for high performance, which will help to embed a new quality management system into professional practice in a way that simple compliance systems can never achieve. This goal will most likely require some creative work with providers, advocates, participants, and families to identify ways to recognize excellence.

Approaches to Bringing about Systems Change

Several Grantees reported lessons learned and made recommendations for bringing about systems change generally, including the need to be realistic about what can be accomplished when attempting to implement change within a specified time period. Because progress is often incremental, it may be necessary to focus initially on one or two small changes, particularly when seeking to make major changes to a state's system for ensuring the quality of HCBS. Instead of trying to introduce changes in multiple agencies at the local, regional, and state level in a short time period, it is better to pilot new programs and policies in a limited area.

To ensure the success and sustainability of systems changes initiatives, Grantees noted the importance of several factors, most importantly, planning for sustainability from the beginning and incorporating grant goals and objectives into a state's long-term system reform plan to ensure that grant-related accomplishments will be sustained beyond the life of the grant. For example, a QA/QI Grantee noted that prior to committing resources to QA/QI initiatives, states need to conduct an assessment to determine which activities have priority and ensure that all activities are aligned with existing or planned quality management initiatives.

Others cited the importance of building on former or current systems change efforts or linking them to ongoing, high-profile initiatives such as an expansion of Medicaid managed care, a new quality assurance and quality improvement initiative, the development of an Aging and Disability Resource Center, or other major grant initiatives.

Recommendations for Changes in State and Federal Policy

Given that the Systems Change grants were intended to be catalysts for incremental improvements in states' long-term services and supports systems, most Grantees reported continuing challenges and made many recommendations for changes in state and federal policy to address them. Although Grantees made many recommendations for policy changes that were state specific, many of their recommendations apply generally to all states, including the following:

Money Follows the Person and Transition Policy

- To facilitate transitions, certain waiver operational policies need to be changed, such as those requiring that residents be discharged from a nursing facility before waiver-funded home modifications such as a ramp installation can be made.
- States with waiver waiting lists need to allocate additional funding for more waiver slots.
- State agencies need to address the liability concerns of home health care staff regarding the health and safety needs of persons with complex needs who are transitioning to the community, so that these concerns do not become barriers to community living.
- To support community living, states should fund development of housing, transportation, and health care in rural areas, which often have far fewer services and supports for people with disabilities than do urban areas.
- Housing authorities should consider giving priority on their waiting list to transitioning nursing facility residents, although this may be difficult given the number of homeless people, particularly women with young children, on the waiting list.
- Because lack of affordable, accessible housing is a major transition barrier, states should implement policies that will permit waiver participants to retain sufficient income to pay for community housing (e.g., through Medicaid rules governing post-eligibility treatment of income). States should also extend the cost-sharing exemption for nursing facility residents from 1 month to 6 months.
- HUD should establish an accessible and easy-to-use process for institutional residents to apply for publicly subsidized housing. Currently, individuals must apply in person, which is difficult if not impossible for nursing facility residents who must arrange for accessible transportation to make multiple trips for multiple applications to multiple HUD housing sites.

Self-Direction

- States should increase efforts to serve individuals with a primary diagnosis of serious mental illness in traditional PASS programs and should develop self-directed support services that can help to prevent institutionalization among this population. For example, self-directed PASS could be used to assist individuals with deficits in instrumental activities of daily living as part of their recovery plan.

- Participants' views are essential for informing self-direction policy and practice, and help to inform planning to expand these services. States should offer participants multiple opportunities to report their experiences, particularly when changes are being implemented in the service system. Although the process can be expensive and difficult logistically, participants should be surveyed about their experiences and satisfaction with services and supports.

- The state should allow more flexibility in Medicaid HCBS programs to enable participants to purchase goods and services that can help ensure more favorable health and functional outcomes.

- The Deficit Reduction Act, which created the §1915(j) authority, requires that financial management services (FMS) 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 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.

Quality Assurance and Improvement

- Quality management for HCBS needs ongoing state and federal financial support. Because investments in information technology are essential to improve QA/QI systems, CMS should provide a 90 percent federal match for states to develop data systems that enable them to meet the waiver assurances, even if they are not directly part of the Medicaid Management Information System. CMS should also consider funding continuing costs for IT systems as well as the initial costs for IT development.

- CMS should amend the Participant Experience Survey to add an option for field notes, which would facilitate the survey process. The PES provides ample aggregate-level outcome data that identify programmatic challenges in many service areas. However, the tool does not provide insight into a program's micro-level dynamics. Adding an option for field notes would compensate for the tool's limitation.

- CMS should shift its primary quality management focus from emphasizing regulatory compliance to measuring outcomes—or at least achieve a better balance between the two.

- CMS needs to provide consistent reinforcement of—and help states to better understand and implement—a systems approach to quality management. Also, CMS regional staff who review and approve waiver applications and those who conduct periodic reviews of waiver programs need to better understand the concepts and requirements of a systems approach to QA/QI. Continuing education for CMS staff in this area would be helpful.

- To help states ensure that the data they collect are in accord with the CMS Quality Framework and the waiver assurances, CMS should clarify that the waiver assurances differ from the domains in the Quality Framework, even though some appear to be the same (e.g., service planning). The Framework needs to be clarified to ensure that states' data meet waiver requirements.

- CMS wants states to automate data collection and reporting, but most states have old hardware and software, and the cost to upgrade is very expensive. To obtain the federal 90 percent match for new hardware, states need to fill out a complicated Advance Planning Document (APD), which is extremely time consuming. One Grantee noted that it would take one employee a full year's work to develop an APD. CMS needs to streamline the process for obtaining the 90 percent match to enable states to update their data systems.

- States should consider contracting with Quality Improvement Organizations (QIOs) to conduct quality management activities, because it can help to assure the public that the reviews will be objective. Another advantage is that CMS provides a 75 percent federal match for approved QIOs.

- CMS should establish uniform requirements for unlicensed Medicaid providers.

Increasing Access to HCBS and Supporting Community Living

- States should consider using one of the new HCBS options under the Deficit Reduction Act of 2005 to develop programs that will serve a broader target group of individuals with a wide range of needs.

- The state should lessen the stringency of its level-of-care criteria for nursing facilities.

- All states without a Medicaid Buy-in policy should adopt one to reduce work disincentives for persons with disabilities.

- 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 (IDAs) 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.)

- HUD should increase funding for housing models that promote independent living and self-direction. To ensure accessibility, HUD should also fund pre-development costs, property acquisitions, and home modifications. Ensuring accessible housing is a HUD responsibility, but because of a lack of funding, it is passed to the Medicaid program, which pays for home modifications.

- CMS and HUD should coordinate housing and services policy to enable individuals with disabilities to live in the community. HUD should increase funding for rental assistance and the development of affordable, accessible housing.

- CMS should provide resources to states to purchase local technical assistance (TA) to help improve the HCBS system. National TA providers often lack knowledge of individual state programs, policies, and politics—knowledge that is crucial for devising strategies to bring about systems change.

- 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 investing resources in state infrastructure development to help improve the HCBS system for people of all ages with disabilities. The Systems Change grants have been invaluable for this purpose: allowing states to tailor the funds to meet unique needs. The grants provided resources that would not otherwise have been available. The flexibility afforded by the grant enabled the states to think “outside the box” and to adapt to changes resulting from frequent staff turnover without “jumping through a lot of hoops.”

  However, much more infrastructure development is needed, along with additional funding to continue it. Systems change initiatives require a considerable amount of time to implement and need funding for more than 3 years. Access to grant funding is and will continue to be critical to help states fully implement the systems and technological innovations necessary to meet CMS requirements for §1915(c) evidence-based reporting.

Conclusion

Bringing about enduring change in any state’s long-term services and supports system is a difficult and complex undertaking that requires the involvement of many public and private entities. As Congress and CMS intended, most states used the grants as catalysts for new initiatives or to expand existing initiatives; many used them to leverage funding for existing state efforts to develop and improve home and community-based services.

Despite their many accomplishments and enduring systems improvements, most Grantees described continuing barriers to community living for people of all ages with disabilities. These barriers include insufficient funding for home and community-based services and for infrastructure changes; lack of affordable, accessible housing and transportation; continuing difficulty in recruiting and retaining direct care workers because of low wages and lack of benefits; and outdated or inflexible administrative, statutory, and regulatory provisions.

This report provides an overview of 73 Grantees’ initiatives to improve their long-term services and supports systems and the enduring systems improvements they achieved. It includes lessons learned and recommendations that can guide states that are undertaking similar initiatives. As the population ages, increasing the demands on the service system, these Grantees' efforts will prove invaluable, helping states to provide a greater choice of high-quality participant-directed home and community-based services. These services will enable people of all ages with disabilities or chronic illnesses to live in the most integrated setting consistent with their needs and preferences.

Part 1

Community-Integrated Personal Assistance Services and Supports Grantees

Exhibits

Section One. Overview

Among the long-term services and supports that enable individuals with disabilities to live independently in the community, personal assistance is the most important. Every state provides personal assistance services and supports (PASS) through a Medicaid waiver program, the State Plan, or both. The goal of the Community-Integrated Personal Assistance Services and Supports (CPASS) grants was to help states design systems that not only offer basic PASS but also afford service users maximum control over the selection of their workers and the manner in which services are provided. In FY 2003, the Centers for Medicare & Medicaid Services (CMS) funded eight CPASS grants, as listed in Exhibit 1-1.

Exhibit 1-1. FY 2003 CPASS Grantees

Arizona	Nebraska
Connecticut	Oregon
Louisiana	Texas
Massachusetts	Virginia

Enduring Systems Improvements

In addition to their numerous accomplishments, all but one of the CPASS Grantees reported enduring improvements in their states' PASS systems, as shown in Exhibit 1-2. This section describes the Grantees' enduring improvements in these five areas.

Exhibit 1-2. Enduring Improvements of the CPASS Grantees

Improvement	AZ	CT	LA	MA	NE	OR	TX	VA	Total
New policies to enable/support PASS and self-directed PASS					X				1
Increased options for self-directed PASS				X			X		2
Increased access to self-directed PASS				X	X	X			3
Improved quality of PASS for persons with serious and persistent mental illness			X						1
New methods to recruit and retain workers	X	X							2

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, designing and implementing a pilot program for self-directed services is an accomplishment, whereas enacting legislation requiring a new self-directed services option to be available in all Medicaid waiver programs is an enduring systems improvement.

New Policies to Enable and Support PASS and Self-Directed PASS

Restrictive Nurse Practice Acts (NPAs) can pose a major barrier to community living for persons with disabilities who also have nursing/medical needs. If a state's Nurse Practice Act mandates that only licensed personnel can perform specific nursing tasks, the cost can be prohibitive, particularly for individuals who need such tasks on a daily basis or multiple times per day.

Although Nebraska's Nurse Practice Act had been amended about 15 years ago to allow individuals to direct their personal assistants to perform health maintenance activities such as medication administration, this provision was not reflected in Medicaid policy. Nebraska grant staff worked to incorporate relevant provisions of the State's Nurse Practice Act into Medicaid regulations; now Medicaid beneficiaries can direct all of their care, including health maintenance activities such as insulin injections and catheterization. In addition, Medicaid program staff developed assessment and care plans based on a self-direction model rather than a medical model, which case managers are mandated to use.

Increased Options for Self-Directed PASS

There are several self-direction service models, which vary in the extent of control and responsibility they give to program participants. At one end of the continuum, the agency-with-choice model allows participants to select their workers and to determine how and when services are provided, while having an agency be the legal employer responsible for all tax withholding and payments. The agency-with-choice service model is attractive to individuals who do not want to assume the responsibility for handling these employer tasks.

At the other end of the continuum is the employer/budget authority service model, which allows participants to both employ their own workers and to manage an individual budget to pay their workers and to purchase other goods and services they need to live in the community. Ideally, programs will offer a range of self-direction service models to allow participants to select the model that best fits their needs and abilities.

Prior to receiving the CPASS grant, Texas's Medicaid State Plan Primary Home Care program (offered under the State Plan Personal Care option) gave participants the ability to employ their workers and direct an individual budget. The major goal of the State's CPASS grant was to implement an agency-with-choice service model—the Service Responsibility Option—in the same program.

Information obtained through early grant activities informed the State's self-direction policy, and in September 2007 the State enacted legislation requiring that the Service

Responsibility Option be available not just in Medicaid State Plan services but in all of the State's Medicaid waiver programs, as well as in its managed care programs. Grant staff later developed the regulatory infrastructure to implement the Service Responsibility Option statewide, and regional and local services staff developed policies and procedures outlining the responsibilities of case managers to facilitate access to and the use of the new option.

Subsequently, the Department of Aging and Disability Services staff and the Health and Human Services Commission developed a State Plan Amendment to add Support Consultation as a State Plan service (a requirement of the Service Responsibility Option). Support Consultation Services include skills training and assistance in meeting employer responsibilities and program requirements, such as the development and implementation of backup plans. The Amendment was submitted to CMS on March 30, 2008, and is currently on hold until another State Plan Amendment regarding self-directed services has been approved. Grant staff also developed a comprehensive range of outreach, education, and training materials about the new option.

Grant staff in Massachusetts conducted a workshop for state legislators and their staff about self-direction, which informed their decision to draft legislation requiring the Department of Mental Retardation (DMR) and the Executive Office of Elder Affairs to develop a plan for offering self-direction in the programs they administer. Grant activities also supported efforts to enact self-determination legislation that requires the DMR to develop recommendations for implementing a self-determination model whereby program participants will personally control (with appropriate assistance) a targeted amount of dollars in an individual budget. The governor signed this legislation into law in September 2008.

Increased Access to PASS

Persons with serious mental illness (SMI) can be excluded from PASS programs if the eligibility criteria for these programs do not recognize their specific functional limitations; for example, by requiring that applicants have physical limitations such as the inability to dress or bathe themselves. Oregon expanded Personal Care Services (PCS) offered through the Medicaid State Plan to serve persons with serious mental illness by revising the eligibility criteria to include functional limitations common among this population. The State PCS manual was also revised to illustrate ways in which the eligibility criteria apply to persons with serious mental illness.

State policies can pose a barrier to community living if they require PASS to be provided in a person's home in order to be reimbursed, as was the case in Nebraska. Grant staff worked to amend Nebraska's regulations to allow Medicaid reimbursement for PASS provided in the workplace, eliminating a barrier to employment for people who receive PASS through the Medicaid program.

Massachusetts awarded two mini-grants to community organizations to better understand the cultural factors that influence participation in self-directed services options. As a result of activities conducted under one of these mini-grants, access to PASS for the Latino community in Holyoke, Massachusetts, was increased by helping a range of community service providers to offer culturally appropriate services.

Improved PASS Quality for Persons with Serious Mental Illness

One of Louisiana's goals was to develop a common definition and PASS service model for persons with serious and persistent mental illness (SPMI), for use by the state Medicaid agency, the Office of Mental Health, and service providers, and to integrate the definition and the model into the service descriptions used in existing programs. Although grant staff were unable to achieve this goal, they used the grant to improve the quality of PASS provided to persons with SPMI. Grant staff and partners developed a curriculum to train personal care attendants (PCAs) to work with individuals with SPMI using a train-the-trainer approach. The PASS curriculum improved the quality of care for people with SPMI by providing PCAs with the knowledge and skills to work effectively with them.

Grant staff also developed public education materials regarding self-directed PASS and a website for marketing the PASS training curriculum to mental health service users and PCAs. The website provides information for service users on how to choose and supervise their PCAs and on their rights as consumers. The evaluation instrument for the curriculum has been incorporated into the Office of Mental Health and the Department of Health and Hospitals policies and procedures for ongoing program evaluations. To help improve workforce professionalism, PCA certification requires completion of the curriculum's skills component.

New Methods to Help Participants Recruit and Retain Workers

A major barrier to community living and the provision of high-quality PASS is the widespread shortage of qualified workers, known in different states by a multitude of names: personal assistants, personal care attendants, direct service workers, paid caregivers, direct support professionals, and others. Thus, efforts to improve access to PASS often include efforts to help participants find workers.

One of the advantages of self-direction programs is that they allow participants to hire friends, neighbors, and relatives, which helps to alleviate worker shortages. However, not all participants have this option—and even those who do, still need to find reliable workers to provide services when their regular workers are unable to work or need respite.

Two Grantees' initiatives were aimed at helping participants find workers. Arizona created consumer-owned and –operated service brokerages known as Human Service Cooperatives (HSCs®) and developed a Federated HSC Development and Support Center (Federated

HSC®) to provide technical assistance to HSCs in Arizona and other states. HSC Companies use both standard advertising methods and other approaches to help members find and share workers. For example, the use of affordable Internet communications has facilitated the development of “grapevine systems” through which members can contact one another and coordinate scheduling and staff sharing to ensure coverage. The HSC Companies also help members to purchase adaptive equipment and supplies from local businesses. To enable other states to replicate the HSC supports brokerage model, the Grantee developed business start-up tools, education, training, and outreach/marketing materials.

In collaboration with staff of the State’s Medicaid Infrastructure grant, Connecticut’s grant staff developed a contractual agreement with http://rewardingwork.org to create a Connecticut-specific web page for use by Connecticut personal assistants and self-directing participants. Between January 2005 and September 2007, 2,082 personal assistants from Connecticut registered on the Rewarding Work website. Grant funds paid to operate the link for the grant’s duration, and when the grant ended the Department of Developmental Services paid an additional fee to enable its case managers to use the site for another year. Self-directing participants who could not afford the annual fee were also able to use the website for another year under this agreement.

In addition, grant staff developed personal assistant recruitment and outreach materials in print and video formats and in different languages for use in high schools, community colleges, and other educational settings. Staff distributed materials to provider agencies and disability groups and used excerpts from the video for TV and radio public service announcements. The Department of Developmental Services is continuing to use these materials, and all grant materials are posted on the website of the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities.

To assist participants who want to direct their services, grant staff also created a training curriculum entitled *You Are the Employer* that covers all aspects of hiring and management. The curriculum is available on various websites, in print, and on CDs, in both English and Spanish. A second curriculum was developed specifically for hiring workers to provide services to participants in programs operated by the Department of Developmental Services.

Systems Improvements Beyond the Grant Period

Virginia’s grant staff conducted a survey of self-directing participants in the State’s waiver programs. Based on their high satisfaction rates and an increase in the number of people using self-directed services in the past few years, Virginia is now planning to increase self-direction options, including one allowing participants to direct an individual budget.

Continuing Challenges to Systems Improvements

Grantees successfully addressed many challenges during grant implementation but reported numerous challenges that continue to hamper states' efforts to increase access to and the availability of PASS generally and self-directed PASS specifically.

Three Grantees mentioned problems related to expanding self-directed PASS and increasing access to existing programs: (1) a lack of political and upper management support, (2) insufficient state and local program staff to conduct outreach and enrollment about PASS for persons with SPMI, and (3) resistance to the idea that individuals with developmental disabilities can direct their services.

One Grantee noted that the state lacks a strategic plan for educating all stakeholders and the general public about the meaning of self-determination and about options for persons of all ages with disabilities to direct their services. In addition, Grantees said that municipalities are often not able to support full community integration for people with disabilities because of the lack of affordable and accessible housing and transportation, as well as programs to help youth with disabilities transition from special education to adult programs.

Funding Issues

Three Grantees mentioned lack of funding in several areas as a continuing challenge: (1) funding for state staff to work full time on worker recruitment and retention activities; (2) funding to expand PASS for persons with SPMI because of multiple competing priorities, such as the focus on building a new hospital and on improving the mental health system for children; and (3) funding for the consumer-owned and -directed service brokerages known as Human Service Cooperatives to provide ongoing technical support to existing and newly forming cooperatives.

Policy Challenges

Massachusetts grant staff noted that the State's Medicaid State Plan Personal Care Attendant (PCA) program lacks the flexibility to customize supports for participants. For example, current PCA rules do not allow personal care attendants to assist individuals in critical areas such as conferring with physicians and specialists and helping them to find supports, particularly important when the personal care attendant also serves as an interpreter.

Currently, in Virginia, waiver participants with mental retardation or other developmental disabilities (MR/DD) are allowed to direct only personal assistance, respite, and companion services. Although the State would like to allow participants to direct a greater range of services, some waiver services—such as day support and sheltered workshop programs—

are currently provided only in large congregate settings. Developing reimbursement rates for more individualized services is difficult because large congregate settings are reimbursed based on a unit cost that favors supporting people in groups, which allows several people to be supported by one staff member.

Another challenge cited by Virginia's grant staff is that reimbursement policies for services facilitators do not permit them to adequately support some individuals with extensive needs. For example, they are paid a flat rate for an initial visit, even though some individuals require much more support than others. The State is analyzing how to structure reimbursement to allow services facilitators to meet more regularly with individuals who need more support.

Workforce Issues

Three Grantees noted the continuing difficulty in recruiting and retaining workers to provide PASS because of low wages and lack of benefits. In Connecticut, when the grant ended more than 2,000 personal care assistants were registered on http://rewardingwork.org. Less than a year later, fewer than 600 were registered. Until personal assistants are paid higher wages and benefits, recruitment efforts will achieve only short-term results because of low retention rates. One Grantee noted that linguistic minority groups are underserved or unserved because of the lack of workers who speak their language and/or are familiar and comfortable with their cultural preferences.

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained considerable experience in changing their states' long-term services and supports systems to increase access to PASS generally and self-directed PASS specifically, and to develop policies and services to support the provision of PASS. CPASS Grantees described numerous lessons learned, which they believe can be useful to other states and stakeholders with program and policy goals similar to theirs.

Lessons Learned

Involving Stakeholders

Four Grantees stressed the importance of involving stakeholders and a consumer advisory team in systems change efforts. One noted that systems change requires buy-in and committed stakeholders to drive progress; sufficient time is essential to promote and sustain teamwork and the collaboration and networking of stakeholders to create the momentum needed to reach consensus on priorities and strategies.

Two Grantees commented on the need to have the buy-in of state staff; one said that grant staff should establish ongoing positive working relationships with state agencies responsible for waiver services to facilitate information exchange and to implement changes based on research findings. The other Grantee said that they realized only when their initiative had failed that they should have ensured the buy-in of all stakeholders at the outset, particularly the state Medicaid agency.

Self-Direction Programs

One Grantee noted that participants who direct their services need training to help them recruit and retain workers and that a combination of individual and small group trainings is effective (group trainings because they provide more peer support). This Grantee also said that group trainings should be facilitated by an experienced trainer and that entities should target trainer recruitment efforts in the specific geographic areas where training is planned to prevent the need for trainers to travel long distances.

Another Grantee said that successful outreach efforts for a new service delivery option, such as self-direction, require that individuals and families be informed about the full range of service options available to them early in the referral process.

Recommendations

Grantees made both general and specific recommendations for bringing about systems change, addressing workforce issues, developing and implementing self-direction programs, and for changes in federal and state policy to support self-direction.

Systems Change

Two Grantees made general recommendations for bringing about systems change:

1. The State should promote an active role for local communities in systems change initiatives aimed at increasing community integration for people of all ages with disabilities. The State also needs to increase funding to grassroots organizations working in underserved communities.

2. To ensure the likelihood that systems change initiatives will be sustained, states should link them to ongoing, high-profile initiatives such as (in Texas) the expansion of Medicaid managed care, the new quality assurance and quality improvement initiative, the development of an Aging and Disability Resource Center, or other major grant initiatives.

Workforce Recruitment, Retention, Education, and Training

Two Grantees made recommendations specific to workforce issues that are applicable in many states: (1) states should ensure that service providers, such as home health agencies, educate their workers about cultural differences to enable them to work effectively with ethnic minority individuals; and (2) providers should increase their efforts to recruit workers from minority language communities to ensure access to services for these communities.

Self-Direction Programs: State Policy

Five Grantees made specific recommendations regarding state PASS policy generally and self-directed PASS, specifically. Although some Grantees' recommendations were aimed at their own state, most are applicable to other states as well.

1. The state should amend the Medicaid Personal Care Attendant program to be more flexible and culturally responsive; for example, by providing skills training for personal care attendants in their—and participants'—native language; by allowing PCAs to function as translators in situations related to physical and medical needs; and by providing interviews and assessments in participants' and their PCAs' native language.

2. States should increase efforts to serve individuals with a primary diagnosis of serious mental illness in traditional PASS programs and should develop self-directed support services that can help to prevent institutionalization among this population. For example, self-directed PASS could be used to assist individuals with deficits in instrumental activities of daily living as part of their recovery plan.

3. The state should allow more flexibility in determining budget allocations, because budgets set at the start of a fiscal year may not be appropriate to address participants' changing needs. The state should also allow for more flexible funding categories to better accommodate individual needs and provide more emergency funding that agencies can use for participants in crisis.

4. The state should minimize the current delay between eligibility determination and the start of services.

5. To ensure that persons who do not speak English understand their home and community-based services and self-direction options, states need to translate information and educational materials into the languages widely spoken in the state.

6. To assist case managers in making the shift from working in the traditional service delivery system to one that allows individuals to direct their services, states first need to understand their fears and concerns and then address them systematically by using research findings and lessons learned from other states' experiences.

7. To reduce the potential for provider resistance to a new self-direction option, it is important that the state frame the new option as one service delivery model in a continuum of options for managing services, including the traditional agency service option. This approach can help to defuse provider opposition as well as to promote informed choice by service users. In addition, to increase professional staff's knowledge of self-direction options, states should provide continuing education or licensing credits for completing training about self-direction.

8. States should offer program participants interested in directing their services several options for handling employer and financial responsibilities, such as an agency-with-choice model and a fiscal agent model.

9. States should offer participants multiple opportunities to report their experiences, particularly when changes are being implemented in the service system. Participants should be surveyed about their experiences and satisfaction with services and supports. Although the process can be expensive and difficult logistically, participants' views are essential for informing self-direction policy and practice, and help to inform planning to expand these services.

10. States should mandate the use of person-centered planning when determining the types of supports needed to increase the likelihood that they will promote full community living, as opposed to planning that simply "matches" participants with available services and programs.

CMS Policy

Systems change initiatives, especially those supporting self-direction, require a considerable amount of time to implement, and need funding for more than 3 years.

Section Two. Individual CPASS Grant Summaries

Arizona

Primary Purpose and Major Goals

A new concept called the Human Service Cooperative (HSC®) is transforming the traditional model for human services by bringing together individuals who use human services. Each member of the cooperative is an owner/director who works alongside other members to collectively direct their service needs. The cooperative works to become incorporated and then applies through the state in which the members live to become a certified human services provider. As certified providers, cooperatives are able to partner with their choices of traditional service providers to best fit the needs of each HSC member. More information is available at http://www.federatedhsc.coop/.

The grant's primary purpose was to determine the effectiveness of HSC companies in addressing the need for self-determination and empowerment, and for implementing self-directed services for people with physical and developmental disabilities in Arizona. The grant had three major goals: (1) to develop HSC companies within a sustainable infrastructure; (2) to develop a Federated HSC Development and Support Center (Federated HSC) to provide technical assistance to HSC companies in Arizona and other states; and (3) to prepare educational, training, and outreach/marketing materials for developing HSC companies.

The grant was awarded to the Arizona Department of Economic Security, Division of Developmental Disabilities. The Division contracted with Bohling Inc. (an organization that promotes participant-driven services) to implement several grant activities, including developing the Federated HSC and assisting member owners of HSCs in implementing business and program operations and establishing provider relationships.

Role of Key Partners

- The University of Colorado Health Sciences Center provided research expertise to the Federated HSC to develop training materials, and also evaluated grant activities.

- ResCare—a human services company supporting people with developmental and other disabilities, youth with special needs, adults experiencing barriers to employment, and older people in their homes—provided paid and in-kind technical assistance to the HSC companies in a wide range of areas (e.g., payroll, staff training and supervision, licensing and certification requirements, and other management activities).

Major Accomplishments and Outcomes

- A contractor helped self-advocates and family members to form three HSC companies. All are currently operating and financially solvent.

- The grant contractor assisted self-advocates and family members from two Arizona-based HSC companies in forming the Federated HSC, owned collectively by the HSC membership. The purpose of the Federated HSC is to provide HSC companies with technical assistance in cooperative governance and business operations, such as information on fundraising, group purchasing agreements, recruiting, screening, and training procedures; and how to run a board, conduct meetings, and obtain insurance.

- The Federated HSC, with assistance from a contractor, developed a national purchasing program to provide best-price purchasing agreements with retailers such as Office Max, US Bank, and Medline to HSC company members and affiliates. The Federated HSC also created a resource library of business start-up tools and training for HSC companies.

- The membership from two HSC companies in the State established the HSC Educational Foundation—a 501(c)(3) nonprofit that uses tax-deductible donations to provide funding for the Federated HSC, and to enhance educational and outreach efforts and assist individual HSC companies.

- The Federated HSC has expanded beyond Arizona and has contracted with consumer-related organizations in Michigan, California, Tennessee, and Illinois to provide technical assistance to develop HSC companies in their communities.

Enduring Systems Change

- HSC companies increased the use of participant-directed supports and improved the quality of services through service user ownership and input into service provision. They also increased the availability of services by using flexible approaches to find and share workers, in addition to using standard advertising methods. For example, the use of affordable Internet communications has facilitated the development of “grapevine systems” whereby members can contact one another and coordinate scheduling and staff sharing to ensure coverage.

- The establishment of the three HSC companies and the Federated HSC promoted community integration of people with disabilities by enabling them to employ their own personal care attendants from the community and to purchase adaptive equipment and supplies needed for their care from local businesses.

- Business start-up tools developed through the grant can be used in other states to develop HSC companies.

Key Challenges

- Because of the “newness” of the HSC concept, it was difficult to attract start-up capital from private investors, grants, and the community at large through fundraising. Consequently, service users and contractors developed community partnerships with other traditional providers, such as management companies, and worked out creative financing packages with local banks and lenders to facilitate acquisition of capital funds. They also have begun to develop alternative revenue streams such as loans and charitable contributions through the new HSC Educational Foundation.

- Community businesses and professional organizations were unfamiliar with HSC companies, which made it difficult to establish business partnerships to arrange for group discounts for adaptive equipment, supplies, and other products. The HSC companies and the Federated HSC educated these businesses and organizations about the HSC concept through ongoing communication and participation in local advocacy groups, professional associations, and individual member contacts and outreach.

Continuing Challenges

Current HSC companies are gradually establishing a strong financial base. However, they must continue to educate new members in the cooperative governance process. The Federated HSC continues to struggle with inadequate resources to provide ongoing technical support to existing and newly forming cooperatives. They have limited human capital and have difficulty raising funds to pay expenses, including premiums for business liability insurance.

Lessons Learned and Recommendations

- Many individuals with disabilities and their families have extensive knowledge and experience, and in the cooperative governance system they are able to establish policy and guidelines to ensure that their needs are met and that funds are allocated to do so. The companies report that their administrative expenses are lower than those of traditional agencies and that direct support workers often receive higher payment through HSC companies, and provide better services when working directly for service users than for an agency.

- As interest in HSC companies grows, they must have strong technical business support and educational opportunities for their newly forming boards. Training for new members regarding management of state-funded services, the cooperative governance process, and their responsibilities as members is essential.

- It would be beneficial for significant new initiatives, especially those supporting participant and family self-direction, to be funded for more than 3 years. Three years is sufficient to get started, but organizations as complex as an HSC company based on cooperative governance require more time to establish a firm foundation.

Key Products

Outreach Materials

The Federated HSC created information packets about the HSC mission, vision, business design, and contact information to help members to develop HSC membership, recruit staff, and establish business partnerships.

Educational Materials

HSC members and contractor staff developed a training manual to meet the needs of HSC Boards of Directors, provider staff, and state government staff on how to, respectively, run, serve, and work with HSC companies. Also, HSC members, self-advocates, families, and professionals developed a coordinated training curriculum on how to develop and establish HSC companies.

Technical Materials

HSC members and contractors developed business start-up tools and a set of templates for policy and procedures that can be used by individuals who are developing an HSC company.

Reports

The University of Colorado Health Sciences evaluated HSC activities and developed a report, *The Arizona Human Service Cooperative: Final Evaluation Report*.

Connecticut

Primary Purpose and Major Goals

The grant's primary purpose was to develop the infrastructure and products to promote the effective recruitment and retention of personal assistants, and ensure that persons with disabilities in the State have the knowledge and resources to maximize choice and control of their services. The grant had four major goals: (1) to develop a tool to recruit personal assistants for permanent and backup employment, (2) to create and implement a strategic marketing plan to recruit personal assistants, (3) to develop and deliver management training for employers of personal assistants, and (4) to develop and implement a voluntary professional development program for personal assistants.

The grant was awarded to the Connecticut Department of Social Services, which contracted with the University of Connecticut Center for Excellence in Developmental Disabilities to manage and operate the grant.

Role of Key Partners

- The Department of Public Health provided a list of every certified nursing assistant and licensed practical nurse training program in the State to aid in developing recruitment initiatives.

- The Connecticut Department of Labor helped design and implement a marketing plan.

- The Department of Development Services, several Independent Living Centers (ILCs), and a contractor used the http://rewardingwork.org website to help self-directing program participants who could not afford the annual membership fee to connect with prospective personal assistants.

- A grant Oversight Committee—comprising individuals with disabilities, family members, advocacy organizations (such as United Cerebral Palsy), Independent Living Centers, state agency staff, and representatives of provider associations—met every other month to monitor grant activities and provide input and feedback. The Committee included two subcommittees, one focused on recruitment and one on training. The recruitment subcommittee worked on the recruitment website, recruitment literature, and the project's video productions. The training subcommittee worked on the development of training modules and also helped recruit training teams to pilot a train-the-trainer curriculum.

Major Accomplishments and Outcomes

- Grant staff identified all recruitment initiatives and registries in Connecticut and secured their agreement to develop a single, centralized recruitment website.

- Grant staff conducted focus groups with employers and personal assistants to obtain information on optimal recruitment methods, training methods, and training materials for both employers and personal assistants.

- Grant staff collaborated with the Department of Labor to design and implement a strategic marketing plan for increasing the personal assistant workforce.

- The Oversight Committee's subcommittee on training identified the specific training needs of self-directing participants, and existing curricula on managing personal assistants to use as resource material for developing training modules for personal attendants. The curriculum includes chapters on the following topics: identifying your needs and wants, hiring a personal assistant, tax considerations, employer responsibilities, stress management, communication skills, and additional resources. Samples of management materials are provided in the curriculum (i.e., sample interview questions, employment application and contract, letters, job description checklist, important information for personal assistants form, and review forms). These materials give participants an opportunity to practice during training and can be modified to meet their specific needs.

- Because self-directing participants expressed a strong preference to train their personal assistants themselves, rather than having someone else do so, the grant funded development of fact sheets to give personal assistants during training. The fact sheets addressed a range of topics, including recognizing abuse and neglect, preparing for emergencies, desirable qualities in a personal assistant, managing stress, self-determination and independent living, and setting boundaries and limits.

- Grant staff created a training curriculum to teach self-directing participants how to hire, manage, and train personal assistants. Grant staff also developed a train-the-trainer curriculum. Approximately 24 teams of trainers attended three train-the-trainer sessions to learn how to conduct in-home training sessions with individuals new to self-direction and its associated employer tasks. Each team consisted of an individual with a disability and his or her personal attendant, or a self-advocate with a developmental disability and a staff member from the Department of Developmental Services. During the grant period, 15 of these teams completed the entire training program and conducted 126 in-home training sessions.

Enduring Systems Change

- In collaboration with the Connecticut Medicaid Infrastructure Grant, grant staff developed a contractual agreement with http://rewardingwork.org to create a Connecticut-specific web page for use by Connecticut personal assistants and self-directing participants. Between January 2005 and September 2007, more than 2,000 (2,082) personal assistants from Connecticut registered on the Rewarding Work website.

  Grant funds paid to operate the link for the grant's duration. When the grant ended, the Department of Developmental Services paid an additional fee to enable its case managers to use the site for another year. Self-directing participants who cannot afford the annual fee can also use the website under this agreement for another year.

- Grant staff developed personal assistant recruitment and outreach materials in print and video formats, and in different languages for use in high schools, community colleges, and other educational sites. Staff distributed materials to provider agencies and disability groups and used excerpts from the video for TV and radio public service announcements. The Department of Developmental Services has continued to use these materials since the grant ended. All grant materials are posted on the website of the University of Connecticut, A. J. Pappanikou Center for Excellence in Developmental Disabilities.

Key Challenges

- Grant staff and the training teams completed only 126 of the 250 planned in-home trainings because of several factors. First, trainer skill varied, and some teams required grant staff to play a more active role. As a result, trainings required much more time to complete and required more staff support than initially planned. Second, transportation was sometimes difficult to obtain and many trainers did not want to travel to various parts of the State, even though travel reimbursement was available. Finally, poor health and family members' concerns about their participation prevented some trainers from participating.

- It was not possible to prepare generic training materials because of differences in the three waiver programs: Mental Retardation and Developmental Disabilities; Adult Residential Care Aged 65 and Older, and Disabled; and Personal Care Assistance for persons aged 18 to 64 with physical disabilities. A considerable amount of time was needed to customize the information for the three waiver programs.

Continuing Challenges

- It is very difficult to recruit and retain personal care assistants because of low wages and lack of benefits. When the grant ended, more than 2,000 personal care assistants were registered on http://rewardingwork.org. Less than a year later, fewer than 600 were registered.

- Finding resources to fund staff to work full-time on recruitment and retention activities is an ongoing challenge.

Lessons Learned and Recommendations

- Self-directing participants need training to help them recruit and retain workers. Grant staff found a combination of individual and small group trainings to be very effective. Although the grant focused on individual in-home trainings, group trainings for young adults with disabilities in the community—and people in institutional settings looking to move into the community—provided more peer support than did individual training.

- Group trainings should be facilitated by an experienced trainer.

- To avoid the need for trainers to travel long distances, entities that are conducting training should target trainer recruitment efforts in the specific geographic areas where training is planned.

- Until personal assistants are paid higher wages and benefits, recruitment efforts will achieve only short-term results, given the lack of retention. As noted above, when the grant ended, more than 2,000 workers were registered, and less than a year later, the number was about 600. Given this situation, states need at least one staff person to work full time on marketing and recruitment.

Key Products

Outreach Materials

- Grant staff developed a brochure, *Being a Personal Assistant*, to distribute throughout the State to educate interested persons about becoming a personal assistant.

- Grant staff produced and distributed a video, *It's Not Just a Job! Exploring a Career as a Personal Assistant.* The video was also made available on the website of the University of Connecticut Center for Excellence in Developmental Disabilities.

Educational Materials

- Grant staff developed a training curriculum, *You Are the Employer*, and distributed it on various websites and in print and CD formats, in both English and Spanish versions. The curriculum instructs individuals who want to direct their services how to hire, train, and manage their personal assistants. The curriculum includes two manuals: one for persons who are elderly and for working age adults with a physical disability, and the other for people with a developmental disability and their families. It is available at http://www.hcbs.org/moreInfo.php/doc/1892.

- Grant staff developed individual fact sheets to help employers of personal assistants with new employee training. The titles of the fact sheets were *Self-Determination & Independent Living, Managing Stress, Abuse and Neglect, Desirable Qualities, Preparing for Emergencies, Boundaries,* and *Limits & Etiquette*.

Reports

The University of Connecticut Center for Excellence in Developmental Disabilities conducted a summative evaluation of the grant and developed a final report.

Louisiana

Primary Purpose and Major Goals

The grant's primary purpose was to identify and adopt a successful model of personal assistance services (PAS) for persons with serious and persistent mental illness (SPMI), and to educate service users and providers about the new model. The grant had four major goals: (1) to develop a common definition and service model of PAS for persons with SPMI for use by the Medicaid Agency, the Office of Mental Health, and service providers; and to integrate the model and definitions into service descriptions in existing programs; (2) to develop and implement a training curriculum for all PAS providers based on the service model developed; (3) to ensure that training activities are sustained after the grant period; and (4) to develop and make available public education materials regarding self-direction of PAS.

The grant was awarded to the Louisiana Office of Mental Health.

Role of Key Participating Partners

- Boston University Center for Psychiatric Rehabilitation developed and pilot-tested a training curriculum designed to improve the knowledge and skills of direct service workers providing PAS to persons with SPMI.

- The Mental Health Association of Greater Baton Rouge funded training for master trainers who would be capable of sustaining the pool of trainers in Louisiana.

- A consumer task force helped to develop the definition and service model of personal assistance services for persons with SPMI, and discussed strategies for using the PAS curriculum with other state programs serving persons with SPMI.

Major Accomplishments and Outcomes

- A consultant provided grant staff and a consumer task force with information about PAS best practices for service users with SPMI and service models in other states. Grant staff and the consumer task force developed a description for a new personal assistance services program for persons with SPMI and a potential service delivery model that could be incorporated in various programs statewide.

- Grant staff explored the potential for adopting the new service model in various programs: (1) the state Medicaid Infrastructure Grant's employment-related PAS service, (2) the state Mental Health Rehabilitation program using the new State Plan option authorized under the Deficit Reduction Act of 2005, and (3) programs funded through non-Medicaid funding streams, such as ACT-378—a state-funded resource for persons with mental illness and/or a developmental disability.

- Boston University developed a curriculum with a self-direction focus that uses a train-the-trainer approach. The curriculum teaches personal care attendants (PCAs) how to deliver personal assistance services for persons with SPMI and clients with behavioral issues. The curriculum's knowledge component describes types of mental illness, available therapeutic supports, recovery/resilience of service users with SPMI, provider/ service user confidentiality, self-direction, and client rights. The skills component helps PCAs to establish an effective working relationship with clients, to coach them in daily activities, to collaborate on problem solving, and manage crises. Completion of the skills component of the curriculum meets annual in-service training requirements for PCAs.

- Boston University staff trained nine mental health service users to conduct trainings, and also trained 35 PCAs who were working with clients with SPMI and other disabilities. The Mental Health Association of Greater Baton Rouges funded three service users to attend additional training sessions to become lead trainers so they can train additional trainers after the grant ends. Boston University staff developed pre- and post-tests to assess the effectiveness of the curriculum and the training in improving PCAs' knowledge and skills. Grant staff also developed a consumer satisfaction instrument to determine whether the provision of PAS using the new service model improved service users' quality of care.

Enduring Systems Change

- The PAS curriculum improved the quality of care for people with SPMI by providing PCAs with the knowledge and skills to effectively serve their clients. In addition, the training helped to decrease the stigma associated with mental illness by describing it within a broader context of physical and mental health and explaining that it is an illness, like diabetes, that can be treated with medication.

- Grant staff developed a website to market the PAS training curriculum to service users and PCAs, which will be maintained after the grant ends. The website provides information for service users on how to choose and supervise their PCAs and on their rights as consumers.

- The evaluation instrument for the curriculum has been incorporated into the Office of Mental Health and the Department of Health and Hospitals policies and procedures for ongoing program evaluations.

- Grant staff worked successfully with the Direct Service Worker Registry Workgroup to link receipt of the curriculum's skills component to PCA certification in order to improve workforce professionalism. The Registry is operated by the Licensing Division of the Medicaid state agency. (The Workgroup was a statutorily created body that operated only for a designated period and no longer meets.)

Key Challenges

- Restrictive Medicaid eligibility criteria for HCBS waiver programs and State Plan personal care services precludes enrollment by persons with SPMI.

- Medicaid staff were unable to develop an adequately funded PAS program to meet the needs of the target population. As a result, grant goals for statewide adoption of an SPMI PAS model with training for PCAs were not fulfilled. Instead, grant staff marketed the curriculum to programs and provider agencies serving clients with SPMI who have other primary diagnoses for which they receive personal assistance services.

- The PAS curriculum training in non-Medicaid programs for which persons with SPMI were eligible, though approved, was not implemented, most likely due to lack of funding.

- The hurricanes in fall 2005 delayed grant implementation.

Continuing Challenges

- The State is unable to meet the support needs of persons with SPMI in traditional PAS programs because the types of PAS needed often differ from those provided in Medicaid programs for persons with developmental disabilities, persons with physical disabilities, and elderly persons.

- State staff found it difficult to develop appropriate SPMI personal assistance services because they are familiar only with traditional PAS (e.g., hands-on assistance with activities of daily living), whereas people with SPMI generally need verbal assistance with instrumental activities of daily living.

Lessons Learned and Recommendations

- When it became evident that a PAS program for SPMI was not going to be implemented by the Medicaid agency, grant staff considered other populations that could benefit from the training curriculum. In retrospect, it would have been better when designing the initiative to ensure the buy-in of all stakeholders at the outset.

- States should increase efforts to integrate persons with a primary diagnosis of mental illness into traditional PAS programs.

Key Products

Outreach Materials

Grant staff developed a website (http://www.omh-training.org/) and program brochure to market the PAS training curriculum to provider agencies and service users.

Educational Materials

The Center for Psychiatric Rehabilitation at Boston University developed a curriculum on SPMI PAS (*Personal Assistance Services Skill Training Curriculum*) that includes a knowledge component (basic education on mental health) and a skills component (training on communication and problem solving using a self-direction approach).

Technical Materials

Grant staff developed pre- and post-evaluation instruments that can be used to assess gains in provider knowledge and skills after receiving PAS curriculum instruction.

Reports

Grant staff developed a report on the results of a survey of SPMI clients in community mental health centers statewide about the need for PAS, and a brief report summarizing the grant's activities and outcomes.

Massachusetts

Primary Purpose and Major Goals

The grant's primary purpose was to increase stakeholder awareness and understanding of self-determination and the factors that might influence enrollment in self-directed services options, such as ethnicity, language, age, type of disability, and geographic location. The grant had four major goals: (1) to ensure that the scope and quality of self-direction programs meet participant needs in a culturally appropriate and timely manner; (2) to promote opportunities for self-direction and flexible use and allocation of supports across age and disability categories; (3) to prepare, support, and empower participants and/or surrogates to select service options allowing different levels of self-determination and control; and (4) to develop a long-range plan for systems change to sustain the grant project's successes.

The grant was awarded to the Massachusetts Department of Mental Retardation (DMR).

Role of Key Partners

- The Arc of Massachusetts partnered with the Arc of Greater Lawrence and the Boston Center for Independent Living to conduct a mini-grant project called Community Access to Services and Supports.

- Multicultural Community Services of the Pioneer Valley conducted a mini-grant project called Otro Puente ("Another Bridge").

- The Massachusetts CPASS Coordinating Council managed the grant project and worked on several grant activities. Members included representatives from the DMR, Bay Path Elders, University of Massachusetts Center for Health Policy and Research, Northeast Independent Living, Massachusetts Rehab Commission, MassHealth Operations, Massachusetts Office of Disability, Soul Touchin' Experience, Massachusetts Developmental Disabilities Council, MetroWest Center for Independent Living, Montachusetts Home Care Corporation, Community Partnerships, and the Haitian American Public Health Institute.

- Numerous community, civic, and religious organizations donated supplies, time, and space for grant-related activities.

Major Accomplishments and Outcomes

- The Coordinating Council conducted three annual self-direction symposia in order to (1) receive input about the grant-sponsored initiatives, (2) identify barriers to implementation and solutions for them, and (3) provide information to the staff of other Systems Change grants in Massachusetts to determine ways to sustain initiatives. The Council also worked with the grant's contractors to develop a paper on quality assurance and procedures to ensure quality within a self-direction model.

- The Coordinating Council's Marketing and Outreach Subcommittee conducted nine participant forums regarding self-direction issues. The forums revealed that local communities lacked the infrastructure to enable self-directed community living, such as affordable housing and transportation. They also identified the lack of cultural and linguistic competencies as a major barrier to self-direction. Local policy makers are now looking for ways to include people with disabilities in the community as part of their planning efforts.

- The Coordinating Council's Policy Subcommittee developed a report that inventoried available self-directed services options in Massachusetts and other states, and recommended steps to address barriers to the provision of self-directed services in all programs statewide.

- Grant funding supported two mini-grant projects that (1) designed and implemented a self-directed services option involving a total of 19 individuals of varying ages and disabilities, and (2) developed training and educational resources on person-centered planning and self-direction. The focus of these mini-grants was to understand the cultural factors that influence participation in self-directed services options. Each mini-Grantee was given funds to create individual budgets in the mini-grant projects.

  The first mini-Grantee, the Arc of Massachusetts, identified key competencies that community advisors (called support brokers in other programs) need in order to educate potential participants about service options, and created a guidebook to help participants identify service options. The Arc also translated its assessment tool—for the self-directed services option—into five languages (Spanish, Creole, Portuguese, Khmer, and Russian).

  The second mini-Grantee, the Multicultural Community Services of the Pioneer Valley, used its mini-grant to (1) create a handbook to help participants identify and organize needed services; (2) conduct a survey of participants and their families who use the self-direction option in the Medicaid State Plan Personal Care Attendant (PCA) service to assess their satisfaction with the service and to understand how to improve it; (3) conduct forums with participants, families, and providers in order to address a range of self-direction issues; and (4) arrange training in Spanish to teach CPR, safety precautions, and basic literacy for Latino individuals and families.

- The grant's contracted evaluator conducted structured interviews of participants in the mini-grant projects to measure their satisfaction with services. Findings indicated that participants and staff were highly satisfied with the services they received and with the person-centered planning process. Participants felt that directing their services had a positive impact on their quality of life.

- Grant staff worked with other DMR staff to develop a website that provides participants, caregivers, and providers with information about local resources for self-direction. Grant staff developed an additional website that described the grant's activities, which has remained operational since the grant ended because it provides information about self-direction generally, and information to help ensure culturally appropriate design and delivery of self-direction programs.

Enduring Systems Change

- Grant staff conducted a workshop for state legislators and their staff about self-direction, which informed their decision to draft legislation requiring the DMR and the Executive Office of Elder Affairs to develop a plan for offering self-direction in the programs they administer. Grant activities also supported efforts to enact self-determination legislation that requires the DMR to develop recommendations for implementing a self-determination model whereby program participants will personally control (with appropriate assistance) a targeted amount of dollars in an individual budget. This legislation was signed into law by the governor in September 2008.

- The grant's Coordinating Council developed the Self-Determination Statement and Principles, which continue to inform self-direction policy development and the advancement of self-determination in the State's self-direction programs. The 10 local grassroots coalitions established by the Council's Marketing and Outreach Subcommittee have continued their work to address local barriers to self-directed community living since the grant ended.

- One of the mini-Grantees increased access to personal care services for the Latino community in Holyoke, Massachusetts, by helping a range of community service providers to offer culturally appropriate services.

Key Challenges

- The two mini-grant recipients encountered barriers in providing self-directed services, such as their inability to find direct service workers because of low wages and lack of benefits, and the fragmented nature of the work (i.e., having to provide a few hours of service at one location and a few hours at another). Moreover, although participants with limited English proficiency and those with cognitive and communication impairments are able to direct their services, they are not able to provide skills training for their personal care attendants. Other barriers included the program's eligibility determination process, which does not offer interviews and assessments in individuals' native language, nor can individuals in temporary or transitional housing schedule assessments.

- There was a shortage of workers who spoke participants' languages: Spanish, Creole, Russian, Portuguese, Somali, Vietnamese, Chinese, and Khmer. Also, cultural differences, such as those related to diets and food preparation, made it difficult to match workers to participants.

- Some individuals and their families came from cultures in which "independence and choice" are abstract and/or unfamiliar concepts. Some needed education and values clarification to understand and accept the philosophy and principles underlying self-directed services.

Continuing Challenges

- Not all Medicaid program participants can choose to direct their services.

- Municipalities lack the infrastructure to support full community integration of people with disabilities, such as affordable and accessible housing and transportation. They also lack programs such as summer camps for children with disabilities and those to help youth transition from special education to adult services.

- The MassHealth (Medicaid) Personal Care Attendant State Plan program lacks the flexibility to customize supports for participants. For example, current PCA rules do not allow personal care attendants to assist individuals in critical areas such as conferring with physicians and specialists and helping them to find supports, particularly important when the personal care attendant also serves as interpreter. The program also needs to facilitate the use of surrogates by providing accommodations and training for participants, training for providers and surrogates, and assessment procedures that are adapted for different cultures and/or different disabilities.

- Low wages and lack of benefits make it difficult to attract and retain skilled personal care attendants.

- Linguistic minority groups are underserved or unserved because of the lack of workers who speak their language and/or are familiar and comfortable with their cultural preferences.

- Massachusetts lacks a strategic plan for educating all stakeholders and the general public about the meaning of self-determination and options for persons of all ages with disabilities to direct their services.

Lessons Learned and Recommendations

- The State should provide continuing education or licensing credits for professional staff completing training in self-direction.

- The State should ensure that service providers, such as home health agencies, educate their workers about cultural differences to enable them to work effectively with ethnic minority individuals with disabilities.

- The State should promote an active role for local communities in systems change initiatives aimed at increasing community integration for people of all ages with disabilities.

- The State needs to increase funding to grassroots organizations working in underserved communities.

- The State should make changes to the Medicaid Personal Care Attendant program to be more flexible and culturally responsive, for example, by providing skills training for PCAs in their (and the participant’s) native language; to allow PCAs to function as translators in situations related to physical and medical needs; and to provide interviews and assessments in the native language of participants and their PCAs.

  Other recommended changes include the following:

  - Create additional materials to educate participants and families and empower them to assist themselves and translate these materials into multiple languages.
  - Change state rules to allow more flexibility in funding allocations for budgets, because budgets set at the start of a fiscal year may not appropriately address participants' changing needs in a specific catchment area.
  - Allow for more flexible funding categories to better accommodate individual needs.
  - Minimize the current delay between eligibility determination and start of services.
  - Provide more emergency funding that agencies can use for participants in crisis.
- Systems change requires buy-in and committed stakeholders to drive progress. Sufficient time is essential to promote and sustain teamwork and the collaboration and networking of stakeholders to create the necessary momentum to reach consensus on priorities and strategies.
- Providers should increase their efforts to recruit workers from minority language communities.

Key Products

Outreach Materials

Grant staff developed brochures and fact sheets about self-directed services generally and about grant activities specifically.

Educational Materials

- Grant funds were used to develop a website providing information about the grant and self-directed services. The website includes many of the grant products listed below. (http://www.mass-cpass.com/)
- The mini-Grantees developed the following educational products as resources to promote participants' service choices:
  - *How Can a Community Advisor Help Me? A Guidebook for Using Community Advisors to Help You Find the Choices and Supports You Want*
  - *First Step Consumer Handbook. How to Get Organized to Find the Help You Need: A Bilingual Guide for Newly Arrived Latino Individuals and Families to the City of Holyoke, Massachusetts*
  - *Tools for Tomorrow* in English, Spanish, Creole, Russian, and Portuguese

Technical Materials

The Arc of Massachusetts developed a training manual, *Suggested Competencies, Attributes and Skills of Community Advisors* (i.e., support brokers).

Reports

Grant staff developed the following reports:

- *MASS CPASS/The Arc of Massachusetts' Community Access to Services & Supports Mini-Grant Project Final Report*
- *MASS CPASS/Multicultural Community Services of the Pioneer Valley—Otro Puente Mini-Grant Project Final Report*
- *MASS CPASS Project Evaluation Report*
- *MASS CPASS Coordinating Council Self-Evaluation Report*
- *MASS CPASS Marketing & Outreach Subcommittee Consumer Forum Series Report*
- *MASS CPASS Policy Paper: Recommendations for Achieving System-Wide, Sustainable Self-Determination and Self-Direction in the Commonwealth of Massachusetts*

Nebraska

Primary Purpose and Major Goals

The grant's primary purpose was to give participants more choice and control over personal assistance services (PAS) provided in the home and workplace. The grant had three major goals: (1) to develop an agency-with-choice self-direction option for the Medicaid State Plan Personal Assistance Services program; (2) to ensure that participants can manage their personal assistance needs using the self-direction philosophy; and (3) to enhance the capabilities of adult protective services staff, law enforcement, and the judicial system to provide services to abused and neglected vulnerable adults.

The grant was awarded to the Nebraska Department of Health and Human Services.

Role of Key Partners

- The State's Medicaid Infrastructure Grant's Community Team members helped to develop several conferences and trainings.

- Grant staff established a Consumer Advisory Committee to provide input on the agency-with-choice model. The Eastern Nebraska Office on Aging, the Developmental Disabilities Council, the University of Nebraska Munroe-Meyer Institute, the Home Health Association, the Nebraska Healthcare Association, private in-home providers, personal assistants employed as independent contractors, individuals with disabilities, Aged and Disabled Medicaid waiver staff, and several individual provider agencies designed specifications, certification standards, and defined the roles and responsibilities of both participants and the new agencies—called Personal Assistance (PA) Organizations.

Major Accomplishments and Outcomes

- Grant staff and the Consumer Advisory Committee worked together to develop the blueprint for the new PA Organizations. Activities included comparative research on other states that have self-directed personal assistance services; research on Nebraska's current PAS infrastructure, policies, and laws; and developing design specifications and quality assurance recommendations for the new PA Organizations.

- Grant staff organized three 2-day conferences. The first conference focused on participant safety and the prevention of abuse and neglect of persons of all ages with disabilities. A consultant trained 75 law enforcement trainers and officers, workers and supervisors from Adult Protective Services, and staff from the Attorney General's office on forensic wound identification and documentation to increase their capacity to identify and document signs of abuse; and strengthened their ability to be expert witnesses and to validate their investigative role. A second consultant provided training on how to assess individuals' cognitive capacity to live independently and protect themselves from abuse and neglect.

The second conference trained 200 Aged and Disabled waiver service coordinators, resource developers, and supervisors to identify, prevent, and document abuse and neglect among individuals of all ages with disabilities. The third conference focused on helping 356 Medicaid eligibility staff, supervisors, economic assistance administrators, and policy staff to increase their awareness of resources, services, and information available to persons of all ages with disabilities; and to increase understanding of the importance of participants having control over their services.

Enduring Systems Change

- Grant staff helped to develop PAS regulations to support self-direction. Although the State's Nurse Practice Act had been amended about 15 years earlier to allow individuals to direct their personal assistants to perform health maintenance activities, such as medication administration, this provision was not reflected in Medicaid policy. Grant staff worked to incorporate the relevant provisions of the Nurse Practice Act into the PAS regulations. Medicaid beneficiaries can now direct all of their care, including health maintenance activities such as insulin injections and catheterization.

- Grant staff worked to amend regulations to allow Medicaid reimbursement for personal assistance services provided in the workplace. In addition, Medicaid program staff developed assessment and care plans using a self-direction model rather than a medical model, and case managers are mandated to use these plans.

Key Challenges

Medicaid reform, competing state priorities, a new gubernatorial administration resulting in a major departmental reorganization, and changes in consultants prevented grant staff from implementing the agency-with-choice model in the State Plan Personal Assistance Services program.

Continuing Challenges

A lack of political and upper management support continues to impede implementation of the agency-with-choice model.

Lessons Learned and Recommendations

- States should conduct a cost analysis of the current PAS delivery system prior to attempting to introduce a self-directed services option.

- States should have a clear idea of the nature of the desired system to be implemented prior to beginning work with consultants.

- States should offer participants interested in self-direction several options for handling employer and financial responsibilities, such as an agency-with-choice model and a fiscal agent model.

Key Products

Reports

A contractor developed a report, *Developing and Implementing Consumer-Directed Personal Assistance Services Using Intermediary Services in Nebraska: An Update*. The report provides an overview of the agency-with-choice model and information for stakeholders on implementation strategies.

Oregon

Primary Purpose and Major Goals

The grant's primary purpose was to increase the number of individuals eligible for public mental health services who have the information, skills, and supports necessary to choose and direct services through the Medicaid Personal Care Services (PCS) program. The grant had five major goals: (1) to increase participants' knowledge of the PCS program; (2) to increase access to participant-directed PCS; (3) to increase the knowledge of mental health case managers about the benefits of the PCS program and how to support participant direction of PCS; (4) to promote the awareness and use of effective practices in participant-directed PCS; and (5) to assess the impact of the project on the use of participant-directed PCS, and subsequently, its impact on users' hospitalization rates, self-direction of personal care services, empowerment, and quality of life.

The grant was awarded to the Oregon Health and Science University as an instrumentality of the Oregon Office of Mental Health and Addiction Services. In its second year, the grant was transferred to Portland State University.

Role of Key Partners

- Oregon's Office of Consumer/Survivor Technical Assistance (a consumer/survivor-run and -directed organization) conducted outreach, recruited participants, and implemented the project work plan in partnership with Portland State University staff.

- Oregon Addiction and Mental Health Services staff implemented many of the grant's activities, including outreach to county mental health agencies, trainings for case managers and mental health agency staff, workshop trainings at the statewide Personal Care Services Symposium, and revision of the State's Mental Health Personal Care Services Manual.

- County mental health programs and drop-in centers participated in a field-test of the PCS learning community model.

Major Accomplishments and Outcomes

- Grant staff conducted focus groups to collect information about how current program participants use PCS and its impact on their lives, and about barriers to using PCS; and also discussed issues related to participant direction of PCS with state and consumer leaders. Grant staff used this information to design a plan for marketing participant-directed PCS.

- The grant funded mini-grants to four consumer/survivor-led organizations in Oregon (The Union, SAFE, SHAMA House, and Empowerment Initiatives) for intensive local outreach efforts to potential PCS participants.

- Grant staff developed, piloted, and evaluated a peer-led PCS learning community model to educate potential participants about the PCS program and participant direction. The model consisted of a comprehensive curriculum, and training and technical assistance for consumer/survivor project participants, both delivered by consumer/survivor group leaders in coordination with county mental health case managers.

  The curriculum was field-tested with individuals in four counties who received mental health services and who were eligible for PCS—individuals in two counties participated in the curriculum while individuals in the other two counties were in a comparison group. Grant staff and consumer/survivor leaders provided face-to-face, telephone, and e-mentoring to participants in the PCS field-test.

- Grant staff trained consumer leaders, case managers, and Addiction and Mental Health Services staff in how to implement the PCS learning community model in communities across the State.

- Grant staff developed materials for a website to provide information that would help individuals to enroll in the PCS program and direct their services. In addition, grant staff and consumer/survivor advisors provided technical assistance to mental health case managers via a web page and listserv to promote and support participant-directed PCS.

- Grant staff, in consultation with consumer/survivor advisors, designed and offered training programs for participants interested in learning and enhancing their PCS participant-direction skills.

- Grant staff evaluated the effect of the grant’s education and outreach efforts on participant-directed PCS use, and its subsequent effect on users’ hospitalization rates, self-direction of services, empowerment, and quality of life.

- Grant staff developed recommendations for systems improvements to expand access to and improve participant-directed PCS and disseminated them to county mental health agencies and state authorities. The recommendations focused on training, supervision, certification of personal care assistants, revision of the Oregon Administrative Rules covering the PCS program, and PCS funding.

- Most Oregon county mental health programs do not have a designated staff person with primary responsibility for determining eligibility for, and enrolling individuals in, the PCS program. Grant staff worked with agency staff in the counties in which project activities took place to develop customized eligibility and approval processes.

Enduring Systems Change

The State clarified that the eligibility criteria for PCS offered through the Medicaid State Plan encompassed the functional limitations common among persons with serious mental illness. The State’s PCS manual was revised to provide examples to illustrate ways in which the eligibility criteria apply to persons with psychiatric disabilities. By expanding how the eligibility criteria could be interpreted, the State increased access to PCS for persons with serious mental illness.

Key Challenges

- Knowledge of the PCS program was not widespread in either the agency provider system or within consumer/survivor organizations. Some county mental health program staff questioned whether mental health service users really needed or would benefit from PCS. Other staff were reluctant—or did not know how—to complete the paperwork and viewed the program as an additional burden on their time.

- Educational outreach about the PCS program was needed prior to establishing agency or consumer/survivor organization participation in the project.

- The activities of daily living assistance for which the PCS program was designed were based on a physical disability model, which did not address the challenges faced by individuals with a psychiatric disability. Consultation with the state head of the mental health PCS program and input from case management staff and project participants resulted in a more psychiatric disability–specific interpretation of support services that could be covered by the program.

Continuing Challenges

- The State is committed to participant-directed PCS, but expansion of the program is unlikely in the immediate future, because of multiple competing priorities such as the focus on building a new hospital and on improving the mental health system for children.

- The current number of state and local PCS staff is insufficient to comprehensively conduct outreach and enrollment, which prevents many individuals who could benefit from the PCS program from receiving information and program services.

- The current statutory definition of personal care services continues to present utilization barriers for persons with mental health disabilities.

Lessons Learned and Recommendations

- Grant staff found that working in partnership with all stakeholders was critical to the grant’s success.

- States should increase the role of participant-directed PCS in addressing participant recovery goals and deficits in instrumental activities of daily living.

- Participant-directed community-based prevention and support services need to be developed and expanded for individuals with mental health disabilities to prevent the need for institutionalization.

Key Products

Outreach Materials

Grant staff developed brochures, flyers, posters, and a compendium of stories and testimonials from participants and case managers to describe the grant activities as a way to attract individuals to participant-directed PCS.

Educational Materials

- Grant staff developed the PCS learning community curriculum containing 12 modules, including the State's PCS program and eligibility criteria, recruiting and hiring personal care assistants (PCAs), and supervising work performance of PCAs once in place.
- Grant staff developed information sheets about the PCS program for potential participants and information about how to work with case managers to apply for PCS.
- Grant staff developed materials for a university website to provide information to help individuals to enroll in PCS and direct their services (http://orocta.org/sites/class/).

Reports

Grant staff developed a policy paper on improving and enhancing the PCS program in Oregon and produced a report on the grant's evaluation.

Texas

Primary Purpose and Major Goals

The grant's primary purpose was to increase participant options for controlling personal care services. The grant had one major goal: to implement a Service Responsibility Option (SRO) in the Medicaid State Plan Primary Home Care program (offered under the Personal Care option) to complement the existing Consumer Directed Services option in which participants manage an individual budget and services. The SRO is an agency-with-choice self-direction model.

The grant was awarded to the Texas Department of Aging and Disability Services (DADS).

Role of Key Partners

- The Texas Health and Human Services Commission, the University of Texas-Austin Center for Disability Studies, the Texas Geriatric Education Center, the Texas Geriatric Association, Centers for Independent Living, Area Agencies on Aging, advocacy organizations, a provider association, and individual providers served on the SRO Task Force.

  The Task Force functioned as a work group whose activities included selecting the sites for a pilot demonstration, developing outreach materials and a training curriculum, developing the protocol for the new option, and participating in the evaluation and sustainability planning. When the grant ended, the SRO Task Force was subsumed under the Consumer Direction Workgroup (described below).

- The Health and Human Services Commission—the state Medicaid Agency—helped to develop the infrastructure for the SRO by providing policy guidance through the legislatively mandated Consumer Direction Workgroup (operating since 1999). The Commission also developed and submitted a State Plan Amendment to cover Support Consultation (the State's term for counseling/support brokering) in the Personal Care Option, a key element in sustaining SRO.

- The Texas Geriatric Association provided guidance on outreach strategies.

- Two Centers for Independent Living in the pilot sites worked with the grant's contractor to conduct SRO orientation activities.

- Advocacy organizations, such as ADAPT and Advocacy Inc, conducted outreach through local offices.

- The Texas Association for Home Care invited grant staff to speak about the SRO at their annual meeting and sent out updates about the SRO.

- The Area Agencies on Aging participated in outreach activities.

Major Accomplishments and Outcomes

- The grant's contractor designed and implemented an SRO pilot demonstration in two regions: the Texas panhandle and San Antonio. DADS local and regional staff enrolled 29 individuals receiving care from 18 home health agencies as participants in the demonstration. Because only 114 Primary Home Care participants statewide use the Consumer Directed Services option, enrolling 29 participants in the SRO pilot in just two areas of the State demonstrated significant interest in the new option.

- The grant's contractor designed outreach materials to inform participants about available self–direction options, including the new SRO option. Grant staff distributed more than 5,000 DVDs and 7,000 brochures. The grant contractor also developed orientation and training materials, including an SRO training curriculum, a toolkit, and a self-training DVD for participants.

  In addition, the contractor developed a case manager handbook and a provider operational protocol, both describing their respective roles in and participant use of the SRO. The contractor trained 24 participants, 722 DADS case managers, Area Agencies on Aging staff, 105 providers, and 43 staff in managed care organizations statewide.

- Two Centers for Independent Living mailed a brochure about SRO to all Primary Home Care participants in the two pilot areas, and conducted in-person SRO orientation with individuals who had selected the option.

- Grant staff fielded and analyzed 43 in-person Participant Experience Surveys. Of these, 21 participants were using the SRO, 5 were using the Consumer Directed Services option, and 17 participants were using agency-directed care. Evaluation of the survey data supported the need for the SRO, especially for those who had prior negative experience with attendants from agencies under the traditional service delivery system.

- The SRO Task Force assessed SRO effectiveness and made necessary adjustments in the service protocol to prepare for statewide expansion.

Enduring Systems Change

- Information provided through early grant activities informed the State's self-direction policy, and in September 2007, the State enacted legislation requiring the SRO to be available in all Texas Medicaid waiver programs, State Plan services, and managed care programs. Later grant activities developed the regulatory infrastructure for SRO as well as a comprehensive range of outreach, education, and training materials.

  For example, to implement the SRO statewide, DADS staff drafted Texas Administrative Code rules, Chapter 43. The proposed rules were approved by the Medical Care Advisory Committee on May 8, 2008, and approved by the DADS Council on June 18, 2008. DADS regional and local services staff developed policies and procedures outlining the responsibilities of case managers in facilitating access to and the use of the SRO.

- DADS staff and the Health and Human Services Commission developed a State Plan Amendment (SPA) to add consultation support as a State Plan service, a requirement of the SRO. The SPA was submitted to CMS on March 30, 2008, and is currently on hold until another State Plan Amendment regarding self-directed services has been approved.

- The Health and Human Services Commission has committed to offering the SRO in the State's managed care program and in the Personal Care Services for Children program (available under the Medicaid State Plan Personal Care option). In addition, training on self-direction—including the SRO—is now a standard part of the Texas Association for Home Care quarterly administrators' training.

Key Challenges

- Provider agencies initially resisted the SRO because of concerns about potential liability issues related to the injury of the provider agencies' employees under the management of individuals using the SRO. To counter provider fears, grant partners developed a quality framework protocol to ensure that participants understand their role and responsibility in reducing risks, and to allow some agency oversight in accordance with participants' wishes.

- Because initial enrollment in the SRO was low, grant staff changed their outreach strategy, targeting information sessions to existing gathering places, such as senior centers, rather than relying solely on the DADS regional and local staff to conduct outreach.

- Self-direction requires case mangers to view the individuals they serve differently from how they are used to viewing them. Because this can be difficult, case manager resistance to SRO was prevalent initially. Some case managers found it difficult to make the paradigm shift needed to support participant-directed services. Training sessions were modified to encourage case managers to discuss their concerns and learn from one another.

Continuing Challenges

The State recently added the Consumer Directed Services option to the Intellectual and Developmental Disability waivers and is encountering resistance to the idea that participants in these waivers can direct their own services. The State continues to offer additional education to shift negative and/or skeptical attitudes toward self-direction among service coordinators, case managers, and program staff (e.g., state staff recently completed a series of town hall meetings across the State, which featured a consumer panel).

Lessons Learned and Recommendations

- Successful outreach efforts for a new service delivery option require that individuals and families be informed about the full range of service options early in the referral process. Also, to reduce the potential for provider resistance to a new participant-directed service option, it is important to frame it as one in a continuum of options for managing services, including the traditional agency option. This approach not only can help to bolster provider support but it can also promote informed choice by participants based on their preferences.

- To assist case managers in making the shift from working in the traditional service delivery system to one that allows participants to direct their services, states first need to understand their fears and concerns and then address them systematically using research findings and the experiences of other states.

- To ensure the likelihood that systems change initiatives will be sustained, states should link them to ongoing, high-profile initiatives such as (in Texas) the expansion of Medicaid managed care, the new Integrated Care Management waiver quality assurance/quality improvement initiative, the Aging and Disability Resource Centers, or other grants.

Key Products

Outreach and Educational Materials

- The contractor developed *It's Your Choice*, an outreach brochure on self-direction for participants, and produced a video—*It's your Choice: Deciding How to Manage Personal Assistance Services*—which describes self-direction for participants.

- The contractor created CD and DVD formats of an SRO orientation for participants, which highlights the roles and responsibilities of the participant, the provider agency, and DADS regional case managers. It also provides an overview of the SRO toolkit.

- The contractor produced *The Service Responsibility Option: Consumer Orientation and Training* curriculum and a toolkit for SRO participants. The toolkit includes information about (1) backup planning; (2) participant skill building; (3) interviewing and hiring; (4) selecting and training an attendant; (5) supervising, coaching, and evaluating the attendant; (6) dismissing the attendant; and (7) educating the home care provider agency to streamline the attendant hiring process.

- The contractor produced training materials for case managers and providers: *The Service Responsibility Option: Provider Protocol and the Service Responsibility Option Case Manager Manual.* The training focused on new agency rules for the Consumer Directed Services option, introduced the SRO, explained the philosophy behind participant choice, and discussed how to offer participants the three service management options—agency-directed, participant-directed, and the SRO.

Technical Materials

The grant's contractor and agency staff developed an SRO protocol for use by case managers and providers implementing the pilot demonstration in two regions.

Reports

The grant's contractor produced a report, *Legal Responsibility under the SRO*, which is an analysis of liability issues regarding the SRO.

Virginia

Primary Purpose and Major Goals

The grant's primary purpose was to increase the awareness and use of, and satisfaction with, self-directed personal assistance services (PAS) in three Virginia waivers: Mental Retardation (MR), Individual and Family Developmental Disabilities Support (DD), and Elderly or Disabled with Consumer Direction (EDCD). The grant had three major goals: (1) to determine participant satisfaction with self-directed PAS and with the process of obtaining services; (2) to ensure that participants have the information, tools, and resources to understand and effectively manage and use PAS; and (3) to provide participants, families, and providers with technical assistance to help them understand and use self-directed PAS.

The grant was awarded to the Partnership for People with Disabilities at Virginia Commonwealth University, with endorsement from the Virginia Department of Medical Assistance Services.

Role of Key Partners

- Representatives from public and private providers, including Centers for Independent Living, Community Services Boards, and others (many of whom were services facilitators, i.e., counselors/support brokers), established an informal network and attended grant-sponsored annual forums to learn about and promote self-directed services, and to share experiences about using such services. Network members shared information with their respective communities by meeting with providers and small groups of interested individuals and family members.

- A Training Advisory Team helped to develop, pilot, and review grant products, including a participant satisfaction survey. The Team included individuals with disabilities, family members, and representatives from the Office of Mental Retardation (Department of Mental Health, Mental Retardation, and Substance Abuse Services) and the Department of Medical Assistance Services. Staff from state, regional, and local agencies either jointly developed or reviewed all grant materials. A second smaller group, the Consumer Advisory Team, was formed for the purpose of developing the survey, assisting with developing interview protocols, and reviewing survey results and findings.

- The Department of Medical Assistance Services presented information on self-directed services at the annual forums.

Major Accomplishments and Outcomes

- Grant staff, with the input of the Consumer Advisory Team, designed and piloted an in-person, 53-question survey of individuals using self-directed PAS. The survey focused on access to information about and the use of self-directed PAS, participant choice and control of services, and participant quality of life and satisfaction with care. The survey was piloted with 10 individuals in two areas of the State. Based on the pilot results, grant staff revised the survey to address identified issues.

- Grant staff selected and trained eight interviewers across the State to conduct the survey: three grant staff members, two services facilitators (the position in Virginia responsible for meeting with and supporting the individual who chooses self-directed services), two participants, and one family member. Grant staff developed a method to contact participants, and the interviewers surveyed 145 participants drawn equally from the three waiver programs.

- Grant staff analyzed survey results and produced and disseminated a report of survey findings. In the satisfaction domain, participants overwhelmingly indicated that the services enabled them to be more independent (96 percent) and that they were more in charge of their life (96 percent). Additionally, 94 percent of individuals reported that they were happy with their self-directed PAS, and 97 percent would tell a friend that they should try to obtain self-directed PAS.

  The majority of survey participants also stated that they could do more things in the community because of their self-directed PAS (88 percent) and that the services made it easier for them to go to work or school (86 percent). Responses in the domains of access, use, and choice and control are also available in the full report.

- Grant staff developed educational materials for individuals, family members, and providers to explain and guide the process to obtain and use self-directed PAS. These materials included awareness brochures and a booklet on PAS choice and control, and workbooks for each waiver, providing detailed information on using self-directed services.

  Grant staff assembled and mailed packets of these materials (including the report of survey findings) to 200 primary contacts in Virginia's service system, including state agency administrative staff members, 40 local Community Services Boards, 16 Centers for Independent Living, services facilitators, and other selected providers. Most materials are available on the self-direction website, and print versions are available on request.

- The State is considering adding self-directed supported employment first to the MR waiver and then to the DD waiver to enable participants to engage in individually meaningful activities, such as community work and volunteer activity.

- Grant staff developed a Consumer Directed Services Resource Network to provide information, training, and technical assistance to participants across the State about using self-directed PAS. Early in the grant period, the Network hosted annual forums to provide an opportunity for members to receive updates on changes in self-directed PAS, such as a new Medicaid contract for fiscal agent services. Because of the progress achieved through the grant, the Network no longer meets.

- All of the self-direction outreach, education, and training materials developed under the grant are still in use. Grant staff updated a website on self-directed PAS to facilitate statewide distribution of all grant materials.

- Based on high satisfaction rates among participants in the State's waiver programs and an increase in the number of people using self-directed services in the past few years, the State is planning an expansion of self-direction options, including an option for participants to direct an individual budget.

Key Challenges

- Finding correct contact information for individuals using self-directed PAS was difficult. Grant staff addressed this problem in one of three ways: by selecting the next name on the randomly sorted list, obtaining additional information from the Medicaid agency about the individuals, and contacting services facilitators.

- The participant survey found that some individuals had experienced late payments to their services facilitator and direct service workers. The Department of Medical Assistance Services resolved the payment issues by contracting with a fiscal agent to perform financial management services (i.e., rather than use the government fiscal/ employer agent model, the State now has a vendor fiscal/employer agent model).

- Developing policies for the use of proxies in the survey was a complex and time-consuming process, which entailed reviewing the research literature, designing informed consent procedures, establishing policies, and obtaining Institutional Review Board approval. However, the time was well spent because the process for identifying when proxies should be used and for obtaining informed consent from all participants, as well as from legal guardians or legally authorized representatives, went very smoothly throughout the survey process.

Continuing Challenges

- Waiver participants lack control over their service funds. The State is developing an individual budgeting option to let them control how their service dollars will be spent.

- The only waiver services that can be directed by participants are personal assistance and respite (in the MR, DD, and EDCD waivers) and companion services (in the MR and DD waivers). The State would like to offer participants a greater choice of services, but some waiver services—such as day support and sheltered workshop programs—are currently provided only in large congregate settings. Developing reimbursement rates for more individualized services is difficult because large congregate settings are reimbursed based on a unit cost that favors supporting people in groups because it allows several people to be supported by one staff member.

- Reimbursement policies for self-directed services facilitators do not permit them to adequately support some individuals with extensive needs. For example, the facilitators are paid a flat rate for an initial visit, even though some individuals require much more support than others. The State is analyzing how reimbursement can be structured to allow services facilitators to meet more regularly with individuals who need more support.

- Services facilitators and self-directed PAS workers earn low wages and lack benefits, making it difficult to recruit and retain qualified individuals for these positions.

- Training and technical assistance are needed whenever changes are made to self-direction policies, procedures, or services or processes to ensure that they are understood and utilized. Participants have also expressed a need for more materials and ideas on how to train their direct service workers. The State is using its Systems Transformation grant in part to develop a more comprehensive range of education and training materials as it develops an individual budget option.

Lessons Learned and Recommendations

- Survey results on the successes and challenges of self-directed services help to inform policy and planning for expanding these services. Participants should be surveyed about their experiences and satisfaction with services and supports. Although the process can be expensive and difficult logistically, participants' views are essential for informing self-direction policy and practice.

- Individuals with disabilities should be given multiple opportunities to report their experiences, particularly when changes are being implemented in the services system.

- Grant staff should establish ongoing positive working relationships with state agencies responsible for waiver services to facilitate information exchange and to implement changes based on research findings.

- Having a consumer advisory team is an excellent method for obtaining input. The grant's team provided important assistance with the survey and other project activities.

- Person-centered practices and planning should be used when determining the types of supports needed to increase the likelihood that services, including self-directed services, promote full community living, as opposed to planning that simply "matches" participants with available services and programs.

Key Products

Outreach Materials

Grant staff produced and mailed 12,000 copies of two brochures that provide an overview of self-directed PAS in Virginia: *Consumer-Directed Services in Virginia's Home and Community Based Services Waivers: Are Consumer-directed Services for You?* and *Medicaid Elderly or Disabled with Consumer Direction Waiver: Are Consumer-directed Services for You?*

Educational Materials

- Grant staff developed three comprehensive workbooks for individuals, families, and providers that present information about self-directed PAS and a step-by-step guide to accessing and using the service: *Consumer-Directed Services in Virginia's Mental Retardation Home and Community Based Services Waiver: A Workbook for Individuals, Families, and Providers*; *Consumer-Directed Services in Virginia's Individual and Family Developmental Disabilities Support Waiver: A Workbook for Individuals, Families, and Providers*; and *Consumer-Directed Services in Virginia's Elderly or Disabled with Consumer-Direction Home and Community Based Services Waiver: A Workbook for Individuals, Families, and Providers*.

- Grant staff produced a booklet, *My Choice, My Control, My Community: An Ordinary Life,* describing the background and principles for living an "ordinary" life.

- Grant staff updated an existing website (http://www.vcu.edu/partnership/cdservices) on self-directed PAS in Virginia to host grant-sponsored materials. Grant funds also paid for the creation and distribution of 45 CDs containing grant-sponsored materials.

Reports

Grant staff produced a report—*Medicaid Consumer-Directed Personal Assistance Services in Virginia: A Survey of Services Recipients*—describing survey findings of the experiences of participants using self-directed PAS in Virginia. The report is located at http://www.vcu.edu/partnership/cdservices.

Part 2

Money Follows the Person Grantees

Exhibits

Section One. Overview

Over the past 20 years, many states have created long-term services and supports systems that enable people with disabilities or long-term illnesses to live in their own homes or other non-institutional settings. Although the proportion of spending for home and community-based services (HCBS) waiver programs, personal care, and home health services relative to institutional care was nearly 73 percent in two states (New Mexico and Oregon), nationally, HCBS spending accounted for only 41.7 percent of all Medicaid long-term services and supports expenditures in fiscal year (FY) 2007.

In FY 2003, CMS awarded $6.5 million in grants to states under its Systems Change for Community Living Grants program to help states serve more individuals in their own homes or other non-institutional settings by implementing Money Follows the Person (MFP) initiatives.

Nine states were awarded grants, as shown in Exhibit 2-1.

Exhibit 2-1. FY 2003 MFP Grantees

California	Pennsylvania
Idaho	Texas
Maine	Washington
Michigan	Wisconsin
Nevada	

MFP is “a system of flexible financing for long-term services and supports that enables available funds to move with the individual to the most appropriate and preferred setting as the individual’s needs and preferences change.” This approach has two major components:

- A financial system that allows Medicaid funds budgeted for institutional services to be spent on HCBS when individuals move to the community.
- A nursing facility transition program that identifies institutional residents who wish to transition to the community and helps them to do so.

When funding is truly able to “follow the person,” the proportion of long-term services and supports expenditures spent on institutions and on HCBS will reflect the choice of Medicaid participants.

The purpose of the MFP grants was to enable states to develop and implement strategies to permit funding to follow individuals to the most appropriate and preferred setting.

Enduring Systems Improvements

In addition to their numerous accomplishments, all but one of the MFP Grantees reported enduring improvements to enable money to follow the person, as shown in Exhibit 2-2. This section describes the Grantees' enduring improvements in these six areas.

Exhibit 2-2. Enduring Systems Improvements of the MFP Grantees

	CA	ID	ME	MI	NV	PA	TX	WA	WI	Total
New assessment and budgeting process for individualized portable budgets			X							1
New MFP funding mechanism									X	1
New infrastructure/funding to support transition services/MFP policy	X			X	X	X	X	X	X	7
Increased access to and funding for HCBS					X				X	2
Increased access to and funding for supported housing			X		X					2
New process to involve consumers in policy development				X						1

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 waiver rate setting methodology and new service definitions is an accomplishment, whereas amending a waiver and revising administrative rules in order to change service definitions and payment rates are an enduring systems improvement.

New Assessment and Budgeting Process for Individualized Portable Budgets

In addition to financing policies that constrain the choice of setting in which an individual can receive services, states' reimbursement policies can also constrain individuals' choice of service provider. This was the case in Maine for participants in the State's mental retardation (MR) waiver.

Maine used its MFP grant to develop a standardized assessment and budgeting process for MR waiver participants that enables them to have individualized person-centered portable budgets. The State amended its §1915(c) Comprehensive waiver and revised the MaineCare (state Medicaid program) rule for services for persons with mental retardation to change service definitions and payment rates to better reflect individual service costs, and to allow individual budgets to follow the person from provider to provider. The new service definitions and associated rates also ensure that participants have sufficient funds to support their service choices.

New MFP Funding Mechanism

For Wisconsin, the grant's primary purpose was to develop the infrastructure to support transitions from intermediate care facilities for persons with mental retardation (ICFs/MR) and from nursing facilities to the community. Grant staff developed and implemented two MFP funding mechanisms: one for ICF/MR residents (the ICF Restructuring Initiative) and one for nursing facility residents (the Community Relocation Initiative). Under these MFP initiatives, institutional funds for transitioning residents are used to pay for community services. As part of the two initiatives, Wisconsin also identified ICFs/MR to be downsized or closed and nursing facility beds to be closed.

New Infrastructure/Funding to Support Transition Services and MFP Policy

Two fundamental components of an MFP policy are (1) a method to identify institutional residents who wish to transition to the community, and (2) a transition process with adequate funding to help them do so. Several states used their grants to develop these components. For example, California developed a survey to identify the preference of individual nursing facility residents to return to community living and a nursing facility transition planning protocol. The State is now using the survey and planning protocol (the Preference Interview Tool and Protocol) and an associated training curriculum in its new MFP demonstration grant and plans to promote its use in all of the State's nursing facilities.

Washington developed, validated, and implemented an assessment tool that provides information on service needs and informal supports to facilitate participant choice regarding services. The tool will facilitate community placement for individuals living in Residential Habilitation Centers who want to live in the community. Staff in the Washington Division of Developmental Disabilities are providing training and support for case/resource managers and social workers using the new assessment tool. Since the tool was finalized, it has been used by Division of Developmental Disabilities field staff to assess and develop service plans for 7,232 participants.

Several states developed transition services and/or methods to fund them. For example, Michigan's Department of Community Health added nursing facility transition services to the MI Choice waiver and began using civil monetary penalty funds to support additional nursing facility transition services. In Nevada, the State Independent Living Program established a Community Transition Fund to help nursing facility residents not eligible for funding through other sources to move to community settings.

In Pennsylvania, as a need for transition services to help facilitate the State's nursing facility transition program became apparent, grant staff helped to facilitate the addition of Community Transition services to 7 of the State's 12 HCBS waivers. Grant staff also helped develop a fund for transition services for individuals who do not qualify for waiver services, supported by the Departments of Aging and Public Welfare. Based on the success of the grant's nursing facility transition initiative, the legislature and the administration increased funding for HCBS waiver programs and the nursing facility transition program.

To enable nursing home residents with complex needs to transition, Texas established regional transition teams to coordinate their services.

Training to Support Transitions and MFP Policy

The Michigan Grantee funded the Michigan Disability Rights Coalition to develop a training curriculum for state, waiver, and case management agency staff on providing nursing facility transition services. The State continues to use this curriculum to develop additional capacity for nursing facility transitions.

One of Texas's grant goals was to ensure that transition staff and other stakeholders use a person-centered approach and consider all available Department of Aging and Disability Services (DADS) program options when conducting transitions. Training provided under the grant increased knowledge about community living options and service users' right to choose any option among transition team members, DADS staff, and community stakeholders, as well as staff from nursing facilities, home health agencies, and other medical providers.

One of Wisconsin's grant goals was to create a regional support system to enable service users, guardians, guardians ad litem, county administrators, and other key stakeholders to understand and choose alternatives to ICFs/MR. As part of this initiative, grant staff helped to educate guardians ad litem and other judicial personnel about their roles and responsibilities during the transition planning process and through the relocation process. The technical assistance and training on person-centered planning during transitions have given service users, their guardians and families, and guardians ad litem a stronger voice in determining the type and intensity of services and supports that will be provided, as well as their location. Grant-funded education and training materials on transition and community living continue to be used since the grant ended.

Increased Access to and Funding for HCBS

People cannot transition from institutions to the community if the services they need are unavailable—either because the state does not offer them or has a waiting list for services. To address this problem, Nevada modified its waiting list policies for the state-funded non-

Medicaid Personal Assistance Services Program and the Independent Living Program to give priority to individuals who want to transition.

The enactment of Wisconsin's new MFP policy for ICF/MR residents gave the State's counties more control over funding, which enables them to create more options for community-based long-term services and supports. For example, the transition of a large number of ICF/MR residents to the community increased demand for community services and supports. To meet the demand, county staff collaborated with MFP grant staff in a range of activities to increase the supply of new providers and to expand the capabilities of existing providers to serve individuals with high or complex support needs. Wisconsin now has new community providers for supported living services, and existing providers have altered service delivery to be more person centered and to enable them to serve individuals with greater physical and behavioral health needs.

Increased Access to and Funding for Supported Housing

In addition to services, institutional residents who want to transition need affordable, accessible housing. One of Nevada's grant goals was to increase access to affordable, accessible housing. To achieve this goal, the Nevada Developmental Disabilities Council created a permanent Housing Specialist position (initially partly funded by the grant) to help transitioning nursing facility residents find appropriate housing, and to educate policy makers about housing issues. The Nevada Office of Disability Services created the Nevada Housing Registry, a website with information on available housing, to facilitate housing searches. The Office has continued to support the Registry since the grant ended. Maine used some grant funds for a contractor to develop a new supported housing option for persons with disabilities, which Medicaid participants are now using.

New Process to Involve Consumers in Policy Development

Although not a specific goal of the MFP grants, CMS required Grantees to meaningfully involve service users, stakeholders, and public and private partners in planning activities. Michigan went further and created a process to give service users and families a central role in defining and implementing the systems changes necessary to realize MFP principles.

Grant staff and contractors participated in a State Long-Term Care Task Force and produced a report on the long-term services and supports system. The Task Force developed recommendations to help achieve a better balance of expenditures between institutional and home and community-based settings, among them recommendations regarding MFP policies. Based on the recommendations, the Governor established the new Office of Long-Term Care Supports and Services, which now coordinates long-term services and supports throughout the State, and also established the Governor's Long-Term Care Commission, which grew out of the State Long-Term Care Task Force. In addition to service users, the appointed Commission members include representatives of county and regional agencies, provider groups, advocates, and nursing facility industry representatives. The Commission serves as a source of public input on long-term services and supports planning.

In addition, the Consumer Task Force, which was established as an advisory body for the grant, continues to meet monthly to advise state staff on long-term services and supports issues, policy, and programmatic features. Other grants will continue to support consumer participation in this activity.

Continuing Challenges to Transition and Balancing

Grantees successfully addressed many challenges during grant implementation but reported numerous remaining barriers to transitioning institutional residents to the community.

Lack of Funding for HCBS

Six Grantees mentioned lack of funding for HCBS as a major continuing challenge, noting weak state economies that have reduced state revenues and general fund appropriations relative to inflation. In one state, the lack of funding is reflected not only in a lack of HCBS but in an insufficient number of state staff, which has slowed implementation of the state's balancing strategy. One Grantee said that increasing costs for health care and social supports make any system changes nearly impossible.

In Nevada, efforts to liberalize Medicaid financial eligibility criteria have not yet been successful because of concerns about their budgetary impact. Maine, which does not fund case management services for persons with brain injury, has been unsuccessful in securing funding from the legislature to establish a trust fund for persons with brain injury to help finance case management, outreach, prevention, and education.

In Wisconsin, because funding for its ICF Restructuring Initiative is approved biennially, once funds are exhausted, individuals who want to transition must wait for the budget to be renewed or additional funds appropriated. Also in Wisconsin, finding resources to educate county staff, judges, guardians, and guardians ad litem to ensure that transitions are in the best interest of institutional residents continues to be a major challenge.

One Grantee said that serving individuals with complex medical needs in the community is difficult because home health agencies are sometimes reluctant to provide the needed services based on concerns about liability and what they view as inadequate reimbursement.

Lack of Affordable and Accessible Housing

Four Grantees cited lack of affordable, accessible housing as a major transition challenge. Two noted the lack of federal funding for housing, and two pointed to inflexible Housing and

Urban Development (HUD) requirements. For example, HUD requires individuals to apply in person to register on a HUD waiting list, which presents a major barrier for many institutional residents. Similarly, an individual who is receiving a housing subsidy and is subsequently institutionalized is required to reapply for the subsidy. Many states have waiting lists of a year or longer for Section 8 vouchers. Individuals can become dependent on institutional services while waiting for the housing subsidy, making it difficult to return to and remain in the community.

Pennsylvania's grant staff noted that the State's aging housing stock is not accessible and that the lack of affordable, accessible, and integrated housing is often the primary reason that individuals entering nursing facilities for short-term rehabilitation end up staying for a long time.

Medicaid and State Policies and Practices

Six Grantees mentioned policy and practice challenges. Even in states with multiple waiver programs, some individuals with disabilities who need long-term services and supports fall through the cracks because each waiver has its own target population, functional or medical criteria, and assessment process. Grant staff in Pennsylvania noted that because the State has a higher income eligibility standard for nursing facilities than for the waiver program, some nursing facility residents may be unable to afford to live in the community.

Three of the Grantees mentioned challenges related to assessment and reimbursement methodologies. Maine's Department of Health and Human Services has not yet identified a standardized assessment/resource allocation tool to use in its published rate system and is currently evaluating what role such tools should play in the establishment of individual budget allocations. Maine also lacks an assessment tool to measure readiness for transition from residential care facility living to a less restrictive setting. Additionally, the State has a reimbursement model for persons with brain injury who live in fully supervised housing but not for individuals capable of living in housing with less than full-time support. As a result, individuals in this population cannot move to settings that provide only partial support.

Nevada's complex funding structure for Medicaid coverage of nursing facility stays has greatly complicated the development of an MFP policy. Counties do not contribute to the cost of waiver services but pay the nonfederal share of institutional care for individuals with income between 156 percent and 300 percent of the federal Supplemental Security Income (SSI) payment. Because many counties do not track these payments, it has been difficult to determine the fiscal impact of an MFP policy for the State. In Washington, developing methods for the State to balance funding between institutional and home and community-based settings cannot be completed until the assessment tool is fully implemented in the case management information system. The first phase of this system was implemented in March 2008, and a second phase will be implemented in May 2009.

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained expertise in developing and implementing policies and programs to achieve their goal to establish a more balanced long-term services and supports system and to ensure that improvements would be sustained. Grantees described numerous lessons learned, which they believe can be useful to states and stakeholders interested in developing MFP policies and a more balanced long-term services and supports system.

Lessons Learned

Washington's grant staff noted several factors that were critical to the success of its project: (1) a strong executive management commitment to project success; (2) a talented and committed in-house project management team; (3) strong and flexible project planning; (4) expert, efficient analysts who write clear documentation; (5) participation of respected and committed service users and advocates; (6) accessible, dedicated, and experienced field service staff; (7) a brilliant, creative, and flexible in-house computer programming team; (8) open, honest, and frequent two-way communication among all project stakeholders; and (9) an adequate budget to support project objectives.

Reflecting the importance of the second factor, another Grantee noted that the scope and scale of the systems change resulting from its grant would have been accomplished in a more coordinated and comprehensive manner had a full-time project manager been assigned from the outset.

Two Grantees stressed the need for training transition staff and other stakeholders. One said that staff needed to learn how to converse objectively and tactfully with individuals and proxy decision makers because decisions about transitioning back to the community can affect many aspects of a person's life—as well as their family's—and family relationships are often very complex. The other Grantee said that HCBS waiver program administrators may need training on person-centered protocols, risk negotiation, and quality assurance for individuals with complex, long-term chronic care needs and/or disabling conditions.

Wisconsin grant staff conducted transition training for county staff, judges, guardians, and guardians ad litem and said that states should not underestimate the time and resources needed to successfully educate these stakeholders. They further noted that talent and commitment are also critical components; without them, transitions will be compliance driven and could have a negative impact on the quality of supports, as well as the health, safety, and personal growth of individuals being transitioned. Guardians and guardians ad litem need to be informed and involved, and mediation occasionally is needed when a lack of trust at any point in the process or among any of the parties jeopardizes transitions that are critical to an individual's best interest.

Recommendations

Program Implementation

Two Grantees pointed out that each transition is unique; many factors determine whether a transition will occur, and nursing facility transition programs cannot anticipate every possible transition barrier. Thus, nursing facility transition programs and policies should have maximum flexibility to cover transition-related services and expenses. This is particularly important when transitioning individuals with extensive and/or complex needs. Another Grantee stressed that nursing facility transition program staff should not limit their efforts to individuals who are easy to transition, thus putting those who face challenges at the bottom of the transition list. With additional time and effort, even individuals who face many transition challenges can move to the community. States also should provide the flexibility to allow the development of customized transition teams to accommodate time, travel, and resource constraints in rural areas.

Involving Stakeholders

Six Grantees had recommendations regarding stakeholder involvement. One emphasized the need, generally, to build strong partnerships and relationships with stakeholders throughout the state in order to improve and sustain systems that serve people with disabilities in the community. Another noted that to accomplish major systems change goals, it is necessary to obtain the commitment of relevant state agencies, such as the Medicaid agency, as well as legislators and other policy makers.

Additionally, comprehensive systems change efforts need an effective strategy for communicating with all stakeholder groups on an ongoing basis. Successful strategies generally require multiple communication methods, such as meetings, e-mail, postings on state department websites, and teleconferences. State agencies should report progress transparently, encourage stakeholders to review and provide comments on early product drafts, and celebrate milestones when achieved. Having a full-time project manager can help states to develop a comprehensive and coordinated communication strategy, and executing Memoranda of Understanding can help to ensure that key stakeholders provide promised support, such as collecting data.

State Policy

Some grant staff targeted their recommendations to their own state, but several are applicable to other states as well.

- State agencies need to address the liability concerns of home health care staff regarding the health and safety needs of persons with complex needs who are transitioning to the community, so that these concerns do not become barriers to community living.

- The state should fund development of housing, transportation, and health care in rural communities, which often have far fewer services and supports for people with disabilities than do urban areas.

- Housing authorities should consider giving priority on their waiting list to transitioning nursing facility residents, although this may be difficult given the number of homeless people, particularly women with young children, on the waiting list.

- Person-centered planning should be the foundation of service planning in all HCBS waiver programs.

State Medicaid Policy

Six states made specific recommendations for changes in Medicaid policy to facilitate transitions. As with recommendations for state policy, most recommendations for a specific state are applicable to other states.

- The state should consider using one of the new HCBS options under the Deficit Reduction Act of 2005 to develop a program that will serve a broader target group of individuals with a wide range of needs.

- To facilitate transitions, certain waiver operational policies need to be changed, such as one requiring that a resident be discharged from the nursing facility before waiver-funded home modifications such as ramps can be made.

- The state should allow more flexibility in Medicaid HCBS programs to enable participants to purchase goods and services that can help ensure more favorable health and functional outcomes.

- The state should lessen the stringency of its level-of-care criteria for nursing facilities.

- Because lack of affordable, accessible housing is a major transition barrier, the state should implement policies that will permit waiver participants to retain sufficient income to pay for community housing (e.g., through Medicaid rules governing post-eligibility treatment of income). The state should also extend the cost-sharing exemption for nursing facility residents from 1 to 6 months.

- The state should level the playing field between nursing facility and home and community-based services by establishing a community spend-down option.

Federal Policy

- HUD should increase funding for housing models that promote self-direction and independent living. To ensure accessibility, HUD should also fund pre-development costs, property acquisitions, and home modifications. Ensuring accessible housing is a HUD responsibility, but because of lack of funding, it is passed to the Medicaid program, which pays for home modifications. The state knows how to develop and finance affordable, accessible housing, but there are insufficient resources to meet the many competing demands for housing.

- HUD should establish an accessible and easy-to-use process for institutional residents to apply for publicly subsidized housing. Currently, individuals must apply in person, which is difficult if not impossible for nursing facility residents who must arrange for accessible transportation to make multiple trips for multiple applications to multiple HUD housing sites.

- CMS and HUD should coordinate housing and services policy to enable individuals with disabilities to live in the community. HUD should increase funding for rental assistance and the development of affordable, accessible housing.

CMS

- CMS should continue investing resources in state infrastructure development. The Systems Change grants have been invaluable for this purpose: allowing states to tailor the funds to meet unique needs. However, much more infrastructure development is needed, along with additional funding to continue it.

- CMS should provide resources to states to purchase local technical assistance (TA) to help improve the HCBS system. National TA providers often lack knowledge of individual state programs, policies, and politics—knowledge that is crucial for devising strategies to bring about systems change.

Section Two. Individual MFP Grant Summaries

California

Primary Purpose and Major Goals

The grant's primary purpose was to develop a survey to identify nursing facility residents who want to return to community living, and to develop a nursing facility transition (NFT) planning protocol. The grant had four major goals: (1) to develop and pilot-test the survey and planning protocol with nursing facility residents, and to publish the results; (2) to identify barriers in accessing Medicaid waiver services for transitioning nursing facility residents; (3) to determine the amount and cost of transition services for nursing facility residents in the pilot project who returned to the community, as well as their self-reported quality of life; and (4) to analyze Money Follows the Person (MFP) systems used by other states in order to identify potential MFP mechanisms and implementation barriers for California.

The grant was awarded to the California Department of Health Care Services.

Role of Key Partners

- The Borun Center for Gerontological Research and the David Geffen School of Medicine at the University of California, Los Angeles (UCLA), developed the survey, the NFT planning protocol, and pilot project.

- The Andrus Gerontology Center at the University of Southern California (USC) helped evaluate assessment instruments used in waiver programs, and in nursing facility, home health, and assisted living settings for potential use in California.

- The State's Olmstead Advisory Committee and several service users participated in grant activities by reviewing reports, the draft survey, and the NFT planning protocol.

Major Accomplishments and Outcomes

- Boren Center and Andrus Center staff evaluated 13 existing needs-based assessment instruments used by California's and other states' home and community-based services (HCBS) waiver programs, nursing facilities, home health agencies, and assisted living facilities for potential survey questions. Their findings informed the development of the survey instrument and the NFT planning protocol by UCLA staff, who worked with the Olmstead Committee to obtain feedback on the survey and the protocol from stakeholders and service users throughout the development process.

  UCLA staff piloted the survey and NFT planning protocol in two nursing facilities, completing interviews with 227 nursing facility residents. They found that 25 percent of residents in one facility and 56 percent of residents in the other expressed a preference for transition. Based on the pilot's findings, staff revised the survey and NFT planning protocol.

The transition protocol was coordinated with care planning protocols for two California waiver programs—the Multipurpose Senior Services Program (MSSP) and the Assisted Living Waiver Pilot Project (ALWPP)—as well as the county-based In-Home Supportive Services (IHSS) program available under the Medicaid State Plan. The MSSP serves Medi-Cal beneficiaries who are 65 years or older, and the ALWPP serves beneficiaries aged 21 or older. The ALWPP covers services provided only in Residential Care Facilities for the Elderly or in subsidized housing projects. The IHSS program serves individuals of all ages who have functional or other limitations that require personal care supports.

- UCLA staff conducted a pilot project using the revised survey and NFT planning protocol with 227 nursing facility residents and with proxies of 148 additional residents, and identified 88 residents or their proxies who expressed interest in transitioning to the community. Of these persons, 13 people actually transitioned.

- UCLA staff developed a list of Medicaid waiver and State Plan service agencies with contact information in order to make referrals using the NFT planning protocol. They also used demographic, referral, and case-specific data on transitioning nursing facility residents to identify challenges and successes in NFT care planning.

- The State developed a job description for a transition coordinator and provided grant funding for a social worker to perform this role in the pilot project in order to gain NFT experience. The transition coordinator job description is being used under the State's Deficit Reduction Act (DRA) MFP rebalancing demonstration.

- UCLA staff made recommendations for using the survey and NFT planning protocol and on how to streamline HCBS waiver programs' intake processes, which will inform the State's DRA MFP rebalancing demonstration.

Enduring Systems Change

The survey and NFT planning protocol (the Preference Interview Tool and Protocol) and an associated training curriculum will be used in California's new MFP Demonstration grant and will be promoted for use in all of the State's nursing facilities.

Key Challenges

- The number of nursing facility residents who actually transitioned (13) was much lower than expected. Transition barriers included the lack of affordable housing; waiting lists for waiver services; difficulty coordinating the change from Medicaid eligibility for nursing facility services to Medicaid eligibility for HCBS; and the need to coordinate the timing of multiple events, including the filing of paperwork to reroute SSI payments from the nursing facility to the individual's new residence after transitioning.

  In addition to waiting lists, services were often unavailable for a variety of reasons, including the following: (1) residential care facilities participating in the ALWPP were not always available in preferred locations; (2) setting up an IHSS assessment could take as long as 60 to 90 days, and there was confusion about whether assessments could be conducted in a nursing facility; and (3) each waiver program has restrictive targeting criteria (age, diagnoses, and functional limitations) that some nursing facility residents did not meet, as well as limitations in service coverage. Finding a waiver that fit the resident—in terms of both eligibility criteria and covered services—was a major challenge.

- Nursing facilities did not have a strong incentive to participate in the pilot, and project staff experienced difficulty recruiting facilities. Project staff also had difficulty setting up interviews with guardians and other proxy decision makers, some of whom opposed transition.

- UCLA staff were unable to obtain Minimum Data Set (MDS) data because it took too long to finalize a data use agreement; the data would have been outdated by the time the project team obtained it. These data can vary over time for the same individual because of cognitive impairment, depression, changes brought about by drug interactions or side effects, and other factors.

  Instead of conducting an MDS section Q data-driven project, UCLA staff used a systematic interview protocol to interview Medicaid-eligible nursing facility residents with a stay of at least 90 days in order to gain as much information and experience as possible with residents' preference for HCBS.

- Because of the small sample of successful transitions, UCLA staff were unable to collect program, cost, or service plan data to inform development of basic fiscal assumptions for a state MFP policy.

Continuing Challenges

- Some individuals with disabilities who need long-term services and supports "fall through the cracks" of the State's multiple waiver programs, each with its own target population, functional or medical criteria, and assessment process.

- Waiting lists for some home and community-based services remain a transition barrier.

- HUD housing requirements, such as those for a face-to-face application to get on a HUD waiting list, pose barriers for individuals residing in institutions.

- The State does not currently operate single points of entry; however, progress is being made under the State's MFP Rebalancing demonstration and under another federal grant (California Community Choices) to develop single entry points using the Aging and Disability Resource Center model.

Lessons Learned and Recommendations

- Transition staff need training to learn how to converse objectively and tactfully with individuals and proxy decision makers. Social networks and family communications are complex, and decisions about transitioning back to community living affect many aspects of a person's life. Conversations and follow-up actions must be highly coordinated and clearly communicated. Also, it is important to clearly define roles and responsibilities to avoid confusion about who is handling the discharge and transition planning.

- States may find it very helpful to obtain technical assistance and to provide training for HCBS waiver administrators on person-centered protocols, negotiating risks, and ensuring quality for individuals with complex, long-term chronic care needs and/or disabling conditions. Technical assistance can also be helpful when states are developing and standardizing fiscal assumptions for HCBS policy.

- The State will be working toward a systematic user-friendly process for ascertaining individuals' preferences regarding their living situation and services, whether in their home, a residential care facility, or a nursing facility.

- Person-centered planning should be the foundation of service planning in all HCBS waivers.

- States may want to consider having integrated waivers (as opposed to separate waivers with separate target population criteria), and using a single uniform assessment process that facilitates transitions. In the absence of a single program or broad eligibility criteria for all waivers, a single service-planning protocol—one that considers all HCBS waiver programs—is needed to determine which program best meets individuals' needs. Alternatively, the State should consider using one of the new HCBS options under the DRA-2005, to develop a program that will serve a broader target group of individuals with a wide range of needs.

  Under the MFP demonstration, California will consider making adjustments in HCBS waiver eligibility criteria and service coverage so that any person transitioning to the community will have access to a comprehensive range of services based on his or her needs and preferences.

- Nursing facility residents seeking to transition require an accessible and easy-to-use application process for publicly subsidized housing. Currently, individuals must apply in person, which is difficult—if not impossible—for nursing facility residents, who must arrange for transportation that is accessible and available to make multiple trips for multiple applications to multiple HUD housing sites.

- Each individual who wants to transition is unique, and many factors determine whether a transition will occur, such as the availability of informal care and an individual's level of motivation. Given this situation, NFT programs and policies should have maximum flexibility to cover transition-related services and expenses.

- Certain waiver operational policies need to be changed to facilitate transitions; for example, requiring that a resident be discharged from the nursing facility before waiver-covered home modifications such as ramps can be made.

Key Products

Educational Materials

The UCLA/USC team developed a training manual for conducting the preference survey in nursing facilities. The same team developed a PowerPoint presentation to be used in training transition coordinators.

Technical Materials

UCLA staff developed and tested the preference survey instrument and NFT planning protocol. A technical paper on the survey was published in the January 2008 issue of the *Journal of the American Geriatrics Society (JAGS):* “Transitioning Residents from Nursing Facilities to Community Living: Who Wants to Leave?” by Nishita, C. M., Wilber, K. H., Matsumoto, S., and Schnelle, J. F. In the same issue, *JAGS* published an editorial on the same subject by Rosalie Kane.

Reports

UCLA/USC staff developed *California Pathways—Money Follows the Person: Final Report*.

Idaho

Primary Purpose and Major Goals

The grant's primary purpose was to improve the ability of people of all ages with long-term services and support needs to live in the community. The grant had four major goals: (1) to facilitate community integration through an anti-stigma campaign; (2) to examine the political and fiscal feasibility of increasing resources for community living and explore ways to create a more hospitable community through a community development project; (3) to study the effect of participant-created, goal-directed community integration plans on functional outcomes; and (4) to identify ways to increase funding for community-based services through a statewide service utilization and economic analysis.

The grant was awarded to the Idaho Department of Health and Welfare, which subcontracted grant activities to the Idaho State University Institute of Rural Health.

Role of Key Participating Partners

- The Idaho State Broadcasters Association helped arrange free air time for public service announcements on Idaho radio and TV stations for an anti-stigma campaign.

- The Idaho Council on Developmental Disabilities and the Idaho Department of Transportation provided funds for printing brochures about the anti-stigma campaign.

Major Accomplishments and Outcomes

- Grant staff conducted a statewide survey to provide baseline data on the needs of persons with disabilities and/or long-term illnesses and the resources available to meet those needs. Grant staff used a complex sampling strategy to ensure representation of persons of all ages with all types of disabilities; 485 respondents participated in the survey. Grant staff also surveyed 98 agencies and organizations to determine what disability populations they were serving and which services and supports were being provided.

- Grant staff conducted three anti-stigma campaigns—two statewide and one regional—to educate the general public about people with disabilities. The surveys that were conducted to evaluate the effectiveness of the campaigns found that they had minimal to no effect for two reasons: (1) only 9 percent of a random sample of 400 persons reported seeing or hearing about the campaign, and (2) 95 percent of respondents said they knew and were comfortable working or living with people with disabilities and therefore did not need to have their attitudes changed.

- A grant-funded contractor worked with a wide range of volunteers—people with disabilities, family members, policy makers, and others—on a community development project in three counties in eastern Idaho. The purpose of the project was to help the communities to develop sustainable community resources that could make community living more feasible and "hospitable" for persons with disabilities. The communities are continuing to work together to develop an accessible playground for children with disabilities.

- Grant staff conducted a study of community integration with 23 individuals with disabilities and/or chronic illnesses and more than 50 family members to determine its economic feasibility and potential benefits. The study found that community integration improves individuals’ quality of life and helps decrease the negative impact of disability on emotional functioning.

- Grant staff provided information and education for service users, advocates, and other stakeholders who were working with the legislature to enact (1) legislation making violations of the ADA a Human Rights violation. With the enactment of this law, individuals who believe their rights under the ADA have been violated can make a complaint to the Idaho Human Rights Commission; and (2) a mandatory seat belt law to prevent injuries that can lead to a need for long-term services and supports.

Key Challenges

The State had several governors within a short period of time, which resulted in many organizational changes that made it difficult to determine strategies for bringing about systems change.

Continuing Challenges

The greatest challenge to improving the home and community-based services (HCBS) system is the weak state economy. Increasing costs in health care make any systems changes, or contemplation of systems changes, nearly impossible, although Medicaid funding for HCBS has increased over the past several years.

Lessons Learned and Recommendations

- Building strong partnerships and relationships with stakeholders throughout the State is essential for improving and sustaining systems that serve people with disabilities in the community.

- Idaho should fund development of housing, transportation, and health care in rural communities, which often have far fewer services and supports for people with disabilities than do urban areas.

- Idaho should allow more flexibility in Medicaid HCBS programs to allow participants to purchase goods and services that can lead to more favorable health and functional outcomes.

- Community development is not synonymous with community participation. It also requires expertise in a wide range of areas including economics, business, and urban and rural planning.

Key Products

Outreach Materials

The anti-stigma campaign used four public service announcements, a brochure, and three posters to increase awareness among the general public about the life experiences of people with disabilities and about the need to better integrate people with disabilities into the community.

Reports

The Grantee developed a report on the Idaho Real Choices project that covers the activities of both the Real Choice and Money Follows the Person grants. The report is available at http://www.isu.edu/irh/technical_reports/reports/real_choices_report_10-18-2006.pdf.

Maine

Primary Purpose and Major Goals

The grant's primary purpose was to develop or improve the infrastructure for providing person-centered, community-based services. The grant had three major goals: (1) to develop a standardized assessment and budgeting process for mental retardation waiver services that generates individualized, person-centered, portable budgets; (2) to increase the number of community service options for persons with brain injury by redirecting resources to participant-directed services in more integrated community settings; and (3) to develop and implement cross-system performance measures to assess success in expanding community service options for persons with disabilities.

The grant was awarded to the Maine Department of Health and Human Services (DHHS).

Role of Key Partners

- The Office of MaineCare Services (the state Medicaid agency), the Office of Information Technology, and other DHHS agencies helped coordinate grant activities, wrote rules to establish new service definitions and rates, and communicated with stakeholders.
- The Maine Association of Community Service Providers worked with grant staff on a wide range of grant activities to develop a standardized assessment and budgeting process for mental retardation waiver services.
- Two consumer groups played significant roles. The Disability Rights Center provided input on proposed rules for rate setting, reviewed existing DHHS service rules and practices, and reviewed individual service authorizations on behalf of individual service users. Speaking Up For Us helped establish and review service definitions for home supports, work supports, and community supports.

Major Accomplishments and Outcomes

- DHHS developed eligibility, service assessment, and budget assessment tools to assist in creating new service definitions, as well as a method for determining new waiver service rates to allow portability of individual budgets, fairness and equity in service determination, and community integration of persons needing services.
- To determine the new rate structure, DHHS obtained and evaluated historical cost data for waiver services from regional offices to identify strategies for adjusting rates.
- A contractor conducted a provider cost survey and follow-up interviews to clarify and confirm survey findings.
- DHHS developed a waiver rate setting methodology for home, community, and work supports and tested the new rates and service definitions with 18 providers to assess their financial impact.

- A contractor and grant and other state staff provided consultation and training for community service providers and regional state staff about the new rates and the service authorization process. Grant staff also worked with MaineCare to revise the claims system to accommodate the new billing procedures.

- DHHS designed and implemented a pilot that offered community service options for persons with brain injury. As part of this effort, DHHS catalogued current housing options for persons with brain injury, and a contractor developed a model to assess participants' readiness for transition to a more independent housing option.

- Grant staff provided information and implementation guidelines for proposed legislation to create a Brain Injury Trust Fund.

- A grant contractor helped the Brain Injury Association to develop and implement leadership and advocacy training for service users.

- DHHS developed survey tools and administrative methods to measure participants' satisfaction with DHHS services using performance measures similar to the National Core Indicators. DHHS also developed a framework for assessing community integration using four domains (access to services, locus of control, place, or setting).

Enduring Systems Change

- The State amended the Section 1915(c) Comprehensive waiver and revised the MaineCare rule for services for persons with mental retardation in order to change service definitions and payment rates. The new service definitions and associated rates better reflect individual service costs and allow individual budgets to follow the person from provider to provider. This will ensure that participants have sufficient funds to support their service choices. State staff also developed a new Support waiver that includes some of the same services as the Comprehensive waiver. The published rates for services are the same in both waivers.

- A grant contractor developed a new supported housing option for persons with disabilities, which Medicaid participants are now using.

Key Challenges

- When the State replaced individually negotiated budgets with a fee-for-service system, providers were concerned that the new rates and definitions for waiver services for persons with mental retardation would decrease their revenues. The change from billing based on individually negotiated budgets to a standard reimbursement rate that is paid only for services actually provided has required providers to become more business oriented, which has been difficult for some. The State developed forms to assist them and implemented a pilot to help providers understand the new system.

- Incorporating a new authorization and rate structure into the Medicaid claims system was challenging because the current MMIS was already undergoing a major change.

- Determining whether it was feasible for waiver participants in residential care facilities to transition to a less restrictive setting was difficult because DHHS did not have an assessment process for that. DHHS addressed this challenge by pilot-testing potential assessment tools with residential care clients to determine whether it accurately identified individuals who were ready to transition.

- Learning a new authorization process and their role in the new system was challenging for DHHS regional staff, including team leaders, resource coordinators, and case managers. It was difficult for management staff to oversee all of the changes while also performing their regular responsibilities.

Continuing Challenges

- DHHS has not yet identified a standardized assessment/resource allocation tool to use in its published rate system and is currently evaluating what role such tools should play in establishing individual budget allocations.

- Maine has a reimbursement model for persons with brain injury who live in fully supervised housing but not for individuals capable of living in housing with less than full-time supports. As a result, individuals in this population cannot move to settings that provide only partial support, which would afford them some independence.

- Maine lacks an assessment tool to measure readiness for transition from residential care facility living to a less restrictive setting.

- Maine does not fund case management services for persons with brain injury. The legislature did not enact the legislation to establish a trust fund for persons with brain injury to help finance case management, outreach, prevention, and education. The bill will be reintroduced during the next legislative session.

Lessons Learned and Recommendations

- The scope and scale of the systems change that resulted from this grant would have been accomplished in a more coordinated and comprehensive manner had a full-time project manager been assigned to the project from the outset.

- Comprehensive systems change efforts need an effective strategy for communicating with all stakeholder groups on an ongoing basis. DHHS used many methods to accomplish this, including meetings, e-mail, postings on the DHHS web page, and teleconferences. As noted above, a full-time project manager would likely have developed a comprehensive and coordinated communication strategy.

- To accomplish major systems change goals, grant staff need to obtain the commitment of relevant state agencies, such as the Medicaid agency, as well as legislators and other policy makers.

Key Products

Educational Materials

- Grant staff and a contractor developed several PowerPoint presentations about the development and implementation of the new rate system for DHHS staff, providers, case managers, families, and service users.

- Grant staff developed a training guide and associated materials for a Brain Injury Advocacy Training course on leadership issues.

Technical Materials

- DHHS developed a template for providers to assess the financial impact of the new rates on their business operations. DHHS also developed a guide for providers who participated in the pilot phase of the new rate structure, an outline of essential elements needed to successfully implement the new rate structure, an authorization rate calculator that converts authorized units of service to a billing rate, and a summary of final rates.

- DHHS conducted an analysis of service claims for persons with brain injury to aid in service planning and developed a report on housing options in Maine for persons with brain injury.

- A contractor compiled a list of performance indicators from a variety of sources (e.g., National Core Indicators, Participant Experience Survey, Maine Core Indicator Project) from which to select community integration indicators.

- A contractor developed a Transition Readiness Analysis comprising two psychometric tools to test the readiness of individuals currently in residential care facilities to transition to supported housing.

Reports

- DHHS developed a report, *The Maine Rate Model: An Overview of the Published Rate Model and Methodology*, to educate stakeholders about the new rate setting model.

- A contractor developed a report, *Establishing the Acquired Brain Injury Trust Fund in Maine*, to provide background information for legislators and advocates involved in developing legislation to establish a trust fund.

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

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[1] 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 control basic features of their life, such as where and with whom they want to live, what services they feel they need, and what they want to do with their time. The term *self-directed* may not imply these features.

- 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 also provide guidance 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 Michigan Partners for Freedom—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). More than a thousand 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 (POSM). 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; and the PCP and other self-determination materials and approaches 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 (e.g., Assertive Community Treatment), 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 (e.g., identifying values and using open-ended questions).

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. The data for the analysis were collected during the bimonthly

Self-Determination Implementation Leadership Seminars, during which participants identified training topics needed to support their job performance.

Nevada

Primary Purpose and Major Goals

The grant's primary purpose was to identify and address systematic barriers to community living for nonelderly people with disabilities and to transition nursing facility residents into the community. The grant had four major goals: (1) to balance Nevada's long-term services and supports system to ensure that the majority of people with disabilities are served in community settings, (2) to develop recommendations to ensure that institutional funding follows transitioning nursing facility residents into the community, (3) to increase access to affordable housing and improve Medicaid home and community-based services (HCBS), and (4) to promote peer advocacy and education for service users and their families about community living options.

The grant was awarded to the Nevada Department of Health and Human Services, Office of Disability Services.

Role of Key Partners

- The Division of Health Care Financing and Policy (the state Medicaid agency) developed a tool to assess nursing facility residents' interest in and resources for community living, conducted nursing facility transitions, and recommended systems changes to the legislature.

- The Strategic Plan Accountability Committee for People with Disabilities, appointed by the Governor to oversee implementation of the State's Olmstead Plan, identified needed systems changes and presented them to the state legislature.

- The Northern Nevada Center for Independent Living developed recommendations for statutory and regulatory changes to facilitate nursing facility transitions. It also partnered with grant staff to educate providers about Olmstead issues and about Money Follows the Person (MFP) policy.

- The Southern Nevada Center for Independent Living developed an inventory of resources and services for people with disabilities.

- The Nevada Independent Living Council provided funding for transition costs to help nursing facility residents return to the community.

Major Accomplishments and Outcomes

- Consultants helped grant staff develop recommendations for state legislative committees to address barriers to community living, such as the lack of an MFP policy and of coverage for the medically needy, restrictive financial eligibility criteria, and limited exemptions from Medicaid cost-sharing obligations. For example, individuals admitted to a nursing facility are given only a 1-month exemption from cost-sharing liability. If their nursing facility stay exceeds 1 month, they have no income other than $30 per month (the personal needs allowance) to maintain their community housing.

- Staff with the Division of Health Care Financing and Policy's Facility Outreach and Community Integration Services (FOCIS) program identified and assessed 1,250 nursing facility residents and transitioned 305 of them to the community. FOCIS staff used $65,419 in Community Transition Funds to pay transition costs for 80 of these residents. Staff contacted all residents transitioned for a follow-up evaluation as part of a quality management strategy.

- The Office of Disability Services created the Nevada Housing Registry, a website with information on available housing to help nursing facility residents who were transitioning to locate housing.

- Consultants developed and—together with grant staff—presented recommendations to the state legislature to (1) require owners of rental units that have received public funding to report available accessible units to the Nevada Housing Registry, and (2) require hospital discharge planners to explore community alternatives to nursing facility placement.

- Grant staff partnered with the Northern Nevada Center for Independent Living to host two conferences to educate social services providers, medical providers, social workers, discharge planners, and nursing facility staff about Olmstead issues and MFP policy.

- The FOCIS program, a county agency, and the largest hospital in Northern Nevada developed a pilot nursing facility diversion program for hospital discharge planners, but it has not been implemented because of a shortage of hospital staff.

Enduring Systems Change

- The state-funded non-Medicaid Personal Assistance Services program and Independent Living program have modified their waiting list policies to give priority to individuals who are seeking transition from nursing facilities to the community.

- The State Independent Living Program will continue to fund the Community Transition Fund to help nursing facility residents move into the community.

- The Office of Disability Services will continue to fund the Nevada Housing Registry.

- The Nevada Developmental Disabilities Council created a permanent Housing Specialist position to help transitioning nursing facility residents and housing providers find appropriate housing placements, and to educate policy makers about housing issues. The position was initially funded partially by the grant.

Key Challenges

- The lack of affordable, accessible housing was a major transition barrier. The State has fewer Section 8 vouchers than in prior years, and Nevada's housing authorities have not been willing to give priority for vouchers to transitioning nursing facility residents. The grant's Housing Registry has helped to identify available housing for these individuals.

- Lack of informal care presented a transition barrier for some individuals, particularly those with extensive and complex needs.
- The pilot diversion program was not implemented because of a lack of interest among hospital discharge planners.

Continuing Challenges

- Finding affordable, accessible housing is a continuing challenge. An individual who is receiving a housing subsidy and is subsequently institutionalized is required to reapply for the subsidy. Nevada has at least a 12-month waiting list for Section 8 vouchers, during which individuals can become dependent on institutional services, making it difficult for them to return to or remain in the community.
- A complex funding structure for Medicaid coverage of nursing facility stays has greatly complicated the development of an MFP policy. Counties do not contribute to the cost of waiver services but pay the nonfederal share of institutional care for individuals with income between 156 percent and 300 percent of SSI. Because many counties do not track these payments, it has been difficult to determine the fiscal impact of an MFP policy for the State.
- Recommendations to liberalize Medicaid financial eligibility criteria have not yet been successful, given concerns about their budgetary impact.

Lessons Learned and Recommendations

- It is important that nursing facility transition program staff not focus their efforts on individuals who are easy to transition while putting those who face challenges at the bottom of the transition list. With additional time and effort, even individuals who face many transition challenges can move into the community.
- The State should lessen the stringency of its level-of-care criteria for nursing facilities.
- The State should extend the cost-sharing exemption for nursing facility residents from 1 to 6 months.
- CMS and HUD should coordinate housing and services policy to enable individuals with disabilities to live in the community.
- HUD should increase funding for rental assistance and the development of affordable, accessible housing.
- Housing authorities should consider giving priority on their waiting list to transitioning nursing facility residents. This may be difficult, however, given the number of homeless people and women with young children on the waiting list.

Key Products

Outreach Materials

The Northern Nevada Center for Independent Living created an *MFP Community Integration Nursing Facility In-Reach Project* brochure.

Educational Materials

- A consultant developed a manual identifying procedures to follow in pre- and post-transition activities.
- Grant staff, consultants, and partners created presentations on Nevada Assessment and Transition. Topics included Reviewing a Medical Record, Understanding Olmstead, Assessment & Transition, Nevada's Strategic Plan for People with Disabilities, and Discharge Planning and After Discharge.

Technical Materials

- The Southern Nevada Center for Independent Living developed a Disability Resource Online Directory containing an inventory of websites, handbooks, and publications on disability services in Nevada (http://www.sncil.org/).
- The Office of Disability Services created the Nevada Housing Registry, which contains a list of affordable, accessible housing units and is available online at http://www.nevadahousingregistry.com/.

Reports

Consultants created white papers on the recommended design of Nevada's MFP policy and on recommended policy and program changes for implementing the State's MFP policy. A consultant also created a report on transition barriers.

Pennsylvania

Primary Purpose and Major Goals

The grant's primary purpose was to determine what changes were needed in Pennsylvania's financing structure to support a single appropriation for long-term services and supports and to develop a Money Follows the Person (MFP) strategy. The grant had two major goals: (1) to conduct Nursing Facility Transition (NFT) demonstrations and to allow funding for nursing facility residents to follow them into the community; and (2) to develop and implement a long-term MFP strategy by consolidating the state budget appropriation and the Medicaid institutional and community long-term services and supports appropriation.

The grant was awarded to the Pennsylvania Governor's Office of Health Care Reform.

Role of Key Partners

- The Departments of Aging and Public Welfare created an NFT program.

- Two Area Agencies on Aging (AAAs) and one Independent Living Center conducted NFT projects in their areas to demonstrate the use of state transition funding and the transfer of state-appropriated Medicaid institutional funding for use in community settings.

- The Pennsylvania Housing Finance Agency worked with local housing agencies to help identify affordable, accessible housing for nursing facility residents transitioning into the community.

Major Accomplishments and Outcomes

- Grant staff and staff from the Departments of Aging and Public Welfare developed an NFT technical assistance guide identifying NFT policies and procedures. They also worked with the Pennsylvania Housing Finance Agency to help increase the number of housing authorities supplying affordable, accessible housing for the NFT program by providing incentives through the Low Income Housing Tax Credit Program. Points were awarded for developing additional affordable, accessible units through the Qualified Allocation Plan, and a system was set up that provides biweekly e-mails listing available units throughout the State.

- Grant staff and staff from the Departments of Aging and Public Welfare conducted monthly technical assistance calls to address issues identified by AAAs and waiver service providers; these issues concerned the use of information systems such as OMNIA, Social Assistance Management System (SAMS), and the Front Door Information System, and identifying housing options and barriers to community transitions.

- Since 2003, the State has funded the transition of more than 2,500 service users from institutions to community living.

Enduring Systems Change

- Grant staff, along with other staff from the Governor's Office of Health Care Reform and the Departments of Aging and Public Welfare, were instrumental in adding NFT services as a Medicaid waiver service. As the need for transition services was identified to help facilitate the grant's NFT program, the staff began discussions about how to address the issue. As a result, 7 of Pennsylvania's 12 home and community-based services (HCBS) waivers were amended to include Community Transition services.

  The staff also helped develop a fund for NFT services for individuals who do not qualify for waiver services. The Departments of Aging and Public Welfare will continue to provide transition funding for nursing facility residents who do not qualify for waivers.

- Based on the success of the grant's NFT initiative, the legislature and the administration increased funding for waiver programs and the NFT program.

Key Challenges

- The State's service delivery system for long-term services and supports spans several departments and many programs, making it difficult to address issues and to manage the system. Grant staff were assigned to facilitate coordination at both the state and local levels to improve management.

- The lack of affordable, accessible housing delayed or prevented some transitions. In addition, some subsidized housing had age-related eligibility requirements, which reduced housing options for some nursing facility residents who wanted to transition.

- Some nursing facility residents who wanted to transition had poor credit histories or a prior criminal record, which made them disqualified for subsidized housing.

- The lengthy bid process for making community housing modifications delayed transitions for some nursing facility residents.

- Some nursing facility residents were afraid to live independently. Nursing facility staff and transition staff required additional time to build a supportive relationship with these residents to help them feel comfortable about leaving a structured setting.

- Local service provision varied greatly across locales and providers within locales, creating a potential transition barrier for individuals who want to live in an area that does not provide the services they need. For example, some service providers allowed aides to transport service users to medical appointments and shopping malls while others did not. Also, few service providers offered care during the night. Informal support systems were available during the day to assist with care, but formal care services were needed at night.

Continuing Challenges

- Because the State has different financial eligibility criteria for individuals living in the community than it does for nursing facility residents, some residents may be unable to return to the community.

- Pennsylvania's aging housing stock is not accessible, and the lack of affordable, accessible, and integrated housing is often the primary reason that individuals entering nursing facilities for short-term rehabilitation end up staying for a long time.

Lessons Learned and Recommendations

- Each transition is unique, and NFT programs cannot anticipate every transition barrier that may arise. Thus, states should allow maximum flexibility in the use of funds allocated to cover nursing facility transition expenses.

- Because lack of affordable, accessible housing is a major transition barrier, the State should implement policies that will permit waiver participants to retain sufficient income to pay for community housing (e.g., through Medicaid rules governing post-eligibility treatment of income).

- The State should "level the playing field" between nursing facility and home and community-based services by establishing a community spend-down option.

Key Products

Outreach Materials

Outreach materials for the State's NFT program have been posted on the Department of Aging's website. The three NFT demonstration sites created long-term services and supports information guides describing options for community living.

Educational Materials

Grant staff and staff from the Departments of Aging and Public Welfare developed a *Nursing Facility Transition Technical Assistance Guide* for AAAs and other HCBS waiver providers.

Technical Materials

Grant staff and staff from the Departments of Aging and Public Welfare developed a Special Funding Request Form for AAAs and other HCBS waiver providers to cover transition costs not reimbursable through the waiver or other state programs.

Texas

Primary Purpose and Major Goals

The grant's primary purpose was to create a system in the State's 11 regions to efficiently and effectively transition nursing facility residents into the community. The grant had two major goals: (1) to ensure that transition staff and other stakeholders use a person-centered approach and consider all available Department of Aging and Disability Services (DADS) program options when conducting transitions, and (2) to establish nursing facility transition (NFT) teams at the regional level to facilitate transitions for individuals facing significant barriers.

The grant was awarded to the Texas Department of Aging and Disability Services.

Role of Key Participating Partners

- The Center On Independent Living (COIL) developed a training curriculum for conducting transitions, a resource manual, and regional needs assessments to identify and address transition needs and barriers.

- Texas Health and Human Services Commission Ombudsman, Area Agencies on Aging (AAAs), and staff from Advocacy, Inc., actively participated in the regional transition teams. Advocacy, Inc., is the federally funded and authorized protection and advocacy system for individuals with disabilities.

- Texas Tech Health Science Center produced a video on Texas's independent living initiative, service options to support independent living, the State's Money Follows the Person (MFP) policy, and the transition process.

Major Accomplishments and Outcomes

- COIL conducted regional needs assessments to determine how DADS and other organizations identify nursing facility residents who are interested in transitioning, and to determine which DADS and other state agency staff and provider organizations should be part of a region's transition team.

- COIL developed a training curriculum for DADS staff and other stakeholders on how to develop and implement MFP transition teams to coordinate services during transitions. The curriculum includes a pre- and post-test, a *Community Options Guide*, and a video on person-centered planning. DADS state and regional staff used the curriculum to train approximately 2,800 state agency regional staff and field workers during in-person workshops in 11 DADS regions.

Enduring Systems Change

- The State established regional transition teams to coordinate services for nursing facility residents to increase their access to community living. These teams include DADS program, clinical, and social services staff; relocation specialists; advocacy representatives; HMO representatives; a Medicaid specialist from the Texas Health and Human Services Commission; AAAs; and provider organizations.

The transition teams established a new procedure to coordinate services for nursing facility residents with complex transition needs. They also developed a procedure to identify individual and systemic transition barriers and brought them to the attention of DADS staff to address.

- Training provided under the grant increased knowledge about community living options and service users' right to choice among transition team members, DADS staff, and community stakeholders, as well as staff from nursing facilities, home health agencies, and other medical providers.

Key Challenges

- High turnover among DADS staff, transition team members, and relocation specialists resulted in a need for continual retraining, which required extra time and resources.

- Although some local housing authorities and community-based organizations did not initially participate in transition team meetings, their participation increased after they received training and support.

- Transition barriers included the lack of (1) housing and transportation, (2) home health agency staff to support individuals with complex medical needs such as ventilator users, (3) mental health services, and (4) knowledge among health care providers about the availability of home and community-based services.

- During the grant period, the Texas Health and Human Services Commission piloted Medicaid managed care in Houston. Staff from the managed care organizations did not initially participate in the regional transition teams. DADS attempted to contractually obligate them to participate but were unable to do so. Eventually, some managed care staff began to attend the team meetings.

Continuing Challenges

Serving individuals with complex medical needs in the community is difficult. Home health agencies are sometimes reluctant to provide the needed services because of liability concerns and what they perceive as inadequate reimbursement for the amount of services they need to provide.

Lessons Learned and Recommendations

- Grant staff should develop Memoranda of Understanding with key stakeholders at the beginning of the grant period and include language to require participation in and support of MFP activities, such as data collection.

- MFP training and the development of transition teams should be customized for rural areas to accommodate time, travel, and resource constraints.

- State agencies need to develop policies to address the concerns of home health care staff regarding the health and safety needs of persons with complex needs who are transitioning into the community, so that these concerns do not become barriers to community living.

- Grant staff should collaborate with local housing and mental health authorities, transportation providers, nursing facility staff, and community medical providers.

- Grant staff should also develop policies to increase affordable, accessible housing opportunities for persons with disabilities, such as housing vouchers. Such vouchers should be available at the time of the request for eligibility for waiver services.

Key Products

Outreach Materials

- Grant staff developed an MFP brochure with information about available DADS programs, services, and supports to facilitate nursing facility transition and community living. DADS staff, managed care organizations, Independent Living Centers, DADS state-level customer service staff, and an advocacy organization are all distributing the brochure to inform nursing facility residents, family members, nursing facility social workers, and other stakeholders about community living options.

- Grant staff developed a poster for display in DADS regional offices to increase awareness about community living options.

- Texas Tech Health Science Center produced a video on the philosophy of Promoting Independence (Texas's independent living initiative), the State's MFP policy, DADS service options for independent living, and the transition process. DADS staff and other stakeholders use the video to increase awareness about home and community-based services and supports. Texas Tech distributed the video to 735 hospitals, and it will be available to more than 500,000 medical professionals who subscribe to a web-based learning management system. Texas Tech is requesting accreditation for social work Continuing Education Units for viewing the video.

- COIL developed an MFP transition brochure for use in statewide outreach activities to recruit transition team members. The outreach material will be revised as needed to sustain MFP transition activities.

Educational Materials

- DADS developed the Community Options and Person-Centered Planning Curriculum, which includes information about community programs, and services and supports available through DADS. The training includes a *Community Options Guide*, an accompanying PowerPoint presentation, and a video on Person-Centered Planning.

- COIL developed an *MFP Transition Team Overview Guide*. The curriculum includes an overview of the *Olmstead* decision and its implications for people with disabilities; the mission, roles, and responsibilities of the team members; and recommended policies and procedures for conducting transitions.

- COIL developed a resource handbook, which includes information on the *Olmstead* decision, the constitutional rights of people with disabilities, outreach, and identification strategies; an advocacy manual, *Moving from the Institution to the Community (101) Legal and Advocacy Basics*; and a brochure entitled *Exploring the Limits of Community Living*. This brochure is specifically for the transition teams and their recruitment efforts.

Washington

Primary Purpose and Major Goals

The grant's primary purpose was to start balancing the State's long-term services and supports system between institutional and community-based service options by determining the amount and cost of appropriate services in order to promote individual choice. The grant had five major goals: (1) to develop an accurate and valid assessment tool that provides information on individuals' service needs and informal supports; (2) to facilitate use of the assessment tool by human services agencies and state agencies serving people with developmental disabilities; (3) to involve service users, agency stakeholders, and public and private partnerships in planning activities; (4) to develop a quality improvement initiative that is consistent with participant-based services; and (5) to establish the infrastructure needed to balance the distribution of funding between institutional and home and community settings.

The grant was awarded to the Washington Aging and Disability Services Administration.

Role of Key Partners

- The Division of Developmental Disabilities helped to develop the computerized assessment tool to meet the needs of people with developmental disabilities. In addition, case resource managers with the Division helped to ensure compatibility with the case management information system that the State was developing, which will be used by case managers, case resource managers, social workers, and others.

- The Children's Administration helped to develop the assessment tool to ensure that it meets the needs of children in out-of-home placements needing Medicaid personal care services.

- The Home and Community Services Division helped to develop the computerized assessment tool to ensure that it meets the needs of elderly persons.

- A Real Choices Advisory Committee—comprising agency staff, service users, parents, advocates and self-advocates, and service providers—produced educational materials on the new assessment tool and the assessment and service planning processes.

Major Accomplishments and Outcomes

- Division of Developmental Disabilities staff developed the computer program design specifications to incorporate the new needs assessment and service plan into the Comprehensive Assessment Reporting Evaluation (CARE) computerized assessment tool to determine level of needs and formal and informal supports.

- Division of Developmental Disabilities staff collaborated with Home and Community Services Division staff to modify the CARE assessment tool to better meet the service and support needs of elderly people.

- Children’s Administration staff helped to develop the computer program design specifications for incorporating the needs assessment and service plan for children with developmental disabilities needing Medicaid personal care services into the computerized CARE assessment tool.

- Grant staff coded, tested, and piloted the adult and children’s needs assessment and service plan software components.

- Grant staff provided assessment tool training and on-site technical support for field staff in developmental disability field offices and implemented the computerized assessment tool statewide.

- Division of Developmental Disabilities staff developed a brief survey in a postcard format for service users to return to the Division with comments, suggestions, or complaints regarding services.

- Division of Developmental Disabilities staff established the computer system’s infrastructure that will allow future development of an Interactive Service Plan System to enable greater participation by individuals in the creation of an individual budget, and to determine the amount of funding that should follow a person from an institutional setting to a community setting.

Enduring Systems Change

Grant staff developed and implemented a validated assessment tool that provides information on service needs and informal supports to facilitate individual choice regarding services. The tool’s needs assessment for people with developmental disabilities incorporates the Support Intensity Scales assessment developed by the American Association for Intellectual and Developmental Disabilities. Since the tool was finalized, it has been used by Division of Developmental Disabilities field staff to assess and develop service plans for 7,232 service users. Division of Developmental Disabilities staff will continue to provide training and support for case/resource managers and social workers using the new assessment tool.

Key Challenges

- Developing a comprehensive, complex assessment tool was a major challenge, given the fixed budget, the changing program and policy environment, and a personnel shortage. The greatest challenge was managing scarce program and field service staff resources because the Division of Developmental Disabilities was concurrently preparing a CMS HCBS waiver renewal application, managing and delivering existing programs and services, and helping to develop the case management information system. Through excellent project management and the outstanding participation of all key stakeholders and partners, the team succeeded in delivering a credible useful tool accepted by all stakeholders.

- Researching, designing, prototyping, developing, and implementing a comprehensive, computerized assessment and service planning tool for children and adults with developmental disabilities challenged the Division's existing business practices, its relationship with other state administrations and divisions, its relationship with service users and advocates, and its own professional staff.

  The Division met these challenges through a three-phased development process using in-house project management with a largely in-house computer program development team. The Division also received assistance from contracted analysts and consultants and external quality assurance contractors, and through active involvement by service users and advocates.

Continuing Challenges

- Limited funding for home and community-based services continues to be a significant challenge.

- Developing methods for the State to balance funding between institutional and home and community settings cannot be completed until the assessment tool is fully implemented in the case management information system. The first phase of this system was implemented in March 2008, and a second phase will be implemented in May 2009.

Lessons Learned and Recommendations

- Critical success factors for this project included the following: (1) strong executive management commitment to project success; (2) talented and committed in-house project management team; (3) strong and flexible project planning; (4) expert, efficient analysts who write clear documentation; (5) respected and committed participation of service users and advocates; (6) accessible, dedicated, and experienced field service staff; (7) a brilliant, creative, and flexible in-house computer programming team; (8) open, honest, and frequent two-way communication among all project stakeholders; and (9) an adequate budget to support project objectives.

- The project team used an integrated software development approach that embedded developers and business experts into development teams. These teams developed draft versions of the software with prototypes that were reviewed regularly by engaged end users and consumers.

- Agencies should plan carefully, staff project teams with all necessary disciplines, manage resources carefully, and include all stakeholders early and continuously. Agencies should also transparently report progress, encourage stakeholders to review and provide comments on early product drafts, and celebrate milestones when achieved.

Key Products

Outreach Materials

Grant staff and advocates developed outreach flyers about the assessment tool for families, self-advocates, and providers.

Educational Materials

Grant staff produced the following training materials for use by case/resource managers, social workers, supervisors, and program managers: (1) Assessment Frequently Asked Questions; (2) Quality Review Template and Shadow Review Template; (3) Individual Support Plan Training Presentation, Policy Training Presentation, Service Level Assessment Training Presentation, and Support Intensity Scale Module—Adult Training Presentation; (4) Support Intensity Scale Training video; and (5) *Assessor's Manual* and *Post Implementation Support Manual*.

Technical Materials

Division of Developmental Disabilities staff produced the Assessment Business Requirements Document and the Assessment computer software (CARE version 4.1.2).

Wisconsin

Primary Purpose and Major Goals

The grant's primary purpose was to develop the infrastructure to support transitions from intermediate care facilities for individuals with mental retardation (ICFs/MR) and from nursing facilities into the community. The grant had four major goals: (1) to develop new procedures and supporting data systems to enable funding to follow residents moving from ICFs/MR into the community; (2) to transition 200 ICF/MR residents into the community; (3) to create a regional support system that will enable service users, guardians, guardians ad litem, county administrators, and other key stakeholders to understand and choose alternatives to ICFs/MR; and (4) to determine the feasibility of a Money Follows the Person (MFP) policy and budget mechanism to transition nursing facility residents into the community.

The grant was awarded to the Wisconsin Department of Health and Family Services, Division of Long-Term Care, Bureau of Long-Term Support.

Role of Key Partners

- Members of People First of Wisconsin, the state Protection and Advocacy system, and other consumer advocacy organizations participated in technical assistance activities and training events for county staff, guardians, providers, service users, and family members. They provided information about methods to improve community inclusion and integration.

- Movin' Out Inc., a statewide housing counseling agency, provided technical assistance on a wide range of housing topics, including housing rehabilitation; accessibility improvements; home ownership; rental property acquisition; and expansion of affordable, accessible housing models. The target audience for these activities included county staff, guardians, providers, service users, and family members.

- The Wisconsin Coalition for Advocacy (a protection and advocacy organization now known as Disability Rights Wisconsin) developed a training curriculum on the role of guardians and guardians ad litem in the transition of individuals from institutions into the community.

- The Syracuse University Center on Human Policy collaborated with a consultant to conduct a formative evaluation of the grant's activities.

Major Accomplishments and Outcomes

- Grant staff helped the State's ICF Restructuring Initiative to transition 444 residents into the community. Grant staff also worked to facilitate closure of 15 facilities and reduce the capacity of 17 additional facilities.

- The Wisconsin Coalition for Advocacy developed a training curriculum and conducted extensive training sessions throughout the grant period regarding the roles and responsibilities of guardians, guardians ad litem, and judges in the transition process.

- Grant staff responded to concerns regarding facility closure and addressed problems with individual transitions, such as guardian opposition or complex care needs. People First of Wisconsin developed web-accessible question and answer bulletins for the guardians and guardians ad litem of transitioning individuals.

- A staff person funded by the grant assisted the Department of Health and Family Services in developing legislative language, policies, and procedures for the Community Relocation Initiative to transition nursing facility residents into the community with funding through the Community Options Program waiver. This person was able to document past experience with nursing facility transitions and provide cost and savings estimates to support the legislation. Grant staff also provided technical assistance to local agencies and care managers to identify resources and options for nursing facility residents wanting to transition. The Community Relocation Initiative subsequently resulted in the transition of 776 nursing facility residents over a 1-year period.

Enduring Systems Change

- Grant staff developed and implemented policies and procedures for Wisconsin’s ICF Restructuring Initiative to transfer state funds designated for ICFs/MR (both privately and county owned) to the Medicaid waiver program. Grant staff also developed a system to monitor the costs of individual care plans and types of residential living arrangements into which individuals moved.

- As a result of the new MFP policy for ICF/MR residents, counties have more control over funding, which enables them to create more options for community-based long-term services and supports.

- The technical assistance and training on person-centered planning during transitions has given participants, their guardians and families, and guardians ad litem a stronger voice in shaping the types, intensity, and location of community services and supports. The increased use of person-centered planning also is helping to ensure that health and safety issues for individuals with complex physical, medical, or behavioral/psychiatric support needs are being addressed in a more comprehensive manner.

- The transition of a large number of ICF/MR residents into the community increased demand for community services and supports. To meet the demand, county staff collaborated with MFP grant staff in a range of activities to increase the supply of new providers and to expand the capabilities of existing providers to serve individuals with complex support needs. Wisconsin now has new community providers for supported living services, and existing providers have altered service delivery to be more person centered and to serve individuals with greater physical and behavioral health needs.

Key Challenges

- The ICF Restructuring Initiative mandated that individuals be served in the “most integrated” and “least restrictive” setting. Ensuring that these provisions were met was complex and time consuming for counties, providers, guardians, and guardians ad litem. All parties involved in transitions needed to develop trusting partnerships to develop effective, efficient, and individualized participant supports. Developing trust was a challenge because so many people who had never met one another—and who had varying levels of knowledge and understanding—had to work together.

- The fast pace of ICF/MR closures significantly hampered the use of person-centered planning and self-direction in the transition process. The State spent considerable time and resources to ensure that person-centered planning was part of the service planning and delivery process, but it could not be mandated. Integrating person-centered planning into the system—so that it is used routinely and not viewed as just a new tool or process—is time consuming.

- Lack of coordination among counties, which administer the waiver program, presented a challenge because some individuals transitioned from a facility in one county into a community living arrangement in another county. When this occurred, county staff serving individuals in the community often knew nothing about the individual or his or her support needs prior to transition.

Continuing Challenges

- Funding for the ICF Restructuring Initiative is approved biennially by the legislature. Once funds are exhausted, individuals who want to transition must wait for the budget to be renewed or for additional funds to be appropriated.

- Finding the resources to educate county staff, judges, guardians, and guardians ad litem to ensure that transitions are in the best interest of persons with disabilities, continues to pose a major challenge.

- Lack of federal funding for housing is a major obstacle to community living for persons with disabilities.

- Ensuring the implementation of person-centered plans and self-direction for individuals in congregate settings such as day programs and vocational sites is a continuing challenge because these settings are controlled for—and not by—the individuals receiving services and supports.

Lessons Learned and Recommendations

- Legislation to promote both the closure of ICFs/MR and the establishment of an MFP policy was essential to help ensure transitions.

- States should not underestimate the time and resources needed to educate county staff, judges, guardians, and guardians ad litem about transitions. Talent and commitment are also critical components; without them, transitions will be compliance driven and could have a negative impact on the quality of supports, health, safety, and personal growth of the individuals with disabilities. Guardians and guardians ad litem need to be informed and involved, and mediation occasionally is needed when a lack of trust at any point in the process or among any of the parties jeopardizes transitions that are critical to an individual's best interest.

- HUD should increase funding for housing models that promote self-direction and independent living, predevelopment costs, property acquisitions, and for home modifications to ensure accessibility. The latter is a HUD responsibility that falls to the Medicaid program because of lack of funding (e.g., to ensure the availability of accessible housing, waiver programs pay for home modifications). The State knows how to develop and finance affordable, accessible housing but has insufficient resources to meet the many competing demands for housing.

- CMS should continue to invest resources in state infrastructure development. The Systems Change grants have been invaluable for this purpose: allowing states to tailor the funds to meet unique needs. However, much more infrastructure development is needed, along with additional funding to continue it.

- CMS should provide resources to states to purchase local technical assistance (TA) to help improve the home and community-based services (HCBS) system. National TA providers often lack knowledge of individual state programs, policies, and politics—knowledge that is crucial in devising strategies to bring about systems change.

Key Products

Outreach Materials

The Wisconsin Department of Health and Family Services published press releases regarding the ICF Restructuring Initiative and the Community Relocation Initiative. The Department also produced flyers announcing the availability of training on transition issues.

Educational Materials

- The Wisconsin Coalition for Advocacy developed A Guardian Ad Litem's Guide to Placing People with Developmental Disabilities or Mental Illness in the Community, a curriculum for educating guardians ad litem on their roles and responsibilities during and after the transition of residents from institutions into the community.

- Grant funds paid for numerous training materials for counties, judges, guardians, and guardians ad litem on topics such as difficult behaviors, crisis management around behavior issues, medical and physical health, matching provider resources to client needs, community integration, health risk screening, post-traumatic stress, the impact of Medicare Part D on transitions, and staff development.

Technical Materials

- People First of Wisconsin developed web-accessible question and answer bulletins for guardians and guardians ad litem of ICF/MR residents who were transitioning.

- Grant staff produced versions of the approved statutory language for the two Wisconsin relocation initiatives, a summary of MFP statute changes for guardians and guardians ad litem, letters regarding statutory changes and facility closures, and a summary of waiver care plan costs.

Reports

Responsive Systems Associates in collaboration with the Syracuse University Center on Human Policy produced a report on the formative evaluation results of the grant's activities, entitled *And Now They Need a Life*.

Part 3

Independence Plus Grantees

Section One. Overview **3-1**

Section Two. Individual IP Grant Summaries **3-17**

Exhibits

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

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[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 Supports[3] providers and participants, an increase in case manger 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

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[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.

- 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.

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[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 apprehension of some stakeholder groups, and helps to ensure the development of a user-friendly program.

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

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[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.

Part 4

Quality Assurance and Quality Improvement in Home and Community-Based Services Grantees

Exhibits

Section One. Overview

Improving the quality of home and community-based services (HCBS) is one of the major goals of the Systems Change for Community Living Grants Program. Although many Systems Change grants have quality assurance/quality improvement (QA/QI) components, CMS awarded 19 grants in 2003 that focused specifically on quality assurance and quality improvement in Medicaid home and community-based services, particularly those provided through Section (§) 1915(c) waiver programs. The 19 grants are listed in Exhibit 4-1.

Exhibit 4-1. FY 2003 QA/QI Grantees

California
Colorado
Connecticut
Delaware
Georgia
Indiana
Maine
Minnesota
Missouri
New York
North Carolina
Ohio
Oregon
Pennsylvania
South Carolina
Tennessee
Texas
West Virginia
Wisconsin

Enduring Systems Improvements

Grantees reported major enduring systems improvements resulting from their initiatives to improve the effectiveness and efficiency of existing QA/QI processes or to develop new Quality Management Systems (QMS) or new components of existing systems.

Several Grantees focused their quality improvement initiatives on a specific area, such as services for persons with mental retardation/developmental disabilities (MR/DD), the design of participant safeguards and the related functions of discovery and remediation, or methods to obtain data on participant outcomes. Others had more ambitious goals, such as designing a coordinated HCBS quality management and improvement system across several waiver programs.

This section of the report provides an overview of Grantees' QA/QI enduring improvements, as shown in Exhibit 4-2. The enduring systems improvements are grouped into six major areas:

- New or improved methodology/tool or indicators to measure participant satisfaction and outcomes

Exhibit 4-2. Enduring Systems Improvements of the QA/QI Grantees

	CA	CO	CT	DE	GA	IN	ME	MN	MO	NY	NC	OH	OR	PA	SC	TN	TX	WV	WI	Total
New/improved methodology/tool or indicators to measure participant satisfaction and outcomes	X	X	X	X	X		X	X		X			X	X		X	X	X	X	14
New provider standards or monitoring tools						X					X							X		3
New/improved system for quality data collection, analysis, and reporting	X	X	X	X				X				X		X			X	X		9
New/improved quality management system to help ensure continuous quality improvement in services	X			X		X	X				X	X		X				X		8
New/improved critical incident reporting and/or remediation process or system		X	X	X		X	X	X			X					X		X		9
New methods to involve participants in QA/QI processes and policy development		X	X	X														X		4

- New provider standards or monitoring tools
- New/improved system for quality data collection, analysis, and reporting
- New/improved quality management system to help ensure continuous quality improvement in services
- New/improved critical incident reporting and/or remediation process/system
- New methods to involve participants in QA/QI processes and policy development

The remainder of Section One describes the enduring improvements that Grantees reported in each of these areas. Many Grantees brought about systems improvements in more than one area.

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 quality indicators is an accomplishment, whereas establishing formal monitoring procedures and funding an annual participant survey are enduring systems improvements.

New/Improved Methods to Measure Participant Satisfaction and Other Outcomes

A frequently expressed concern about traditional quality assurance systems is their lack of a consumer focus and failure to measure outcomes that are important to program participants. Grantees in 14 states established new or improved methods for measuring participant satisfaction and other outcomes, several of which are described below.

Grant staff in Colorado's Division for Developmental Disabilities standardized critical elements of a participant/family survey to be used statewide. The standardization allows the Division to collect and report consistent participant and family satisfaction data across years, programs, and providers. The consistent collection and reporting of these data has significantly advanced Colorado's ability to improve the performance of the developmental disabilities services system, to support informed choice for participants/families, and to support transparency in the provision of information to the general public.

Grant staff in Connecticut's Department of Developmental Services developed quality indicators and review methodologies for all services and settings—including some that were not previously monitored as part of the formal quality assurance system, such as employment services, day services, and in-home settings. The Department also modified its quality service review tools for all service settings.

To align its discovery processes with newly developed quality indicators, grant staff in Delaware's Division of Developmental Disabilities modified its Community Living Arrangement review to focus more on person-centered quality outcomes. The Division also developed a complaint process for participants, families, and providers to help identify and/or resolve concerns.

Georgia's grant staff and a contractor evaluated current performance measures for the State's DD system and worked with stakeholders to create performance indicators based on the CMS Quality Framework. After cross-walking the resulting set of outcome measures with the National Core Indicators (NCI) and evaluating the Division's data system for NCI compatibility, the State decided to join the NCI. The first NCI survey was funded by the grant, and the Division has committed to conducting the NCI survey annually.

Three States modified the Participant Experience Survey (PES) to tailor it to meet their needs. Maine added items related to the assessment and care planning process, worker availability, backup plans, and interest in participant direction; and Minnesota added measures related to maintaining and enhancing social roles and relationships, caregiver outcomes, and items applicable for participant-directed services. West Virginia modified the PES to measure the experiences of waiver participants who self-direct a portion of their services. In addition, based on PES reports, Maine modified contracts with case management agencies to include more specific provisions related to health and welfare monitoring, development of backup plans, and linking participants with other community resources that support independence.

Grant staff in Oregon's Department of Human Services, Seniors and People with Disabilities (SPD), developed a participant survey that can be used across three waiver programs to measure overall participant satisfaction with services and provide participant perspectives on how well their supports meet health and safety needs and preferences. SPD will administer the participant survey every 2 years to individuals directing their services: people with developmental disabilities, older adults, and people with physical disabilities.

Pennsylvania's grant partner, the Center for Survey Research at Penn State Harrisburg, developed two standardized survey instruments to assess participants' satisfaction levels with services, processes, and providers' responsiveness. These instruments included add-on modules for each specific HCBS waiver, non-Medicaid programs, and the Program of All-inclusive Care for the Elderly (PACE). The first survey instrument is an intake survey for newly enrolled participants and the second is an annual satisfaction survey. After pilot testing and possible adaptation, the instruments will be used statewide with multiple programs, including eight waivers and two state programs.

After assessing several methods for measuring participant experience outcomes that are currently used in the State's various long-term services and supports programs, Wisconsin adopted a set of 12 participant experience outcomes to be used in all HCBS programs serving adults with physical or developmental disabilities and frail elderly persons. The set of 12 participant experience outcomes will form the basis for the development of a reliable and valid measurement tool for the State's HCBS managed-care programs.

New York developed a complaint hotline to obtain information from waiver participants and their families about the quality of services received. The information is being used to improve service quality by responding to issues and eliminating problems. The complaint line was fully operational in 2005. By the end of the contract period 245 complaints and concerns had been received, several of which required immediate intervention and were addressed.

An unexpected benefit of the complaint line was its usefulness as a mechanism to correct and/or prevent errors in Medicaid billing. Regional service coordinators were able to compare providers' billing statements against complaints regarding direct care staff no-shows and initiate prompt billing corrections where appropriate. The complaint line has become a part of the waiver's quality management program, adding an additional level of protection for participants' safety by enhancing the ability of contract and Department staff to address and resolve issues in an appropriate and timely manner. It has also proven to be an extremely useful tool for uncovering deficiencies on the provider, regional, and state levels and for obtaining valuable information on individual and systemic issues.

New/Improved Provider Standards or Monitoring Tools

Indiana grant staff helped to develop, promulgate, and implement a new rule regarding the certification and monitoring of providers of unlicensed services, such as Adult Foster Care, Adult Day Services, and attendant care services (including both agency staff and participant-directed workers). The rule defines provider standards and includes provisions for monitoring and corrective actions, revocations of provider approvals, provider appeals processes, and processes to ensure the protection of individuals receiving services (e.g., incident reporting and coordination efforts with adult and child protective services entities). The rule also requires all providers to have a QA/QI process. A grant contractor developed a provider survey tool to monitor compliance with the new rule's standards.

In North Carolina, Local Management Entities (LMEs) manage mental health, developmental disabilities, and substance abuse services at the local level. Grant staff developed critical performance indicators and a comprehensive quality management plan for oversight of the LMEs.

West Virginia revised its automated provider monitoring tools and process to ensure that necessary quality management data are collected. Quality reviews are now entered directly into electronic forms, which are merged into a centralized database. The data are now more readily available and easier to use for quality monitoring. The State also revised the initial certification process for providers and developed a recertification process that examines compliance with the basic standards on an annual basis.

New / Improved System to Collect, Analyze, and Report Quality Data

Many Grantees had initiatives to address problems with current data systems. Some systems could not provide consistent data across programs and populations, and others could not produce useful quality data. In addition, key data elements were not computerized, so the information could not easily be aggregated or analyzed. Nine Grantees had initiatives to improve data systems, several of which are described below.

Connecticut developed several new approaches for collecting data on quality outcomes. Previously, only state-level reviewers collected data and assessed quality as part of the State's quality service review system. Now, case managers and regional quality monitors collect data through participant interviews, direct care worker interviews, document or record reviews, safety checklists of the environment, and observation of participants during service provision. Case managers also now help individuals and their families to review the quality of their supports and services, and regional quality monitors look at service patterns and trends and evaluate vendor performance at the regional level through quality review visits with individuals in their homes or day services settings.

Connecticut also developed a web-based software application (launched in July 2008) to compile and report data related to the quality of services provided by both state staff and private, contracted providers. The application enables the provision of more timely, comprehensive, and integrated data for quality assurance reports that will lead to improvements in service quality and also fulfill evidentiary requirements for the CMS waiver assurances. Because the new application allows data to be sorted by participant, provider, service type, or administrative region, it will facilitate the analysis of quality indicators and will enable the State to track performance measures over time as well as corrective actions taken to address identified problems.

Minnesota moved data sets from three sources (Department of Human Services [DHS] Licensing, the Ombudsman for Managed Care, and Appeals) into the DHS data warehouse. In addition, as part of the Vulnerable Adult Reporting Information System, county intake staff and county adult protection investigators now have a common system for (1) the intake of maltreatment reports, (2) the distribution of reports to investigative agencies, and (3) the capture of investigative outcome data and data from participant surveys resulting from county-based investigations. The Data Mart also now houses participant survey data.

Both the Data Mart and the Vulnerable Adult Report Tracking System were piloted in December 2007 and have been available statewide since March 2008.

Ohio developed and implemented a new information management system and its associated training activities in five pilot counties. The new system will facilitate QA/QI activities by reducing redundancy in reviews conducted by different agencies, facilitating reporting, and enabling comparison with other reviews and with data from other units and state agencies. After the grant ended, all of the tools needed to expand the new information management system were scheduled to be ready by the end of 2008, and statewide implementation was planned for 2009.

Texas implemented a QA/QI Data Mart to draw existing data from the Department of Aging and Disability Services' disparate automated systems. The Data Mart also provides data for quality measures based on the HCBS Quality Framework. The State has started using the Data Mart to generate reports to help identify the current state of program effectiveness, and to help management set goals for improvement by measuring the impact of new policy on program performance. The Data Mart will also enable the analysis of participant outcomes and fulfill evidentiary report requirements mandated by CMS for waiver renewal.

West Virginia developed templates for quality management reports that incorporate data on services and budgets, quality indicators, and quality improvement projects. The templates are used in both the MR/DD waiver and the Aged/Disabled (A/D) waiver to compile and organize data and to generate reports.

New/Improved Process or System to Help Ensure Continuous Quality Improvement in Services

Eight Grantees developed or improved quality management processes or systems to help ensure continuous quality improvement. California's grant staff and partners designed the Bay Area Quality Management System, which includes a Quality Service Review, and provides a standard and consistent set of service quality expectations and measurements and a platform for regional centers and providers to work as partners in pursuit of continuous quality improvement in services.

The Bay Area QMS was piloted with everyone involved in transitioning residents from Agnews Developmental Center: family members, providers, regional center staff, and Department of Developmental Disabilities Services (DDDS) staff. After the grant ended, Agnews was scheduled to close by June 2008, and funding for the full implementation of the QMS pilot was secured through June 2008 and projected to be secured through 2009.

Once the QMS is established and validated, DDDS will consider expanding its use beyond the pilot project population to include all the participants and residential services of the three Bay Area Regional Centers, which serve more than 30,000 individuals with developmental disabilities. Once this initial expansion is accomplished (and information is available from this larger implementation), DDDS will consider expanding its use statewide.

Delaware's Division of Developmental Disabilities developed and implemented a new quality management system and formed a Performance Analysis Committee to collect and analyze data on specified indicators and to deliver data analysis reports to various quality-related Division committees and administrators. At the time of the grant's final report, the Committee had generated more than 20 data analysis reports for the system's continuous quality improvement cycle. The reports, which cover a variety of subjects and are cross-referenced with the CMS waiver assurances, are intended to help the Division's senior management and various entities charged with quality improvement to judge the quality of DD services and to develop improvement strategies to address weaknesses identified in the reports.

Indiana developed a more comprehensive quality management strategy than existed prior to the grant across a broader base of service delivery. The strategy includes both intra-agency and interdivision collaborations, and is now part of all aspects of service planning, implementation, review, and reporting.

Maine's Department of Health and Human Services created an integrated management team that promotes cross-program communication, information sharing, issue identification, and opportunities for collaborative quality improvement activities. The integrated management team includes the office directors responsible for managing HCBS waiver programs.

North Carolina's Division of Mental Health, Developmental Disabilities, and Substance Abuse Services developed a comprehensive quality management plan based on the CMS Quality Framework for HCBS. The plan includes mechanisms and activities that promote adherence to basic standards as well as improvements over time. Essential quality assurance monitoring activities have been continued to the extent that they directly serve the goal of ensuring the viability of the system, safeguarding participants, and improving the quality of services; and ongoing quality improvement activities have been developed and coordinated across all levels of the State to guide policy and practice.

For example, the Division implemented structures and processes for continuous quality improvement through the establishment and training of local, divisional, and statewide quality improvement committees. In addition, Local Management Entities are now required to submit annually at least three quality improvement reports that describe how they have used quality improvement processes to address service delivery issues in such areas as increasing service capacity, ensuring continuity of care, and ensuring the use of evidence-based practices.

Ohio developed a Quality Management Framework, which served as the foundation for aligning the State's MR/DD system with the CMS Quality Framework and the waiver assurances. In the future, the Quality Management Framework will be incorporated into the processes that will be used to determine actions that are needed to improve quality, such as additional training, or regulatory and other policy changes. Ohio also established an Office of Quality Management, Planning, and Analysis, which is working with several state-supported stakeholder groups to carry on the work of improving the quality management system.

Pennsylvania developed a three-tiered quality management system, which was included in two waiver renewal applications and approved by CMS. The State appropriated funds to implement the system, as well as provider report cards, information technology systems changes, a training institute, a public relations campaign, and the management of a quality council.

West Virginia established a Quality Improvement Team to coordinate and oversee quality initiatives in two waiver programs, and developed quality indicators to support the evidentiary requirements for CMS's six waiver assurances. A number of changes regarding quality management roles and responsibilities were incorporated into the contracts between the state Medicaid agency and the agencies that administer the waivers. These changes include commitments to stakeholder involvement through the waiver Advisory Councils established through the grant, the ongoing development of quality indicators that exceed CMS requirements, and an annual retreat process for the Advisory Councils that includes training, Quality Management Work Plan development, and quality improvement projects.

New/Improved Critical Incident Reporting and/or Remediation Process or System

Critical incident reporting and remediation systems are essential components of a quality management system that includes activities designed to correct identified problems at the individual level. To remedy problems expeditiously and effectively, it is essential to collect and evaluate information in a timely manner. Grantees in nine states made enduring systems improvements in these areas, examples of which are described below.

Colorado implemented a new web-based critical incident reporting system that has increased the timeliness and quality of reporting and provided a system for data analysis. Critical incident data are stored in a data warehouse, and business intelligence software is used to support data-based decision making and remediation and quality improvement processes. In addition, the system is integrated with the community contract management system, providing more data elements to analyze, which can facilitate analysis of areas that would benefit from targeted quality improvement activities. For example, the combined system enables the State to link information about critical incidents to participants' disability diagnoses, utilization of specific waiver services, and specific service providers.

Connecticut's Department of Developmental Services established a standardized process for reporting, documenting, and following up reportable incidents involving individuals who receive waiver services in their own or a family home. Information obtained through this reporting system is used to identify, manage, and reduce overall risk, and to assist the Department in quality oversight and improvement efforts. The Department also established a formal process of "root cause analysis" to review selected sentinel events in order to analyze potential factors that increase risk, and to facilitate the design and execution of effective risk prevention strategies. To fairly compare providers who support people with the most challenging needs with other providers, the Department also developed methods to risk adjust the incident data.

Indiana developed a statewide web-based incident reporting system to immediately capture information about factors that might adversely affect the health and welfare of program participants. Complaints may also be made by phone, fax, and e-mail. The system alerts case managers, the Division of Aging, and the Office of Medicaid Policy and Planning of critical (i.e., sentinel) incidents requiring immediate response and then monitors that response and remediation. System processes include the daily review of sentinel incidents and a weekly review of other incidents. The Division of Aging's QA/QI unit reviews the data to identify trends; patterns of critical incidents; and the need for revisions in policy, procedures, and/or training. Complaint data are integrated with the incident reporting/reviewing process when the complaint affects, or has the potential to affect, an individual's health and welfare.

Maine grant staff and partners developed cross-waiver health and welfare indicators, which can be measured using linked Medicaid and Medicare claims data (e.g., avoidable hospitalizations, use of preventive health services, and use of emergency rooms). They also developed a common approach for mapping discovery methods with the CMS assurances, and a database that enables a consistent approach for assessing strengths and gaps in discovery methods across waiver programs. The database can be used by other waiver programs to create a similar inventory. Grant staff also developed an event reporting system with the Office of Elder Services that includes a common reportable event form, and definitions and data elements ranging from death and serious injury to exploitation and medication errors. Event definitions and time frames are consistent across waiver programs, enabling improved reporting and monitoring.

Minnesota developed a Vulnerable Adult Report Tracking System that allows electronic submission of county data to the Department of Human Services and established investigative agencies. The system will enable DHS to use investigative outcome data for continuous quality improvement related to incident management and the prevention of maltreatment. All county Adult Protection units are required to use this system for reporting alleged maltreatment and for all local Adult Protection investigation activities. Importantly, the new system also allows DHS to "match" people who are receiving publicly funded services to reports of their alleged maltreatment and investigation results.

North Carolina's Division of Mental Health, Developmental Disabilities, and Substance Abuse Services developed a new incident response and reporting system, which requires Local Management Entities to review all serious incident reports submitted to them by service providers in their areas, and to report quarterly on trends and efforts to reduce incidents and respond to complaints. Procedures are in place to involve state agencies for the most serious incidents. Because the agency responsible for technology projects is being restructured, implementation of the system has been delayed until July 2009.

Prior to 2004, Tennessee's Division of Mental Retardation Services (DMRS) definitions of abuse, neglect, and exploitation were extremely complex, making it difficult to understand when and what to report. The DMRS investigative Protection from Harm Unit held many meetings with all stakeholders to establish definitions of abuse, neglect, and exploitation that would be more easily understood. Although the new definitions are clear and concise, if in doubt, program participants can report questionable incidents to DMRS staff, who will determine whether the incidents meet the definitions.

The Protection from Harm Unit also made changes in operational procedures to ensure that participants' legal representative and/or designated family member know about allegations of abuse, neglect, or exploitation and understand the investigative process. Finally, grant staff developed a new communication system for reporting incidents. Formerly, information was provided only in aggregated form, which did not include all of the information needed for Adult Protective Services and the Protection from Harm Unit to follow up. The new system requires that reports provide more detailed information about each incident.

West Virginia developed a process to track abuse and neglect as part of the incident reporting template, and training in abuse and neglect was added to the required provider training. As the incident management system was being developed for the Aged/Disabled waiver, the MR/DD incident management work group was developing a web-based data system that tracks critical incidents and produces mandatory reports for Adult Protective Services. Aged/Disabled waiver staff were involved in the development of this data system, which has the same structure for both waiver programs. Provider testing by region was conducted during the grant period, and the web-based system was fully implemented in 2008.

New Methods to Involve Participants in QA/QI Processes and Policy Development

State policy on long-term services and supports historically was developed without participant input, and quality assurance systems have traditionally lacked a participant focus. Four states developed processes to promote more active and effective involvement of participants and families in QA/QI processes and policy development, examples of which are described below.

Colorado's Division for Developmental Disabilities convened a Self-Advocates Advisory Council to provide direct input and feedback to the Division director on policy issues in the State's DD system, and Connecticut's Department of Developmental Services hired nine permanent, part-time self-advocate coordinators to fulfill leadership and mentor roles focusing on QA/QI initiatives. In addition to working with service users and their families, the self-advocate coordinators provide new employee training for state staff, particularly on human rights and self-determination, self-advocacy, and self-direction initiatives, and influence policy development as committee and work group members.

Delaware's Division of Developmental Disabilities instituted a Quality Council as an external review body. The Council is composed of a volunteer group of 18 stakeholders—waiver participants, family members, providers, and direct support staff—who meet to review quality reports and to recommend systems improvements as part of the continuous quality improvement process for performance reports.

West Virginia established a Quality Assurance and Improvement Advisory Council in both its A/D and DD waivers to monitor quality initiatives and promote networking and partnerships among stakeholders. Each Advisory Council comprises 15 members, 5 of whom must be current or former service recipients, the other 10 being family members, advocates, and providers. The Advisory Councils meet quarterly and provide an opportunity for nonmembers to offer input on issues of concern, and also participate in an annual retreat to develop Quality Management Work Plans for quality improvement projects.

Continuing Challenges

Grantees successfully addressed many challenges during grant implementation but reported many that remained.

Lack of Funding

Five Grantees noted that obtaining funding for new initiatives as well as ongoing funding to support quality assessment and management activities for HCBS waivers was very difficult. One of these Grantees pointed out that components of the quality service review are challenging to implement because they are time, labor, and resource intensive. This Grantee also said that grant funds had been used to keep case management ratios manageable during the closing of an Intermediate Care Facility for persons with mental retardation, which enabled the provision of high-quality planning to develop individualized supports but that resources may not be available in the future to maintain this level of support. Another said that because Medicaid coverage of nursing facility services is an entitlement but waivers are not, it is a major challenge each year to convince the State's budget office to spend money on HCBS infrastructure.

Organizational and Administrative Issues

Three Grantees mentioned organizational or administrative challenges in developing and implementing quality management systems, including (1) managing QA activities and assurances across multiple waiver programs; (2) staff turnover in the agencies that administer waiver programs; and (3) changing state priorities. One Grantee said that restructuring and privatization of the State's Bureau of Quality Improvement Services had led to fragmentation in the quality review processes and interfered with ongoing QA/QI operations.

Information Technology and Data Collection Issues

Six Grantees mentioned challenges related to information technology (IT). Two noted that technology-related initiatives may depend on support from the state IT agency, which is not always available or timely because of competing IT projects.

Others said that lack of resources, staff, and technological capacity (i.e., old computer hardware and software) make it difficult to share data among county MR/DD boards, service providers, and state staff, and that finding resources to update outdated computer systems is an ongoing challenge. Some states' computer systems are so outdated that no one working today can fix them without a very steep learning curve.

Three Grantees indicated that their data systems either did not allow the collection and analysis of needed data or that collecting and analyzing data from various systems posed a challenge, as did distributing the data to various stakeholders. One state established a single organizational structure that now manages eight waiver programs, but grant staff said that reconfiguring and standardizing several data management systems to fit with the new system will be difficult.

Another Grantee noted that the need to implement new technology and databases that are compatible with two existing data collecting systems had led to poor data aggregation and an inability to identify trends and conduct patterns analysis. As a result, a great deal of analysis and trending continues to be conducted manually, as does documenting required follow-up on incidents and complaints and management of mortality review processes. Finally, one Grantee said that given the various restrictions in state and federal law regarding data sharing among government agencies, it is challenging to find ways to allow quality assessment across services and programs while ensuring data privacy.

Policy and Practice Issues

Three Grantees commented on the challenge of combining monitoring for regulatory compliance with outcome measurement. One said that balancing regulatory compliance with quality improvement activities is challenging because there is always a tendency to revert to an event-based compliance system, rather than fully embrace a quality improvement system. Another noted that the QA/QI field is not as well developed in HCBS as it is in primary and acute health care, so the state and local HCBS agencies have to develop QA/QI methods and indicators specific to HCBS. Professionals in the long-term services and supports system have traditionally addressed quality issues on a case-by-case basis, and it can be very difficult for them to incorporate a systems approach into their assumptions and expectations regarding quality assurance.

Further, one Grantee said reaching consensus on the development and the use of quality indicators can be difficult because some stakeholders, including staff and managers, do not understand the appropriate use of indicators in quality management. Only a few recognize that indicators by design seldom do more than indicate (i.e., they are not intended to serve as a direct justification for action but as a pointer to areas for more in depth discovery). Many HCBS professionals and managers still think that “assuring quality” means writing more and better specifications and do not comprehend the concept of objective discovery.

Stakeholder Involvement

One Grantee noted that developing provider certification panels is challenging because they include a mix of professional and volunteer panel members who must be educated on the quality review process so they can make informed decisions based on voluminous data. In addition, because the certification panels need to review as many as 30 or more residential homes per year, workload intensity may become a problem for some members. Another pointed out that it is difficult to ensure participation in the Self-Advocate Advisory Committee by those who live in geographically isolated parts of the state, some as far as 8 hours’ travel time from the state capital.

Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees gained experience in developing policies, processes, and procedures to improve their states’ quality management systems. They described numerous lessons learned and made many recommendations, which may be useful to states and stakeholders interested in ensuring the quality of their long-term services and supports systems.

Lessons Learned

Many of the QA/QI Grantees developed and implemented some form of participant survey, and several shared insights they had gained about this process. Others shared lessons learned related to grant implementation issues generally.

Implementing New Participant Surveys

Implementing a participant survey for the first time can require a steep learning curve regarding the most efficient process for carrying out the various required steps. Giving responsibility for a particular step to entities that do not consider it a priority can significantly delay implementation. For example, in California, initial implementation of the National Core Indicators survey was considerably delayed because the task of obtaining informed consent was given to regional center service coordinators who already had very busy schedules. To address this problem, the grant’s contractor identified a method (in accordance with confidentiality statutes) whereby participants’ names and addresses were released directly to the contractor, who then obtained consent and scheduled the interview at the same time.

Several Grantees mentioned problems they had had in obtaining consumer participation for a variety of reasons: (1) residential care facility staff were reluctant to let surveyors speak to residents because of concerns about the effect of survey results on the facility and concerns about client confidentiality; (2) locating the clients’ guardians was time consuming, and obtaining permission for their participation in the survey was often difficult; and (3) some waiver participants were distrustful and unwilling to participate in interviews. To reduce these participation barriers, states should first conduct outreach and education about the survey to allay concerns and improve collaboration and participation.

To ensure a representative sample, one Grantee suggested that states (1) recruit participants from different ethnic groups through outreach letters written in several different languages, and by using bilingual schedulers to arrange interviews; (2) incorporate cultural diversity training in the interview training curriculum to ensure proper cultural etiquette and sensitivity to cultural variations, which can improve interview results; and (3) over-sample in less populated areas to enable a more comprehensive examination of the unique issues they face compared with issues in more populous areas.

Grant Implementation

Several Grantees stressed the need to be realistic about what can be accomplished when attempting to bring about systems change within a specified time period because progress is often incremental, and it may be necessary to focus initially on one or two small changes. They also emphasized the need to be flexible—to be prepared to immediately change goals and methods to achieve goals—based on emerging opportunities and insurmountable barriers identified through formative evaluation.

One Grantee noted that prior to committing resources to QA/QI initiatives, states need to conduct an assessment to determine which activities have priority and ensure that all activities are aligned with existing or planned quality management initiatives. Incorporating grant goals and objectives into the division's long-term system reform plan ensured that grant-related accomplishments would be sustained when the grant ended. Another pointed out that using existing department senior staff as primary grant staff ensures integration of grant goals into existing systems and structures, resulting in more enduring systems changes.

Enlisting the support of top administrators and securing the commitment of relevant leaders can help to ensure that resources will be committed to a new initiative and that information about systems changes will be communicated to those whose work will be affected by them. Two Grantees stressed the importance of constant communication with executive management at every stage of the project and of the need to provide information about grant activities to internal and external stakeholders. Project directors also need to establish mechanisms to inform key agency program staff about quality-related initiatives pertaining to their respective programs and to solicit their feedback. One Grantee noted that having the Medicaid agency and the two agencies that administer the waivers constantly at the same table was critical in reaching agreement on various issues.

One Grantee said that establishing a single office responsible for all long-term services and supports programs, including nursing facility and waiver services, had been critical to developing and implementing an integrated approach to quality assurance and improvement.

Recommendations

Grantees made numerous recommendations for the operation of grants generally and for changes in state and federal policies to facilitate and support quality management strategies. Grantees' recommendations, discussed below, are grouped into seven broad categories.

Using Peers in Participant Surveys

States considering the use of peers to conduct participant satisfaction surveys should consult with other states that have experience with such programs. Many of the problems grant staff encountered would have been minimized had they first spoken to those with experience.

Involving Stakeholders

- Before changes in quality management systems can be made, time and resources are needed to achieve buy-in from key stakeholders and to convince them to adopt new ideas and approaches. Stakeholders need to be involved in many activities—from advisory groups to work groups to focus groups. It is also essential to ensure broad, strategic participation of stakeholders with the authority and responsibility to bring about change. Project staff need to clarify what is expected of stakeholders, and, if their input is solicited, be prepared to respond to it.

- States should develop a clear work plan at the outset to obtain stakeholders' understanding, buy-in, and commitment. Project staff and all stakeholders need to understand that a continuous quality improvement process is iterative and has to occur over a long period: 5 to 10 years at a minimum. Internal communication among state decision makers is crucial to obtain buy-in by management and to ensure ongoing success.

- States seeking to implement a single Quality Management System for multiple service delivery systems serving different populations are well advised to spend the time needed to engage all stakeholders in establishing priorities for the project *prior* to submitting a request for funding. When representatives of different service populations could not agree about design and implementation features, grant staff found it helpful to remind them of their initial agreement about priorities in order to get them back on track.

- The involvement of all stakeholders can help to bring about systems change, but to provide helpful input, stakeholders must be knowledgeable. Education and training may be needed for them to understand quality management principles and CMS expectations.

- Conducting focus groups in different regions is a very effective way to obtain information that is both specific and reflects regional needs and differences. Also, dividing the focus group into a participant group and a provider group allows both to speak freely and provide better insight into different program issues. Using an advocacy organization that is viewed as both unbiased and knowledgeable to conduct focus groups enables participants and providers to freely express concerns and complaints. If waiver participants have difficulty expressing themselves, hiring facilitators who are skillful in communicating with people with impaired speech and/or cognitive abilities is crucial.

Involving Participants

- Systems change initiatives should always include activities to develop self-advocates' skills and self-advocacy because participants help drive systems change in ways that state staff cannot.

- When developing a quality management system, states should base the analysis of the system's performance on what program participants consider to be most relevant to them. Focus groups can be useful in identifying what is important to participants. Obtaining participants' input validates and provides credibility for the performance measures.

- States should ensure that all information regarding quality management initiatives—including written documents, multimedia materials, websites, and web-based services—is fully accessible to individuals with disabilities.

- Including participants and families in any effort to improve quality assurance programs can be key to success. For example, hiring individuals with disabilities to survey their peers can help to increase response rates, because participants feel more comfortable when being interviewed by individuals with similar experiences.

Information Technology and Data Management Systems

- States should determine where additional funding might be needed to finish work begun under a grant, and/or to supplement grant funds because technology development often costs more and takes more time than anticipated, especially when integrating new systems with existing ones. This is particularly true when information about the existing system is unavailable and must be researched during the project.

- Grantees should carefully analyze the amount of grant and state resources available prior to committing to developing state-of-the-art applications that use the most advanced software platforms. Grantees must closely scrutinize their state's long-term commitment to supporting these types of applications. Where possible, they should combine any data system development projects in the quality area with other data systems and projects related to financial systems or other mandated reporting systems. Doing so will help to ensure ongoing financial and technical support for the quality data systems.

- Using a separate data analysis committee to deliver performance reports to other quality review committees, rather than having each committee conduct its own data analysis, can be beneficial for several reasons: (1) the data analysis committee can be structured to include members with considerable expertise in data analysis and reporting, (2) having a single data analysis committee can help ensure a common format for all reports, and (3) a separate data analysis committee reduces the workload for other committees.

- It is important to conduct an analysis of the state's information technology capabilities prior to establishing database development goals. One Grantee found that its goal was too ambitious and premature: to develop a single relational database that would pull together the various spreadsheets and information collection tools used by a division to analyze information.

- Before designing new data management systems, it is essential to carefully consider how the data will be used and who is the target audience for particular data (e.g., CMS or the state legislature). Doing so will help to ensure that the new system provides the needed data. Systems should be designed to provide sound information when needed and to have the capability to quickly and easily identify trends, key issues, and patterns, to enable rapid resolution of program participants' problems.

- When using an information technology contractor and/or consultant, states should use different vendors for (1) analyzing the organization's needs and (2) choosing a technology solution and/or developing the system that the state selects. Doing so will help to ensure that all available technology solutions and options are explored and that they are evaluated in regard to how they will meet the state's needs and selection criteria, rather than being based on the vendor's preference.

- The audience for quality data may need to be educated about how to interpret it. If data are misinterpreted and used against providers, they will be reluctant to provide data in the future.

Quality Management Systems

- States that want to implement new quality management systems need to have a systematic way to analyze the current system, to determine what is needed and to plan for future investments. Such an analysis can provide information to (1) guide future investments; (2) coordinate investments across programs, populations, and funders; and (3) avoid duplication of effort in these investments. This information can be used both in the short term (to guide a specific project) and over the long term to highlight areas that need the most attention and investment.

- States should find ways to identify high performers and provide incentives for high performance. Doing so will help to embed a new quality management system into professional practice in a way that simple compliance systems can never achieve. This goal will most likely require some creative work with providers, advocates, participants, and families to identify ways to recognize excellence.

State Policy

Grantees made several recommendations for changes in state policy to facilitate quality assurance and improvement. Some of these recommendations were directed at their own state, but many are relevant to other states as well. Their recommendations included the following:

- While person-centered planning (PCP) is being implemented in the state's programs and policies, additional activities are needed to ensure that the PCP philosophy and processes are understood and adopted statewide at the community level.

- The state needs to update its information technology system to make communication more efficient and timely and to reduce paperwork.

- The state needs to revise the certification processes for unlicensed service providers to help ensure the provision of high-quality services.

- States need to provide ongoing financial support for HCBS quality management.

- The state should standardize training on the implementation of Individual Service Plans and fund more training for providers.

- The state should provide more training on reporting abuse, neglect, and exploitation to professional staff, direct care workers, and individuals with disabilities.

- Because quality management is resource intensive, to the extent possible, states should assign staff to this task as part of a dedicated and focused activity. They should also determine what quality activities already exist to ensure that new activities are not duplicative and to identify activities that can inform new efforts.

- States should consider contracting with Quality Improvement Organizations (QIOs) to conduct quality management activities, because it can help to assure the public that the reviews will be objective. Another advantage is that CMS provides a 75 percent federal match for approved QIOs.

CMS

- Quality management for HCBS needs ongoing state and federal financial support. Because investments in information technology are essential to improve QA/QI systems, CMS should provide a 90 percent federal match for states to develop data systems that enable them to meet the waiver assurances, even if they are not directly part of the Medicaid Management Information System. CMS should also consider funding continuing costs for IT systems as well as the initial costs for IT development.

- CMS should amend the Participant Experience Survey to add an option for field notes, which would facilitate the survey process. The PES provides ample aggregate-level outcome data that identify programmatic challenges in many service areas. However, the tool does not provide insight into a program’s micro-level dynamics. Adding an option for field notes would compensate for the tool’s limitation.

- CMS should shift its primary quality management focus from emphasizing regulatory compliance to measuring outcomes—or at least achieve a better balance between the two.

- CMS needs to provide consistent reinforcement of—and help states to better understand and implement—a systems approach to quality management. Also, CMS regional staff who review and approve waiver applications and those who conduct periodic reviews of waiver programs need to better understand the concepts and requirements of a systems approach to QA/QI. Continuing education for CMS staff in this area would be helpful.

- To help states ensure that the data they collect are in accord with the CMS Quality Framework and the waiver assurances, CMS should clarify that the waiver assurances differ from the domains in the Quality Framework, even though some appear to be the same (e.g., service planning). The Framework needs to be clarified to ensure that states' data meet waiver requirements.

- CMS should establish uniform requirements for unlicensed Medicaid providers.

- CMS should continue providing grant funding to facilitate systems changes. The grants were invaluable, providing flexible resources "without strings" to improve the state's QA/QI system—resources that would not otherwise have been available. The flexibility afforded by the grant enabled the state to think "outside the box" and to adapt to changes resulting from frequent staff turnover without "jumping through a lot of hoops." Access to grant funding is and will continue to be critical to help states fully implement the systems and technological innovations necessary to meet CMS requirements for §1915(c) evidence-based reporting.

- CMS wants states to automate data collection and reporting, but most states have old hardware and software and the cost to upgrade is very expensive. To obtain the federal 90 percent match for new hardware, states need to fill out a complicated Advance Planning Document (APD), which is extremely time consuming: it would take one employee a full year's work to develop an APD. CMS needs to streamline the process for obtaining the 90 percent match to enable states to update their data systems.

- The national technical assistance vendors for the grants were an invaluable resource that could have been better utilized if Division grant staff had understood all of their capabilities. Because of staff turnover, grant staff were not always aware of the full range of technical assistance (TA) that was available. TA providers should spend more time with individual Grantees to ensure that the Grantee understands the type and extent of TA available.

Section Two. Individual QA/QI Grant Summaries

California

Primary Purpose and Major Goals

The grant's primary purpose was to address system weaknesses in two critical areas of home and community-based services delivery: provider capacity and capabilities, and the ability to measure participant outcomes and satisfaction. The grant had three major goals: (1) to design and pilot a Quality Management System (QMS) to improve the provision of person-centered and participant-directed services and supports to individuals with developmental disabilities (DD) in the San Francisco Bay area, (2) to adopt a systems approach to measuring participant satisfaction with services and supports at key intervals to guide system improvement efforts, and (3) to apply "lessons learned" from grant project activities to make statewide system reforms.

The grant was awarded to the Department of Developmental Disabilities Services (DDDS) and was subcontracted to the San Andreas Regional Center for implementation.

Role of Key Partners

- The Bay Area Leadership Group, the grant project's Steering Committee, received monthly progress reports on all grant activities and made final policy and funding decisions. The Group included representatives from the DDDS, the Director of the state-owned and -operated Agnews Developmental Center, and the Executive Directors of the three Bay Area regional centers—Golden Gate, East Bay, and San Andreas. (Regional centers are private nonprofit entities that provide case management services and administer DD waiver programs.) Other stakeholders attended meetings but did not have decision-making authority. The Leadership Group was formed as part of the Agnews closure plan prior to the State receiving the grant.

- The Community Development Team included a wide range of stakeholders—service users and family members, service providers, advocacy organizations, representatives from the Agnews Developmental Center and three regional centers, DDDS staff, and other stakeholders. The Team was the grant's advisory body, meeting quarterly and providing expertise, input on grant products, and guidance on grant activities. This team was one of six that helped to write the plan for closing the Agnews Developmental Center.

- The Quality Assurance Work Group (QAWG), an advisory body to the grant, collaborated with DDDS to develop the conceptual model and final design of the Bay Area Quality Management System. The QAWG was created by the grant project director to deal specifically with operational issues (e.g., the review and development of provider survey tools). Several members of the Community Development Team served on the QAWG.

- A Quality Management Review Commission was established to serve in an advisory capacity to review data reports generated by the Bay Area Quality Management System and to make recommendations for system improvements and capacity building to the

Bay Area Leadership Group. The members include two service users, seven parents, an advocate from Protection and Advocacy, Inc., and one service provider.

- The three regional centers collaborated with the DDDS and a grant-funded consultant to design a Quality Service Review (QSR) process and produce a two-volume technical manual.

Major Accomplishments and Outcomes

- A contractor conducted a comparative analysis of California's many consumer satisfaction instruments and an analysis of California's information system with respect to the requirements of participation in the National Core Indicators (NCI). The Quality Assurance Work Group simultaneously conducted its own informal review of the same existing surveys and reviewed the contractor's final recommendations. The purpose of this duplicative effort was to obtain stakeholder input via the QAWG prior to any decisions being made by the Steering Committee. Recommendations in the contractor's report and from the QAWG informed the Steering Committee's decision to use both the NCI Consumer and Family Satisfaction surveys as part of the QSR process.

- Using the NCI survey instruments, a grant contractor conducted in-person interviews with approximately 750 DD waiver participants aged 18 and over; a mail survey of approximately 400 families from the same population; and in-person interviews with every individual who had transitioned from Agnews Developmental Center from July 2003 through March 2005. Survey findings from the first year of the grant were published in late 2007. Findings from the second year were scheduled to be published in mid-2008. The DDDS is considering conducting another NCI survey of individuals who have transitioned from Agnews as well as NCI surveys of waiver program participants.

Enduring Systems Change

- Grant partners designed the Bay Area Quality Management System, which includes a Quality Service Review, and provides a standard and consistent set of service quality expectations and measurements and a platform for regional centers and providers to work as partners in pursuit of continuous quality improvement in services. The Bay Area QMS targets everyone involved in transitioning residents from Agnews Developmental Center—family members, providers, regional center staff, and DDDS staff. Agnews was scheduled to close by June 2008, and funding for the full implementation of the QMS pilot was projected to be secured through 2009.

  As the pilot project began to implement the QMS approach, tools, and information system developed over the 3-year grant period, important data about provider capacity and quality, participant outcomes, and the actual process of deploying the QMS became available. The Quality Management Commission used this information to make recommendations to the Bay Area Leadership Group for changes in the policies and processes of the three Bay Area regional centers.

Once the QMS is established and validated, the DDDS will consider expanding its use beyond the pilot project population to include all the residential services of the three Bay Area regional centers who serve more than 30,000 individuals with developmental disabilities. When this initial expansion is accomplished (and information is available from this larger implementation), the DDDS will consider expanding its use statewide.

- A key component of the QSR is its focus on quality outcomes for individuals through the use of several monitoring tools for provider services. These tools are implemented by professional staff at regional centers (registered nurses, psychologists, QMS Specialists, and service coordinators) as well as by family members, friends, and other visitors to individual's homes. In December 2006, the grant project director began intensive training on the use of the new monitoring tools, primarily for professionals and families.

  In addition to the annual NCI surveys, the QMS includes an ongoing Quality Snapshot survey to measure individual outcomes and satisfaction. Using this tool, visitors to a participating residential home can provide information about their perspective on the home's environment and staff and a resident's well being. Quality Snapshot surveys are mailed directly to the QMS Coordinator and data from returned Snapshots are being reviewed, utilized, and entered into a central information system.

- A Quality Management Information System was developed and implemented to manage QMS data storage and display. The system will aid QMS Specialists in their work with providers to continuously improve their services and ensure that services meet the entire array of provider quality expectations. In addition, the system will include a response tracking process that will enable follow-up for any areas or discoveries needing attention during the quality improvement efforts.

- The grant's work has laid the foundation for using data on participant and family satisfaction to continuously improve services at the individual provider level, the regional center system level, and, potentially, at the statewide system level.

Key Challenges

- During the development process for the QMS components, it was difficult to avoid re-creating a traditional quality assurance program based on compliance and an "event-based" review, but the grant succeeded in doing so.

- The survey sample size for the NCI survey of individuals who recently moved from the Agnews Developmental Center to the community was about a quarter of that recommended, making useful comparisons and conclusions from the data extremely difficult. The NCI results from the much larger Medicaid waiver Consumer and Family surveys have provided more useful, reliable, and comparable data for the QMS.

- The NCI indicators describe primarily "satisfaction with services" and do not for the most part portray the "condition" of service users in the community. Satisfaction surveys were not meant to specifically describe, for example, health and wellness, safety, and environmental conditions. For stakeholders concerned primarily with these aspects of community living, the NCI survey is not particularly useful. Nonetheless, the State decided to use the NCI survey because its pros outweighed its cons (e.g., it is a valid and reliable tool that can be benchmarked).

- In a service system the size of California's, which serves more than 200,000 individuals with developmental disabilities, it is very difficult to bring about statewide systems change in a 3-year grant cycle.

Continuing Challenges

- The components of the Quality Service Review are challenging to implement because they are time, labor, and resource intensive.
- Developing certification panels is a challenging process because a mix of professional and volunteer panel members must be educated on the QSR process and methodology in order to make important decisions based on voluminous data. The certification panels need to review as many as 30 or more homes per year, so workload intensity may prove problematic.
- Balancing regulatory compliance with quality improvement activities is challenging because there is always a tendency to revert back to an event-based compliance system, rather than fully embrace a quality investment/quality improvement system.
- Keeping case management ratios manageable, as they are in the Agnews Closure process, is needed to provide high-quality planning to develop individualized supports. Resources may not be available in the future to maintain this level of support and attention.

Lessons Learned and Recommendations

Lessons learned relate to the methods used to conduct the NCI Consumer surveys. In the first year, the contractor was only able to schedule survey interviews after consent was obtained from service users by a regional center Service Coordinator. Since the Service Coordinators had to work this task into their already busy schedules, the consents were received very intermittently, which created enormous delays. To address this problem, the contractor identified a method (in accordance with statutes related to confidentiality) whereby service users' names and addresses can be released directly to the contractor, who can then obtain consent for and schedule the interview at the same time.

Key Products

Educational Materials

- Grant partners developed materials to educate stakeholders and participants about the QSR process.

- Materials were produced to train specific professionals (e.g., service coordinators, registered nurses, behavioral analysts) on the application of QSR tools and how to input data into the Quality Management Information System.

Technical Materials

Under the new Quality Management System, each agency or organization providing community residential services and supports must be certified to do so. The Quality Service Review provides the means for this certification and new versions of the QSR Manual (Volumes I and II) will incorporate revisions based on implementation feedback and will be distributed semi-annually.

- *The Quality Service Review, Volume I* delineates (1) provider expectations and measures of those expectations; (2) the working collaboration between providers and regional centers to meet those expectations; (3) the review tools used by professionals, families, and friends to provide feedback and information on the activities and conditions of the homes; and (4) a series of interview tools to provide a wide variety of information and data to corroborate or remediate the QSR process.

- *The Quality Service Review, Volume II* describes the interpretive guidelines for each expectation and measure and provides technical assistance and resources to aid the provider and regional center staff (the QMS Specialist) to improve the quality of support services in the home. Also included in Volume II are several Training Modules (for professionals, friends, and family members), which are used as training tools to clearly describe the process for utilizing the monitoring tools of the QSR.

Reports

The Human Services Research Institute produced a grant-funded report—*Measuring Consumer Outcomes and Satisfaction in California: Identifying a Survey to Provide A Foundation for Quality Management*—that included a comparative review of consumer satisfaction survey instruments considered for use in California and an analysis of California’s information system with respect to the requirements of participation in the National Core Indicators. This report will continue to be used as a reference.

Colorado

Primary Purpose and Major Goals

The grant's primary purpose was to improve the efficiency and effectiveness of existing Quality Assurance/Quality Improvement (QA/QI) systems. The grant had three major goals: (1) to define and standardize a critical subset of QA measures and apply these statewide, (2) to acquire and adapt the information technology needed to improve critical incident reporting and general communication, and (3) to promote more active and effective involvement of service users and families in QA/QI processes through web-based information technology and direct assistance to strengthen self- and family advocacy.

The grant was awarded to the Department of Human Services, Division for Developmental Disabilities (hereafter, the Division).

Role of Key Partners

- The Project Advisory Committee—comprising service users and their families, and representatives of provider organizations, state agencies, and advocacy organizations—developed and reviewed grant products and outreach materials, and provided input for the CMS Annual Reports.
- Grant staff formed a project team to develop web applications. The team included several experts on a range of subjects (e.g., critical incidents, program quality data), information technology professionals within the Department of Human Services, and consultants.

Major Accomplishments and Outcomes

- The Grantee standardized critical elements of the participant/family survey conducted by the Division's Community Centered Boards (CCBs) that will be used on a statewide basis.[6] In addition, as part of an effort to improve the timeliness and efficiency of data reporting, the Division obtained technical equipment and software to enable regulatory survey forms and participant/family survey forms to be scanned and the information entered in a database.
- The Grantee defined a set of performance measures specific to different provider organizations (e.g., those providing case management, supported employment, or residential care services) and developed a system to track and report on such measures.

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[6] The Division for Developmental Disabilities contracts with Community Centered Boards (CCBs) to offer community-based services to persons with developmental disabilities. CCBs are private nonprofit organizations designated in state statute as the single entry point into the long-term services and supports system for persons with developmental disabilities. As the case management agency, CCBs are responsible for intake, eligibility determination, service plan development, arrangement and delivery of services, monitoring, and many other functions. CCBs deliver services directly and/or contract with other service organizations. Provider agencies also contract directly with the State.

- Grant staff standardized required critical incident elements and implemented a web-based system for reporting them. Division staff trained CCBs' targeted case management staff to use the system, and the Division generated summary data reports for analysis and follow-up.

- The grant supported a total of 13 projects in urban and rural communities to help strengthen self- and family advocacy through technical assistance, cash grants, and in-kind support. Of the projects funded, 8 addressed training in advocacy and self-advocacy for participants and family members, 4 addressed development of new local self-advocacy organizations, and 1 focused on development of new training/support materials on self-advocacy. The total number of persons who participated in the projects was as follows: individuals with developmental disabilities and family members—1,379; advocates and case managers—57; provider agency staff—507; other persons—286. Also, Colorado Arc published a newsletter with grant funds, which was disseminated to 1,571 service users and their families.

Enduring Systems Change

- The consistent collection and reporting of participant/family satisfaction measures and organization-specific performance measures has significantly advanced Colorado's ability to improve the performance of the developmental disabilities system, to support informed choice for participants/families, and to support transparency in the provision of information to the general public. The standardization of the satisfaction and performance measures ensures that basic variables are included in the data to be collected, analyzed, and reported. Such standardization allows the Division to provide consistency across reporting years, programs, and providers to facilitate quality improvement and systems improvement.

  Additionally, although the Division had previously collected and reported data from core indicator surveys on a periodic basis, the acquisition of data capture technology and the data warehouse will enable the Division to collect, track, and report core indicator data at the provider level on an ongoing basis. The use of business intelligence software to support analysis and reporting of data is also a significant improvement in this area.

- The new web-based critical incident reporting system has increased the timeliness and quality of reporting and has provided a system for data analysis. Critical incident data are stored in a data warehouse, and business intelligence software is used to support data-based decision making and remediation and quality improvement processes. In addition, the system is integrated with the community contract management system, providing more data elements to analyze, which can facilitate analysis of areas that would benefit from targeted quality improvement activities. For example, the combined system enables the State to link information about critical incidents to participants' disability diagnoses, use of specific waiver services, and specific service providers.

- Grant staff and consultants designed and launched a new website targeted to service users, families, and service providers, which includes information that indicates and can have an impact on quality; for example, provider offerings, safety alerts, results of quality reviews, information on self-advocacy, and eligibility criteria. The information can be accessed at http://www.cdhs.state.co.us/ddd/InformationforConsumersFamilies.htm.

The website also includes a compendium of training and technical assistance information intended specifically for service providers and advocates, and includes all directives concerning requirements for the provision of Medicaid services issued by the Division to service providers and targeted case management agencies. The information is downloadable and printable and can be accessed at http://www.cdhs.state.co.us/ddd/UserGuidesManualsReferenceMaterial.htm.

All currently available educational materials have been posted to web pages, and the Division has conducted training for qualified providers about accessing and using them. The Division will continue to revise the website and its content to make it more user friendly for waiver participants and to make information to support informed choice more readily available.

- The Division convened a Self-Advocates Advisory Council to provide direct input and feedback to the Division's director on policy issues in the developmental disabilities (DD) system in Colorado. For example, Council members provided feedback on issues and concerns related to the development and submission of a Section (§) 1915(c) waiver amendment application for Colorado's DD waiver. The Council meets every month and includes representatives from different geographic areas of the State.

Key Challenges

- State budget crises during the first several months of the grant delayed the initiation of grant activities.

- The amount of funds budgeted for web applications was insufficient to accommodate the significant increases in the cost of hardware and software from the time the grant proposal was written to when a request for proposals was released. As a result, no proposals were submitted. To address the cost issues, the Division determined what could be done with available funds and decided to combine the quality data system with the contract management system to ensure long-term financial and technological support. Combining the two systems also reduced operating costs.

- The State and its approved contractors had limited expertise with the most current version of the software chosen to develop the web reporting tool. This challenge significantly delayed the development of summary data reports on critical incidents and performance measures.

- Differing views about the State's web design requirements and specifications delayed the deployment of all web applications funded under the grant.

- Disparate viewpoints and opinions among advocacy and service provider organizations regarding provider performance measures and participant/family satisfaction measures slowed the implementation of some grant activities but were eventually resolved through compromise.

- Lack of project management experience and expertise undermined several local grassroots efforts to improve or expand advocacy and self-advocacy. The very limited funding (i.e., less than $5,000 per project) did not allow for the hiring of individuals with management expertise. Although several projects produced good work, the benefits were not sustained or did not allow for knowledge transfer to other entities or communities.

Continuing Challenges

It is difficult to ensure participation in the Self-Advocate Advisory Committee by those who live in geographically isolated parts of the State, some as far as 8 hours' travel time from the state capital.

Lessons Learned and Recommendations

- Grantees should carefully analyze the amount of grant and state resources available before committing to developing state-of-the-art applications using the most advanced software platforms. Grantees must closely scrutinize their state's long-term commitment to supporting these types of applications. Where possible, they should combine any data systems development projects in the quality area with other data systems and projects related to financial systems or other mandated reporting systems. Doing so will help to ensure ongoing financial and technical support for the quality data system.

- The national technical assistance (TA) vendors for the grants were an invaluable resource that could have been better tapped had grant staff understood all of their capabilities. Because of staff turnover, grant staff were not always aware of the full range of TA available. TA providers should spend more time with individual Grantees so that they understand what is available.

- Grantees should be prepared to immediately change goals—and methods to achieve them—based on emerging opportunities and insurmountable barriers identified through formative evaluation.

- Because investments in information technology are essential to improving QA/QI systems, CMS should provide a 90 percent federal match for states to develop data systems that enable them to meet the §1915(c) waiver assurances, even if they are not directly part of the Medicaid Management Information System.

- CMS should continue to provide grant funding to facilitate systems changes. The grant was invaluable, providing resources to improve the State's QA/QI system that would not otherwise have been available. Access to grant funding will continue to be critical to helping states fully implement the systems and technological innovations necessary to meet CMS requirements for evidence-based reporting.

Key Products

Outreach Materials

The Arc of Colorado developed and published a newsletter entitled *Connecting with the Arc* as part of its sub-Grantee project. The newsletter is available to all recipients of DD services and their families and provides information on advocacy, self-advocacy, and self-direction.

Educational Materials

- The self-advocacy development project completed by the Colorado State University Center for Community Partnerships developed a workbook entitled *From Here to There—The Self-Advocacy Handbook*.
- Grant staff developed and distributed the *Quick Guide—Critical Incident Reporting Criteria* for use by case management and service provider agencies.

Technical Materials

- To develop the critical incident reporting system and the performance indicator tracking and reporting system, consultants developed the following documents:
  - *Choice Grant Technologies Project Revised Requirements* provides a listing of high-level requirements that were used to fully describe all of the requirements of the web-based applications.
  - *DDD Web Applications Development (Choices Grant): System Design Document Version 1.3* describes the configuration and functionality of the web-based applications funded under the grant. This document is intended for use by the designers of the system and those who may be required to maintain it.
  - *DDD Web Applications Development Project Phase-I (Choices Grant): Software Requirements Specifications Version 2.4* describes the software requirements that were captured through a detailed study of the business work flow and functions for the web-based applications funded by the grant. This document is intended for use by the designers of the system and those who may be required to maintain it.
- Information technology contractors developed a set of 10 predesigned critical incident data summary reports for use by case management agencies, the Division of Developmental Disabilities, and the single state Medicaid agency. They also developed a set of three predesigned performance indicator data summary reports for use by the Division and the Medicaid agency.

Connecticut

Primary Purpose and Major Goals

The grant's primary purpose was to strengthen Connecticut's new quality service review (QSR) system by developing web-based data applications that will enable the State to identify trends in service quality and provide a foundation for quality improvement (QI) initiatives. The QSR web-based application is a major component of the State's overall quality management system. The grant had four major goals: (1) to develop the capacity to input, store, analyze, and report quality data; (2) to ensure and improve service quality for individuals living in their own or family homes; (3) to involve program participants and their families in defining, implementing, and improving service quality; and (4) to develop and provide a wide range of training activities for users of the new QSR system.

The grant was awarded to the Department of Developmental Services (hereafter, the Department), formerly the Department of Mental Retardation.

Role of Key Partners

- The grant's Steering Committee—comprising participants, family members, providers, and state agencies—provided direction and feedback on all aspects of grant implementation and evaluation.

- The State's Department of Information Technology supported grant staff and consultants to create and implement a software application to compile and report data related to service quality.

- The Department established a work group of participants, family members, and public and private provider staff—with the support of medical and psychological services professionals—to design quality indicators and QI methodologies in the areas of home safety, emergency preparedness, and participant safeguards.

Major Accomplishments and Outcomes

- The Department conducted focus groups to obtain consumer input on participant safeguards and quality review processes and tools, and presented recommendations to the grant's Steering Committee and to various Department leadership groups. The Department also formed a committee to update interpretive guidelines for the quality service review customized for family, supported living, and participants' own home settings. In addition to the guidelines, the Committee developed 10 recommendations for enhancing quality service reviews in these settings, including the creation of standard materials to use when conducting reviews.

- Grant staff developed QSR orientation and training curricula for participants and families, provider agencies, state-level quality management staff, regional quality monitors, and case management staff. The Department also developed emergency and safety-related resource and training materials for participants and families who hire and manage their own staff. The Department's fiscal intermediaries provide these materials to participants so they can share them with their employees.

- Grant staff worked with a nonprofit corporation, Rewarding Work, to pilot a state-specific link for Connecticut on the Rewarding Work human services recruitment website.[7] The link provides the only comprehensive and current list of individuals in Connecticut who are seeking employment as in-home direct care workers for elderly persons and individuals with disabilities. The site enables people of all ages with disabilities to recruit staff they wish to hire directly. The site also provides private agencies a resource for recruiting direct support professionals and other staff.

  Training on how to use the site was provided to participants, families, and Department staff, and grant funds were used to purchase subscriptions for them—about $90 a year each—so that the initial cost would not be a deterrent. The subscriptions were not as widely used as anticipated initially, but have increased in the past year. Future training and additional promotion will continue to highlight the website as an effective resource. In response to feedback from Connecticut's users, Rewarding Work made changes to the website to refine the search capability, making it more responsive to user needs.

Enduring Systems Change

- The Department developed a web-based software application, which was launched July 17, 2008, to compile and report data related to the quality of services provided by both state staff and private, contracted providers. These data are captured via the State's existing QSR tool, and the application is accessed via a secure website. Case managers and regional and state staff can conduct quality reviews using the QSR tool on laptops while onsite. The application enables the provision of more timely, comprehensive, and integrated data for quality assurance (QA) reports that will lead to improvements in service quality and also fulfill evidentiary requirements for the CMS waiver assurances. Because the new application allows data to be sorted by participant, provider, service type, or administrative region, it will facilitate the analysis of quality indicators and will enable the State to track performance measures over time as well as corrective actions to address identified problems.

- The Department used the grant to develop quality indicators and review methodologies for all services and settings, including those not previously monitored as part of the formal QA system (e.g., employment, day service, and in-home settings). The Department also modified its QSR tools for all service settings, and grant staff piloted the tools for home settings.

- The Department used the grant to develop several new approaches for collecting data on quality outcomes. Previously, only state-level reviewers collected data and assessed

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[7] The website is a collaborative effort of the Massachusetts Department of Mental Retardation; the University of Massachusetts Medical School, Center for Health Policy and Research; the New Jersey Division of Disability Services; the Connecticut Department of Mental Retardation; and the Rhode Island Department of Human Services.

quality as part of the State's QSR system. Now the Department also uses case managers and regional quality monitors to collect data through participant interviews, direct care worker interviews, document or record reviews, safety checklists of the environment, and observation of participants during service provision.

In addition to collecting data, case managers help individuals and their families to review the quality of their supports and services; and regional quality monitors look at service patterns and trends and evaluate vendor performance at the regional level through quality review visits with individuals in their home or day services setting.

- The Department established a standardized process for reporting, documenting, and following up reportable incidents involving individuals who receive waiver services in their own or a family home. Information obtained through this reporting system is used to identify, manage, and reduce overall risk and to assist the Department in quality oversight and improvement efforts.

- The Department established a structured and formal process of "root cause analysis," which is a systematic method to review selected sentinel events in order to analyze potential factors that increase risk, and to facilitate the design and execution of effective risk prevention strategies. The Department also developed processes that include methods to risk adjust incident data so that providers who support people with the most challenging needs can be compared fairly with other providers.

- The Department established Quality Review and Improvement Councils led by regional QI directors in all three regions of the State, and appointed a central office QI director to work with the regional QI directors and provide statewide oversight of QI initiatives. The regional QI directors produce data on provider performance and develop QI plans for follow-up when necessary. Service users and family members were recruited as volunteer Council members to participate in the review of quality information and monitoring of QI plans.

- The Department hired nine permanent part-time consumer/self-advocate coordinators to fulfill leadership and mentor roles, provide training, and influence policy development as committee and work group members. During the grant period, half of their work was related to QA/QI grant activities, with the remainder focused on regional initiatives. The self-advocate coordinators helped participants and their families understand the requirements of being an employer; produced training materials on self-direction and waiver services; and were involved in new employee training for state staff, particularly on human rights and self-determination, self-advocacy, and self-direction initiatives.

- During the grant period, the State expanded self-directed services options. Because the Department's quality management system has to cover all service models, a strong commitment to self-direction has been systemically embedded through all the structures and educational components that have been put into place as a result of the grant. Participants have increased access to self-direction as a result of newly available self-direction materials and resources and enhanced information on the Department website. In addition, the employment of the nine self-advocate coordinators has resulted in an ever-improving culture of increased respect for service users and their inclusion in all aspects of the service system.

Key Challenges

- Several features of the new software application were quite complex, which led to significant implementation delays. Problems were addressed though frequent and ongoing status and problem-solving meetings among all parties involved.

- The vendor working on the incident management application was also working on another department priority that took longer than anticipated to complete, so the web-based incident management application work had to be discontinued as it could not be completed within the time constraints of the grant.

Continuing Challenges

Some of the grant's technology-related initiatives depend on support from the state technology agency, support that is not always available or timely. This situation delayed implementation of the QSR software application, which eventually was launched on July 17, 2008.

Lessons Learned and Recommendations

- Although it was beneficial to have the same or similar vendors support various activities in this and the concurrent Independence Plus grant, vendor schedules and commitments sometimes prevented them from accomplishing all activities in a timely fashion.

- Using existing Department senior staff as primary grant staff ensures integration of grant goals into existing systems and structures, resulting in more enduring systems changes.

- It is best to assume that any Information Technology project will take more time, money, and human resources than anticipated.

- Because consumers help drive systems change in ways that staff cannot, it is essential to include activities to develop self-advocates' skills and self-advocacy into systems change initiatives.

Key Products

Educational Materials

- Grant staff developed and published *Understanding the Connecticut DMR Home and Community-Based Services Waivers: A Guidebook for Consumers and Their Families* to help participants and their families make informed decisions about their supports. Grant staff also developed and published two guides on self-direction: *An Introduction to Your Hiring Choices* and *Making Good Choices About Your DMR Supports and Services*. English and Spanish versions are available for all the guides on the Department's website (http://www.ct.gov/dds/cwp/view.asp?a=2042&q=335512).

- The Department developed a series of fact sheets—*Health Identifiers and Symptoms of Illness Series*—to increase participants', families', and workers' knowledge and skill in recognizing the signs and symptoms of illness. The fact sheets provide guidance on whom to contact if signs and symptoms are observed. The Department also developed training materials and fact sheets on Abuse and Neglect, Fire and Other Emergencies, Human Rights, Person-Centered Planning, Approved and Prohibited Physical Management Techniques, and Incident Reporting Requirements.

- The Department produced the *Quality Service Review Data Application Reference Manual* to provide guidance for people using the web-based data application.

Technical Materials

- The Department developed an overview of the QSR tool that includes a master set of all the quality indicators to be used in various service settings, and identifies who collects the data (e.g., case manager, case manager supervisor, regional quality monitor, or state quality monitor).

- Grant staff produced policy and procedures documents and various reporting forms for the new systems for Root Cause Analysis and Incident Reporting.

Delaware

Primary Purpose and Major Goals

The grant's primary purpose was to institute a new Quality Management System for individuals with developmental disabilities receiving residential and day services. The new system will also cover services to be provided under a new waiver (once approved) for individuals living with their families. The grant had six major goals: (1) to assess current quality management functions for waiver and non-waiver services with reference to the CMS home and community-based services (HCBS) Quality Framework and waiver assurances; (2) to revise or establish processes for measuring the quality of community services and supports, correcting problems, and making system-wide improvements; (3) to test the new processes and develop a strategic plan to fully implement the Quality Management System; (4) to establish a Quality Council as an external review body; (5) to develop a Quality Management System for a proposed Family Support waiver; and (6) to assess current developmental disabilities (DD) data systems to determine future information technology development needs and make recommendations to meet them.

The grant was awarded to Delaware Health and Social Services, Division of Developmental Disabilities (hereafter, the Division), which contracted with the Human Services Research Institute (HSRI) to assist with grant implementation.

Role of Key Partners

A Consumer Task Force—comprising individuals with disabilities, advocacy organizations, and staff from several state agencies and councils, including Medicaid—was formed at the grant's inception to oversee and direct the project. Task Force members participated in the selection of HSRI as the grant contractor, and were instrumental in helping the Division prioritize the quality performance indicators to be used in the new Quality Management System.

Major Accomplishments and Outcomes

- The Division conducted a comprehensive assessment of its policies, practices, and data in relation to the six CMS HCBS Quality Framework domains and the waiver assurances, and presented the findings to and solicited input from all stakeholders (people and families served by the Division, advocacy groups, contracted day and residential service providers, and Division staff and administrators). A total of 161 consumer outcomes and performance indicators were subsequently identified and classified under their associated waiver assurance, and the Division prioritized 37 indicators for initial development. These formed the foundation of the Division's new Quality Management System.

- In addition to covering residential and day programs, grant staff decided to have the new Quality Management System cover a new Family Support waiver as well. The Family Support waiver will provide an increased array of services and the option for participants who live with their families to direct their services. However, because the Family Support waiver has unique characteristics, the grant contractor—in consultation with Division staff—developed a quality management system specifically for the proposed waiver and prepared the document *Division of Developmental Disabilities Services (DDDS) Appendix H: Quality Management*, which will be included in the waiver application once state funding for the new waiver has been approved.

- The Grantee hired a consultant to assess the Division's information technology (IT) data collection methods and needs. The consultant examined the experiences of several states, conducted surveys with the Division's IT section, and surveyed a number of contracted providers regarding their experience using the State's various IT systems. The consultant prepared a report of findings and recommendations, which provided the Division with a cost-effective plan to meet its data collection and analysis needs.

Enduring Systems Change

- The new Quality Management System has been developed and put into operation, and a Performance Analysis Committee has been formed to collect and analyze data on specified indicators and to deliver data analysis reports to various quality-related Division committees and administrators. At the time of the grant's final report, the Performance Analysis Committee had used the new system to generate more than 20 data analysis reports for the system's Continuous Quality Improvement cycle. A number of these reports are being used to prepare the Division's evidentiary report for CMS regarding the State's waiver for individuals with mental retardation or other developmental disabilities (MR/DD), which is due to expire in June 2009.

  The Committee also produced a number of data analysis reports on selected performance indicators, which have been shared with the Division's senior management, various committees (internal and external) charged with quality improvement, and with contracted agencies providing services, as well as with other divisions in the Delaware Health and Social Services Department.

  The reports, which cover a variety of subjects and are cross-referenced with the CMS waiver assurances, are intended to serve as a basis for helping these entities judge the quality of DD services and to provide the foundation for developing improvement strategies. The entities receiving these reports are encouraged to identify strategies to improve identified systems weaknesses noted in the reports.

  Services and supports currently incorporated into the Quality Management System include contracted agency-managed residential and day services, and state-operated day programs and shared living (e.g., foster care) services—most of which are funded under the State's MR/DD waiver. State-funded respite care services are also included in the system, and the State's intermediate care facility for mental retardation (ICF/MR) has been partially integrated (i.e., included when there are existing survey tools/ processes that address both community services and the ICF).

- To align its discovery processes with the new quality indicators, the Division modified its Community Living Arrangement review to focus more on person-centered quality outcomes. The Division also developed a complaint process for participants, families, and providers to help identify and/or resolve concerns. As part of this process, the Division implemented a toll-free number for the Division's central and regional offices to enable participants and their families throughout the State to make complaints or suggestions about the DD service system. The number can also be used to provide positive feedback about services.

- The Division instituted a Quality Council as part of the Continuous Quality Improvement process for performance reports, and HSRI provided 2 days of orientation and training to Council members. The Council consists of a volunteer group of 18 stakeholders (waiver participants, family members, providers, and direct support staff) who meet to review quality reports and to recommend systems improvements. Individuals who do not generally serve on committees, councils, or boards were chosen through an application process in order to obtain a more diverse viewpoint than is available when the same people serve on several bodies. Some of the Division's executive staff attend each Council meeting as do various regional management staff.

- The Division now uses a web-based incident reporting system (adopted originally in January 2007 by its contracted service providers) for its own service delivery programs: primarily state-operated day centers and foster homes. The system has proven very useful in the analysis of data and the production of reports by the Performance Analysis Committee, and the Division transitioned from its paper-based incident reporting system to the web-based system in January 2008.

  The initiation of this and other data collection systems (internally and by contractors) will enable faster and more comprehensive data analysis using a variety of performance indicators. Contractors, as well as all levels of Division staff, will be able to carry out their own data analyses quickly and easily.

- The Performance Analysis Committee received approval to issue provider-level reports to agencies fully disclosing each firm's performance. In addition, the Division has begun publishing the Neighborhood Home licensing results on the Internet so that families can review them easily when choosing residential options (http://dhss.delaware.gov/dhss/ddds/survey_main.html).

Key Challenges

Educating members of the various review committees in reading data reports was challenging. Division staff and members of the Performance Analysis Committee used a variety of data presentation methods—charts, tables, simple narrative—to facilitate communication of findings. Also, reliability of data entry was an issue, particularly in counties that have high staff turnover among data entry personnel.

Continuing Challenges

The State legislature did not fund the Family Support waiver, so the application could not be submitted in state fiscal year (FY) 2008. A coalition of advocacy groups has been formed to lobby both the legislature and the governor to provide the state match so that the Division can submit the application to CMS in FY 2009.

Lessons Learned and Recommendations

- Basing the analysis of system performance on what program participants feel is most relevant to them proved quite helpful in developing the Quality Management System. Using focus groups to identify what was important for participants gave a lot of weight to the performance measures that were chosen and their validity was not questioned. Additional insight was gained from cross-matching quality indices to the CMS assurances and then prioritizing them for reporting purposes.

- Using a separate data analysis committee (the Performance Analysis Committee) to deliver performance reports to the various review committees, rather than having each committee conduct its own data analysis, was beneficial for several reasons: (1) the Committee included members with considerable expertise in data analysis and reporting, (2) it facilitated use of a common format for all reports, and (3) it reduced the workload for all of the other committees.

- The goal of developing a single relational database that would pull together the various spreadsheets and information collection tools used by the Division to analyze information was found to be too ambitious and premature without first performing an analysis of the Division’s IT needs and capabilities.

- CMS should consider funding continuing costs for IT systems as well as the initial costs for IT development.

Key Products

Technical Materials

- *Phase I Assessment Report of Quality Assurance and Improvement for the State of Delaware, Division of Developmental Disabilities Services (DDDS)* is a summary of major systems strengths as of 2005 and includes recommendations for improvements. In completing the assessment, HSRI gathered information from multiple sources, including Division staff and providers; documents describing the current quality assurance and quality improvement processes and tools; management reports; and policies and procedures; as well as focus groups with individuals and families.

- *Delaware Health and Social Services, Division of Developmental Disabilities Services (DDDS), Quality Management System* describes how the Division’s Quality Management System uses outcomes and indicators to measure quality; the processes of discovery, remediation, and improvement; sources of information used to measure performance; and key roles and responsibilities for managing quality.

- *Information Systems Development in Support of the Delaware Division of Developmental Disabilities Services: Moving Forward* was developed to inform decision making as the

Division continues its planning and development efforts to improve the accessibility and use of information technology.

- *Performance Analysis Committee Policy* outlines the role and function of the Division's data analysis committee. This group plays a central role in the collection, analysis, and reporting of performance indicators data. The policy offers definitions, standards, procedures, and a flow chart to illustrate the continuous quality improvement cycle and is available at http://www.hcbs.org/moreInfo.php/doc/1894.

Reports

- In June 2007, HSRI produced a final grant report *(Delaware Division of Developmental Disabilities Services System Change Grant: Accomplishments and Next Steps Recommendations)* that describes the grant project's accomplishments and recommends additional steps to further improve the Quality Management System.
- The Division produced a formative evaluation—*A Quick Glance*—to help the state Medicaid agency's Quality Improvement Initiatives Task Force to review the progress of the Performance Analysis Committee in its reporting of the piloted performance indicators, as well as the use of the information by the recipient committees/administrators for systems improvement.

Georgia

Primary Purpose and Major Goals

The grant's primary purpose was to improve services for persons with developmental disabilities. The grant had three major goals: (1) to promote greater statewide understanding and implementation of person-centered practices, (2) to design participant outcome measures that are objective and person centered, and (3) to ensure that persons who are involved in and affected by the developmental disabilities (DD) service system have a meaningful impact on decisions regarding the system.

The grant was awarded to the Department of Human Resources, the operating agency for the State's two DD waiver programs. The project was implemented by the Division of Mental Health, Developmental Disabilities, and Addictive Diseases (hereafter, the Division).

Role of Key Partners

- A Consumer Task Force with 55 members provided input on grant activities.

- The participation of 10 public and private partners in local person-centered planning (PCP) groups provided resources and contacts that helped the individuals who were the focus of the groups' efforts to achieve personal goals, which was critical to the groups' success.

Major Accomplishments and Outcomes

- Grant staff and consultant facilitators developed and piloted five PCP projects for individuals with developmental disabilities and their community supports to teach them how to develop and implement person-centered plans, with a focus on identifying and encouraging natural supports in their communities (i.e., unpaid support). Each PCP group focused on about five individuals with developmental disabilities, including some in middle school or transitioning from high school. One group targeted individuals living with aging parents.

  Community members who participated in this training included members from schools and places of worship; potential employers supporting the PCP process; and in one area the mayor, sheriff, fire chief, and a day care director attended the training. Guest speakers were invited to the PCP group workshops to provide information on special topics, such as vocational rehabilitation, special trust funds, and communication devices. Grant staff had monthly contacts with the PCP training participants to provide technical assistance and to ensure that the person-centered plans were being implemented. The five PCP groups have continued to meet since the grant ended, and they are extending their activities to other DD service users in their areas and increasing the use of natural supports in their communities.

- The Division has formed a coalition with a supported employment agency and two advocacy agencies (Parent to Parent of Georgia and Atlanta Alliance on Developmental

Disabilities) to promote person-centered planning and the use of the PATH process to provider agencies, support coordinator agencies, advocacy organizations, self-advocates, and families. PATH—one of many methods used in person-centered planning—is a planning tool that helps individuals set goals and determine feasible steps for achieving them.

- Grant staff worked with a contractor, who evaluated current performance measures for the DD system, and worked with stakeholders to create performance indicators based on the CMS Quality Framework. After cross-walking the resulting set of outcome measures with the National Core Indicators (NCI)[8] and evaluating the Division's data system for compatibility with the NCI, the State decided to join the NCI, thereby achieving the goal of designing objective, person-centered participant outcome measures. Grant funds were used for NCI start-up costs and to train interviewers to implement the survey.

- The grant coordinator and grant assistant collaborated with the Division Evaluation Unit to implement the NCI survey and to collect and report NCI data. More than 400 waiver participants were interviewed about their home, friends and family, satisfaction with services/providers, and self-determination. Also, two Family Surveys were mailed; data were collected on 400 families in which the individual receiving services lives at home and 400 families in which the individual receiving service lives in a residential care setting. In addition, approximately 90 providers serving 10 or more individuals were asked to complete an online survey, which requested data in particular about participant and family representation on their governing boards and staff turnover.

Enduring Systems Change

- PCP concepts and values have been written into program policies at the state level. Support coordinators who were involved with the PCP pilot groups have reinforced the changes by using person-centered planning to develop Individualized Service Plans. The entire DD system is now more focused on person-centered planning, and the Division will continue to train direct care workers, waiver participants, families, and community members in PCP principles and practice. In addition, the activities of the PCP pilot groups have led to increased use of self-directed services options, improved access to the community, and increased employment opportunities.

- The State has developed a facilitators' forum and a train-the-trainer program to train, support, and provide collaborative opportunities for family members and state staff on how to use person-centered planning and how to start and facilitate a PCP group. The State offers the 3-day training quarterly and arranges quarterly meetings of the forum. The State provides transportation assistance for some members to attend the meeting.

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[8] The National Core Indicators is a collaboration among participating member National Association of State Directors of Developmental Disabilities Services state agencies and the Human Services Research Institute, with the goal of developing a systematic approach to performance and outcome measurement.

- NCI survey data are being reviewed for systems improvement, and the Division will continue to conduct the NCI survey annually and use the data to improve the quality of services and programs. The results of the survey have had a major impact on systems improvement in Georgia. Although the survey revealed significant strengths in certain areas, it identified deficits in others that require systems improvement. The State is taking steps to address these deficits.

  For example, the State has submitted applications to CMS to amend two waiver programs in order to add self-direction options, which will enable people to direct their own service budgets, with support as needed. This will address the lack of personal choice deficits that were identified in the areas of exercise, daily schedule, and personal spending money, and will also allow for preventive dental services. The State also implemented the "Good to Great" program, the aim of which is to institute Essential Lifestyle Planning into systems processes and provider programs. Essential Lifestyle Planning is a guided process that helps individuals to identify their daily living and lifetime goals and to develop a plan to reach them.

Key Challenges

- A PCP group that had been developed in one region was cancelled because of lack of family response/interest.

- Throughout the grant the Division experienced frequent staff turnover, which resulted in the grant's coordinating position being held by three people. The staff changes interrupted documentation of grant activities and resulted in missed opportunities. For example, the second grant coordinator disbanded the Consumer Task Force at the end of the second year of the grant so it was unavailable to provide input on the NCI survey results. The staff turnover, however, also brought new perspectives, which allowed for new opportunities; for example, the addition of another PCP group.

- Finding local transportation presented a challenge for participants. Transportation was offered but not used. Although information about transportation support was provided to support coordinators and participants' families, grant staff heard anecdotal reports that some people did not know about the transportation options.

- The main challenge for the NCI Participant Survey project was to determine the best way to implement it. Support coordinators were trained and they administered the survey during the third year of the grant. Georgia is developing an RFP process to obtain an outside agency to conduct the NCI survey in the future.

Continuing Challenges

Although person-centered planning is being implemented in the State's programs and policies, communities and schools have been slow to grasp the PCP process. Additional activities are needed to ensure that the PCP philosophy and process are understood and adopted statewide at the community level (e.g., by inviting potential employers and education contacts to attend PCP group meetings).

Lessons Learned and Recommendations

- PCP groups coordinated by family members were more successful in identifying and developing natural supports than were groups coordinated by professional staff. Family coordination promoted a sense of ownership that helped them to increase acceptance of person-centred planning outside the formal DD system. States that want to support PCP groups should encourage family members to develop and coordinate such groups and should facilitate their efforts.

- States that want to implement PCP groups should address technical assistance needs through a formal process at each group meeting to ensure that problems, such as lack of transportation, do not impede participation. A possible option to address the lack of transportation for members is to have groups in multiple local areas rather than have multiple groups from different areas meet in one place.

- CMS should continue to fund Systems Change grants. Georgia's grant was invaluable in helping the State to make major improvements in its quality assurance/quality improvement system. The flexibility afforded by the grant enabled the State to think "outside the box" and to adapt to changes resulting from frequent staff turnover.

Key Products

Outreach Materials

Flyers and invitations were developed for the PCP projects' meetings.

Educational Materials

Grant staff and consultants developed PowerPoint presentations, information on resources, and planning tools to train direct care staff, families, individuals receiving services, and community members about person-centered planning and how to create PCP groups.

Indiana

Primary Purpose and Major Goals

The grant's primary purpose was to develop a Quality Assurance/Quality Improvement (QA/QI) system for home and community-based services (HCBS) programs that facilitates communication among all stakeholders and institutes uniform policies and procedures across the various state agencies and contractors that provide services. The grant had four major goals: (1) to develop methods for obtaining data about providers and individuals receiving services; (2) to design a QA/QI system that enables staff to evaluate incident and complaint data and determine appropriate action in an expeditious manner; (3) to develop systems that enable staff to analyze data, identify patterns and trends, and continuously evaluate the QA/QI system; and (4) to implement an automated reporting system by which data can be collected, synthesized, and stored for retrieval by QA/QI personnel.

The grant was awarded to the Indiana Family and Social Services Administration, Division of Disability and Rehabilitative Services. Responsibility for grant operations was transferred from the Bureau of Quality Improvement Services (hereafter, the Bureau), to the Division of Aging early in 2007.

Role of Key Partners

- The grant's Consumer Advisory Council—comprising HCBS waiver participants and family members, advocacy groups, providers, and other community representatives (e.g., a doctor and a social worker)—included three subcommittees: Mortality Review, Provider Standards, and Risk Management. These groups met monthly and were involved in project implementation, monitoring, and evaluation.

- As providers of case management services for the majority of waiver participants, the State's Area Agencies on Aging (AAAs) provided the operational structure for the development of incident, complaint, and mortality review processes.

- Electronic Data Services, the Medicaid fiscal agent, developed guidelines and a survey instrument based on the State's new waiver provider standards, and conducted the field audits of nonlicensed service providers.

Major Accomplishments and Outcomes

- Grant staff held community focus groups with participants and/or their families, waiver case managers, and other service providers. The focus groups were conducted statewide in both urban and rural areas. The input from these focus groups consistently highlighted the same needs: affordable and accessible housing, transportation, nutrition services, and service accessibility. Staff analyzed data from the focus groups and shared it with the Division of Aging, the entity responsible for developing plans to improve services and participant safety.

- A contractor trained the Bureau's quality monitors to conduct the Participant Experience Survey (PES) annually with a minimum of 20 percent of waiver participants. The Bureau's management staff provided training for the Bureau's monitors. Between October 2005 and September 2006, 436 participant surveys were completed, and the data were analyzed and used to set service priorities.

  Because of restructuring and staff reduction, the Bureau stopped conducting the surveys in 2006; the Division of Aging has since relied on the AAAs' surveys of a minimum of 10 percent of their participants in all programs, including waivers. The Division of Aging entered a contract effective April 24, 2008, with Liberty Corporation of Indiana to complete PES surveys with Aged and Disabled (A&D) and Traumatic Brain Injury (TBI) waiver participants.

- Grant staff conducted training statewide with waiver participants, service providers, and advocates on new provider standards and reporting requirements, as well as the provider survey process. A total of 273 service providers for the A&D and the TBI waivers were trained on the processes for reporting complaints, incidents, and deaths. Since the grant ended, the Division of Aging's Quality Assurance and RN staff have continued training for case managers on a quarterly basis.

Enduring Systems Change

- Grant staff developed a more comprehensive quality management (QM) strategy than what had existed prior to the grant across a broader base of service delivery. The QM strategy includes both intra-agency (Indiana State Department of Health, the entity responsible for surveying and licensing home health providers) and intradivision (Office of Medicaid Policy and Planning, Division of Disability and Rehabilitative Services) collaborations, and is now part of all aspects of service planning, implementation, review, and reporting. Some quality review efforts have been expanded to include participants in the State's CHOICE (Community Home Options for Indiana's Challenged and Elderly) program.

- The Division of Aging's new QA/QI unit became fully operational with the hiring of the director and the formal integration of Adult Protective Services and the Long-Term Care Ombudsman program. The unit meets weekly to coordinate responses to incidents and to review trends in the incident reporting process. The unit also has been involved in waiver renewal applications and in new program planning, such as the Money Follows the Person program, to ensure the inclusion of QM processes.

- The grant facilitated the crafting, promulgation, and implementation of the State's new Aging Rule (460 IAC 1.2, Home and Community Based Services), which applies to the certification and monitoring of providers of unlicensed services, such as Adult Foster

Care, Adult Day Services, and attendant care services, including agency staff or participant-directed workers.[9]

The rule defines provider standards and includes provisions for (1) monitoring and corrective actions, (2) revocations of provider approvals, (3) provider appeals processes, and (4) processes to ensure protection of individuals receiving services (e.g., incident reporting and coordination efforts with adult and child protective services entities); it also requires all providers to have a QA/QI process. The rule applies to providers in Medicaid waiver programs as well as programs administered through the Division of Aging, such as CHOICE and programs under the Social Services Block Grant and the Older Americans Act.

- A grant contractor developed a provider survey tool to monitor compliance with the new Aging Rule standards and surveyed 131 unlicensed providers. Wherever deficiencies were found, a plan of correction was required, and 10 providers chose to discontinue being listed as service providers rather than develop and comply with a correction plan. Aggregate data from the complaint tracking system are now included on the provider survey tool so that surveyors are aware of types and number of complaints received for individual providers.

- The grant enabled the development of a statewide web-based incident reporting system to immediately capture information about factors that might adversely affect the health and welfare of program participants. Complaints may also continue to be filed by phone, fax, and e-mail. The system alerts case managers, the Division of Aging, and the Office of Medicaid Policy and Planning to critical (i.e., sentinel) incidents requiring immediate response, and then monitors that response and remediation. System processes include the daily review of sentinel incidents and a weekly review of nonsentinel incidents.

  Data are reviewed by the Division of Aging's QA/QI unit to identify trends; patterns of critical incidents; and the need for revisions in policy, procedures, and/or training. The unit has a QA/QI committee that includes staff from the Medicaid agency, Adult Protective Services, and other relevant agencies, which provides another level of review. The committee identifies at-risk populations based on their review and develops preventive strategies to mitigate risks.

  Complaint data are integrated with the incident reporting/reviewing process when the complaint affects, or has the potential to affect, an individual's health and welfare. Contrary to expectations, the complaint process identified only one provider with problems affecting health and welfare.

- Inadequate home modifications generated the greatest number of noncritical complaints about providers. To address this issue, grant staff developed a new policy and procedure regarding home and environmental modifications, which were implemented in 2008. The

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[9] Since January 2008, personal service agencies providing attendant care to more than seven individuals must be licensed by the Indiana State Department of Health.

new policy and procedure enhances provider standards and requirements, adds a qualified independent evaluator to the process, and offers better oversight and monitoring from initial need for a modification through the final approval and payment for the work. The policy applies to all Division of Aging and Division of Disability and Rehabilitative Services programs, including all waivers.

- The Division of Aging streamlined mortality review procedures for reporting participants' deaths when they occur within a licensed facility, as a result of concerns expressed by HCBS providers. They maintained that having to report all deaths and nursing home placements was overly burdensome because the population they serve is typically elderly and frail and placement in a nursing home or a death is not necessarily unusual or unexpected. The Division also developed an agreement with the Indiana State Department of Health to collect death certificates at the state level rather than at the local level to reduce case managers' time and travel.

- Focus group input and the efforts of grant staff contributed to two major changes in policy to improve access to services: (1) reimbursement rates were increased to encourage expanded service delivery, especially in rural areas, which helped to reduce the number of people on waiting lists due to limited service capacity; and (2) the State changed the financial eligibility criteria for the A&D waiver, increasing the income limit to 300 percent of the SSI level to increase access to the waiver.

Key Challenges

- In April 2005, advocates and providers convinced the legislature to void the Aging Rule (460 IAC 1.1) that established standards for unlicensed but approved service providers for the HCBS waivers, which had been developed by the Grantee, signed by the governor, and promulgated in the early years of the grant project. The primary objection to the rule was that it was based on an existing rule that focused exclusively on the needs of persons with developmental disabilities and did not adequately address the needs of other populations, including older persons.

  As a result, a new Aging Rule was developed (460 IAC 1.2, see *Enduring Changes)* within parameters set by the legislature. Survey tools and interpretive guidelines based on the previous rule had to be revised, leading to delays in the implementation of policies and procedures as well as in staff and provider training.

- The reorganization of divisions within the Family and Social Services Administration and the transfer of the grant operations from the Bureau to the Division of Aging in the last 9 months of the grant resulted in several challenges.

  - Grant staff needed to revise work plan timelines many times and had problems recruiting staff for new QA/QI roles in the Division of Aging.
  - Many of the operational processes and procedures for the complaints, incident reporting, and mortality review systems that were based on the models that best

  served the population with developmental disabilities (the Bureau’s major focus) needed to be reviewed and tailored to the population served by the Division of Aging.

  - Delays in executing contracts for the incident reporting system caused delays in compiling and reporting aggregate data.

  For all these reasons, a fully integrated data management system incorporating both the participant information and eligibility system and the web-based incident reporting system has not been accomplished.

- Grant staff were unable to use the PES database to generate reports for specific periods. After much effort, the State’s Information Technology department set up a separate database for the PES results, so that 1 year’s data could be compared with another’s. The State is developing a new comprehensive participant satisfaction tool to replace the PES, which does not include measures for minor children.

- Although it was an asset to have a diverse group of individuals serving in the grant’s provider work groups, the difficulty in reaching a consensus because of members’ strong opposing opinions sometimes hindered progress on grant initiatives.

- Finding service users and providers to participate in the grant’s focus groups was challenging because of a lack of interest/response.

Continuing Challenges

- The restructure and privatization of the Bureau of Quality Improvement Services led to fragmentation in the Division of Aging’s quality review processes and interfered with ongoing operations. The Bureau’s Risk Management Committee, Sanctions Committee, and Quality Improvement Executive Committee (QIEC) did not meet during the last 2 quarters of 2007.

- The need to implement technology and databases that are compatible with the Division of Aging’s two existing data collection systems has led to poor data aggregation and an inability to identify trends and conduct patterns analysis. A great deal of analysis and trending continues to be conducted manually, as do the documenting of required follow-ups on incidents and complaints as well as management of mortality review processes.

Lessons Learned and Recommendations

- Before designing new data management systems, it is essential to carefully consider how the data will be used and who the target audience is for particular data (e.g., CMS or the State legislature). Doing so will help to ensure that the new system provides the appropriate data. Systems must be designed to provide sound information when it is needed and to have the capability to quickly and easily identify trends, key issues, and patterns, to enable rapid resolution of consumers’ problems.

- The State should revise the certification processes for unlicensed service providers to help ensure the provision of high-quality services.

- CMS should establish uniform requirements for unlicensed Medicaid providers.

Key Products

Educational Materials

- Grant staff developed a brochure for Division of Aging programs to educate individuals and families about the complaint process. The brochure is distributed to HCBS participants through their AAA case managers.

- The Division of Aging developed and widely distributed bulletins addressing health and safety issues, including smoking, influenza, and pneumonia vaccinations; and preventing complications for individuals with swallowing problems. Materials were distributed to community centers, health fairs, key constituent groups, case managers, meal sites, and advocacy groups. The Division has continued to disseminate this information since the grant ended.

- The Division of Aging developed provider training materials on the new provider standards and on incident reporting through the web-based data collection system.

Technical Materials

The Division of Aging developed a provider survey tool and interpretive guidelines for the HCBS provider standards based on the second Aging Rule.

Reports

The Division of Aging developed reports based on complaints analysis, incident reporting, the results of the PES, and the mortality review process, which enable quality assurance staff to identify consumer satisfaction, trends, problem areas for systemic remediation, and other issues.

Maine

Primary Purpose and Major Goals

The grant's primary purpose was to design a cohesive and coordinated quality management and improvement system across several waiver programs for older adults and adults with various disabilities. The grant had five major goals: (1) to create and formalize participant-centered interdepartmental infrastructures and develop a coordinated interdepartmental approach for quality management and improvement; (2) to engage participants in an active role in the planning, design, and evaluation of home and community-based services (HCBS); (3) to develop a coordinated incident management system for waiver programs; (4) to assess system performance on a regular and real-time basis; and (5) to develop a plan for sustainable interagency collaboration, participant involvement, and a coordinated quality improvement system.

The grant was awarded to the Department of Human Services, which was later merged with the Department of Behavioral and Developmental Services into the new Department of Health and Human Services (hereafter, the Department). An Office of Integrated Services and Quality Improvement (QI Office) was established as part of the merger.

The Department contracted with the Muskie School of Public Service to provide assistance throughout the grant on a wide range of activities, including managing the project; conducting participant surveys; writing reports; and assisting with the development of the common event form and instructions, the quality management plan, and the peer interviewing pilot.

Role of Key Partners

- An interagency work group was formed to coordinate grant activities across the three departments responsible for waiver programs (Human Services, Behavioral and Developmental Services, and Labor) and with the Medicaid agency. The purpose of the group was to share best practices and identify areas for collaborative quality improvement activities. As the grant activities progressed, subgroups were formed to work more intensely on specific topics (e.g., a common event reporting system, a peer interviewing project, and program-specific issues).

- The Quality Technical Assistance Group—comprising participants (older adults and individuals with physical or developmental disabilities), advocacy organizations, providers, and staff from the waiver programs and the Medicaid office—provided general oversight, advice, and input on grant activities.

- The Office of Integrated Services and Quality Improvement and the Office of Adults with Cognitive and Physical Disability Services (OACPDS) developed a peer-interviewing model for individuals with developmental disabilities. The QI Office created the standardized interview tool and protocols, and OACPDS provided expertise on community inclusion and linkages with providers and recipients of developmental services.

Major Accomplishments and Outcomes

- Grant staff modified the Participant Experience Survey (PES) to tailor it to Maine's long-term services and supports system. Items related to the assessment and care planning process, worker availability, backup plans, and interest in self-direction were added. The survey was modified for use by participants in two waiver programs: the waiver for older adults and adults aged 18 to 64 with physical disabilities, and the waiver for adults aged 18 to 64 with physical disabilities who self-direct services. Both surveys included a number of common questions that allowed the State to compare participants' experience in the two waiver programs.

- Grant staff also tested a variety of approaches to obtaining participant input, such as a web-based version of the modified PES for people who self-direct services.

- Grant staff prepared annual assessment and performance reports on the use and cost of services and the experience and satisfaction of participants across three waiver programs using quality indicators that were aligned with the CMS HCBS Quality Framework. The indicators were developed from a number of data sources, including participant surveys, mortality review data, and Medicaid/Medicare claims data. Many of the people served by HCBS waiver programs are dually eligible for Medicaid and Medicare. For this reason, it is necessary to link Medicaid and Medicare claims data at the individual level in order to obtain a complete picture of service utilization.

  The linked Medicare and Medicaid data were available for the fiscal years 2000 and 2003. Based on the annual reports' analyses and recommendations, the Department identified areas for enhanced quality assurance and quality improvement activities, such as additional training materials for participants who self-direct services. The Department developed a template to facilitate preparation of future reports.

- Grant partners developed a process by which people with disabilities partner with community members to interview individuals receiving developmental services about their quality of life. Three teams were recruited and trained, and the Co-Interviewing Model was piloted in August and September 2006 with three recipients of developmental services. All pilot participants were asked to provide feedback on the process; specifically, what worked and what could be improved.

Enduring Systems Change

- The Department of Health and Human Services created an integrated management team that promotes cross program communication, information sharing, issue identification, and opportunities for collaborative quality improvement. The integrated management team includes the office directors responsible for managing the HCBS waiver programs.

- Grant staff and partners conducted a comprehensive inventory and assessment of policies, procedures, operations, data sources, and information systems for the (1) Older Adults and Adults with Disabilities waiver program and (2) the Adults with Physical Disabilities Consumer Directed waiver program. They developed a common approach for mapping discovery methods with the CMS assurances and a database that enables a consistent approach for assessing strengths and gaps in discovery methods across waiver programs. The database can be used by other waiver programs (e.g., Adults with Mental Retardation/Developmental Disabilities) to create a similar inventory.

- Grant staff and partners developed cross-waiver health and welfare indicators, which can be measured using linked Medicaid and Medicare claims data. The indicators include avoidable hospitalizations, use of preventive health services, use of emergency rooms, use of medications, and use of multiple practitioners and pharmacists.

- Grant staff developed an event reporting system with the Office of Elder Services that includes a common reportable event form, and definitions and data elements ranging from death and serious injury to exploitation and medication errors. Event definitions and time frames are consistent across waiver programs, enabling improved reporting and monitoring.

- Based on the participant survey reports, the Department modified contracts with case management agencies. The modified contracts include more specific provisions related to health and welfare monitoring, development of backup plans, and linking participants with other community resources that support independence.

- Department staff involved with the grant developed an increased appreciation of the importance of including provisions that help to ensure quality during the design of programs and policies. This understanding was reflected in policies and programs developed during the grant period. For example, when developing the Family Provider Service Option, a self-direction option offered through one of the waiver programs, the State included program requirements related to training and background checks that help to ensure quality.

Key Challenges

The grant activities were undertaken during a time of major transition and competing priorities within the State. The merger of two major departments into the Department of Health and Human Services required the time and attention of many senior managers, and the quality management activities often had to compete with other leadership priorities. At the same time, the Department was implementing a major new management information system, which also consumed many hours of staff time. As a result, grant project meetings had to be planned carefully with well-constructed agendas.

Continuing Challenges

More resources and funding are needed to support quality management activities for HCBS waivers.

Lessons Learned and Recommendations

Quality management is resource intensive. To the extent possible, states should assign staff to this task as part of a dedicated and focused activity, and determine what quality activities already exist that might be duplicative or could inform current efforts.

Key Products

Educational Materials

Grant partners produced *Maine's Co-Interviewing Pilot Project Training Manual* for peer interviewing of people with developmental disabilities.

Technical Materials

Grant staff and partners developed (1) a database for conducting an inventory of discovery methods cross-walked with the CMS waiver assurances, (2) a template for producing ongoing participant reports of quality indicators, and (3) a common event reporting form and definitions for use by all waiver programs.

Reports

The Muskie School of Public Service produced several reports, including the following:

- Individual and combined participant survey reports for each waiver program (Older Adults and Adults with Disabilities, Adults with Physical Disabilities who self-direct, and Adults with Mental Retardation/Autism).
- *Maine's Co-Interviewing Model and Pilot* report, which outlines the key components of the model and presents feedback from the project pilot.
- *Our Stories Booklet of Florence and Jackie*, a qualitative approach to obtaining participant input that tells the stories of two HCBS participants.
- *Lessons Learned and Plan for Sustainability* describes the infrastructure for ongoing participant involvement in and quality management of home and community-based services.
- *Quality Management Plan for Waiver Services for Elders and Adults with Disabilities*, which is a summary of major quality management functions carried out at the departmental, program, and operating-agency levels.

Minnesota

Primary Purpose and Major Goals

The grant's primary purpose was to improve the design of participant safeguards and the related functions of discovery and remediation, and to assess provider performance and measure participant outcomes in waiver programs. The grant had two major goals: (1) to enhance capacity for ensuring the health and safety of clients by improving the State's vulnerable adult report tracking system, and (2) to develop a comprehensive statewide quality assurance/quality improvement (QA/QI) data mart that will incorporate provider monitoring data as well as participant feedback on quality of care and quality of life.

The grant was awarded to the Department of Human Services (DHS). The DHS Continuing Care Administration, the agency that administers all of the State's waiver programs, was responsible for overseeing all aspects of project implementation and evaluation. Contractors were engaged to provide technical assistance to identify the business information system needs of end users and to develop the QA/QI data mart as well as the Vulnerable Adult Reporting Information System (VARIS, as it came to be known).

Role of Key Partners

- The 15-member Quality Design Commission—comprising service users and family members, service providers, and representatives from advocacy and community organizations and state and county agencies—was established in 2001 through the State's Real Choice grant. As the QA/QI grant's advisory body, the Commission provided input and recommendations on project planning, implementation, and evaluation. It also informed the development of the QA/QI data mart, the consumer survey, the selection of outcomes to be measured, and decisions on how information will be used to improve the system.

- Grant staff established three design teams (Data Mart, Vulnerable Adult Report System, and Participant Survey), each of which included members of the Quality Design Commission as well as key stakeholders. The Teams reported directly to the grant project manager.

- The Minnesota Department of Health provided technical support to identify data already collected and maintained that might be useful for home and community-based services (HCBS) quality management purposes and that could be incorporated into the QA/QI data mart, and provided grant project staff access to data system documentation. Also, the Department partnered with the DHS to identify maltreatment investigation outcome data to support HCBS quality management and improvement activities, and the Department's Office of Health Facility Complaints partnered in the design and development of VARIS.

- Ten county Adult Protection units helped to develop the online maltreatment report intake form and the protocol for distribution to investigative agency county-to-state reporting. They also helped to document how Adult Protection activities interface with county and state incident reporting, investigation, and resolution. Finally, they helped to finalize the end user requirements for VARIS, and participated in the pilot and statewide testing of the new system.

- The Ombudsman for Mental Health/Developmental Disabilities, which receives maltreatment reports and investigates serious injury and death, helped design the vulnerable adult report tracking system. In addition, this office participated in preliminary analysis sessions so all project members understood the Ombudsman data system, and also provided systems documentation, such as their software specifications and data dictionaries. This office also assisted in the identification of quality indicators and performance measures and in the development of strategies for using the QA/QI data mart to improve home and community-based services.

- The Minnesota Board on Aging provided ongoing funding for the HCBS consumer survey and funded subsequent completion of the second survey completed in 2007.

- The Ombudsman for Long-Term Care (formerly Older Minnesotans) recruited volunteers to conduct face-to-face survey interviews with HCBS participants statewide, and provided feedback and recommendations about the survey process and tool, and the role of the volunteer as interviewers.

Major Accomplishments and Outcomes

- The Vulnerable Adult Design Team integrated county-level Adult Protection units into VARIS by developing or redesigning forms for vulnerable adult report and investigation data collections and submissions, and by outlining interagency processes. Statewide training was conducted for county staff on their roles and responsibilities, as well as on the new technology.

- The Consumer Survey Design Team adapted the CMS Participant Experience Survey to include measures related to maintaining and enhancing social roles and relationships, caregiver outcomes, and items applicable for participant-directed services. Ombudsman volunteers were recruited and trained to pilot the instrument in face-to-face interviews with 96 participants in the Elderly waiver. The survey tool and volunteer training curriculum were revised based on the pilot and the two statewide surveys of participants conducted during the grant period. One of the surveys was funded by the grant and the other by the Minnesota Board on Aging.

Enduring Systems Change

- A Vulnerable Adult Report Tracking System that allows electronic submission of county data to the DHS Continuing Care Administration and investigative agencies has been established. The system will enable the DHS to use investigative outcome data for continuous quality improvement related to incident management and the prevention of maltreatment (e.g., providers needing technical assistance to improve quality of care and/or prevent maltreatment can be identified more readily). All county Adult Protection units are required to use this system for reporting alleged maltreatment and for all local

Adult Protection investigation activities. Importantly, the new system also allows DHS to "match" people who are receiving publicly funded services to reports of their alleged maltreatment, and the results of investigations.

- The Data Mart Design Team identified data sources developed by other agencies that are needed for systematic quality assessment in HCBS waivers and moved three targeted data sets into the DHS data warehouse (Ombudsman for Managed Care, DHS Licensing, and Appeals). In addition, as part of VARIS, county intake staff and county adult protection investigators now have a common system for the intake of maltreatment reports, for the distribution of reports to investigative agencies, and for the capture of investigative outcome data, as well as data from consumer surveys resulting from county-based investigations.

  The Data Mart houses consumer survey data as well as maltreatment investigative data, and data extracted from other sources such as Appeals and Licensing. Both the Data Mart and the Vulnerable Adult Report Tracking System were piloted in December 2007 and have been available statewide since March 2008. The Minnesota Board on Aging will continue to fund the consumer survey every other year.

- The grant project has provided the State with improved tools to assess and measure quality of care and quality of life for HCBS clients, as well as to assess provider performance in more direct, evidence-based ways. The participant-level information will help the DHS target systems improvement in the Elderly waiver. In addition, to help participants make informed choices regarding providers, preliminary provider review data for developing provider profiles have been captured in the Medicaid Management Information System, and the DHS continues to create and expand data systems for evidence-based provider profile data.

Key Challenges

Throughout the grant period, the major challenge was to integrate the work proposed within the scope of the grant with other major technology proposals or projects under way within the DHS. As the Department continued to make major technology investments to improve financial accountability, quality assessment, and evaluation capability across all Minnesota health care programs, the grant activities were at times delayed to ensure that integration, interface, management coordination, and communication among other divisions and administrations occurred. Integrating the grant's quality management model with the broader DHS quality strategies was also necessary periodically.

Continuing Challenges

- Given the various restrictions in state and federal law regarding data sharing among and/or between government agencies, it will continue to be challenging to find ways to allow quality assessment across services and programs while ensuring data privacy.

- Ongoing funding for quality assessment and management as a specific activity is often jeopardized.

Lessons Learned and Recommendations

- Quality management for home and community-based services needs ongoing state and federal financial support. States should recognize quality management as an important business area within HCBS programs.

- States that want to implement new quality management systems need to have a systematic way to analyze the current system, to determine what is needed, and to plan for future investments. Minnesota used the QA/QI grant to do this, which helped to develop a blueprint of Minnesota's increasingly complicated HCBS system that extends beyond the publicly funded waiver programs. The blueprint provides information to (1) guide future investments; (2) coordinate investments across programs, populations, and funders; and (3) avoid duplication of effort in these investments.

  Developing a blueprint for both the existing system and the desired system has helped focus work across several divisions. Although this process was completed during the grant period, it could be very helpful to go through the process in preparation for grant applications in the future, because it can highlight areas that need the most attention and investment.

- Internal communication among state decision makers is crucial to obtain buy-in by management and to ongoing success.

- Technology development often costs more than anticipated, especially when integrating new systems with existing ones. This is particularly true when information about the existing system is unavailable and must be researched during the project. Thus, states should determine where additional funding might be needed to finish work begun under the grant, and/or to supplement grant funds.

- When using an information technology contractor and/or consultant, states should use a different vendor for the analysis of the organization's needs than for selecting a technology solution and/or to develop the system that the state selects. Doing so will help to ensure that all available technology solutions and options are explored and that they are evaluated in regard to how they will meet the state's needs and selection criteria, rather than being based on the vendor's preference.

Key Products

Educational Materials

- The State Adult Protection Division produced training materials for county Adult Protection staff on the new policy mandate for reporting maltreatment of vulnerable adults, and the roll-out of the new business information system that will support discovery and remediation activities.

- A contracted volunteer field coordinator and the grant project manager produced training materials for volunteers to conduct face-to-face interviews for the consumer survey. The training discussed the purpose of the survey, the survey process, and use of the survey instrument.

- Grant staff developed several PowerPoint presentations related to quality management and presented them to lead agencies responsible for quality assurance and at national conferences.

Technical Materials

- The grant contractor produced functional requirements and high-level architecture documents for VARIS and the QA/QI Data Mart.

- The DHS Continuing Care Administration and the Consumer Survey Design Team produced a final Consumer Experience Survey tool.

- Grant staff developed an “Alternatives Analysis” for technology investments, along with test criteria and a testing plan. They also developed a business analysis, data documentation, test criteria and test results, and programming specification documents for DHS Licensing, Appeals, and the Ombudsman for Managed Care databases integrated into the Data Mart.

Reports

- A contracted volunteer coordinator produced a report on the role of Ombudsman volunteers as surveyors that included recommendations for changes in future survey implementation.

- Grant staff developed three reports:

  1. The *Vulnerable Adult Reporting Information System and Quality Management Data Mart Project: Baseline Analysis Report,* which presents an overview of the operational and technological environment of HCBS waivers.

  2. *Home and Community Based Services, Quality Assurance and Data Mart: Best Practices Summary,* which explored how other states collect information about adult maltreatment and how—or whether—those data are used for program evaluation.

  3. A report of the Elderly waiver consumer survey pilot phase and a summary report of the first and second statewide Elderly waiver survey results.

Missouri

Primary Purpose and Major Goals

The grant's primary purpose was to develop a consistent method for gathering quality assurance (QA) data for all home and community-based services (HCBS) programs to discover and remediate problem areas. The grant had four major goals: (1) to identify the information systems currently in use or in development by various state agencies and evaluate their commonalities and differences; (2) to assess the processes for building a statewide automated system for storing data, and design a universal data system that can be used to report complaint information to the Division of Medical Services; (3) to develop accurate and consistent methods for tracking complaints and resolving recurring issues; and (4) to implement a pilot program within a rural and an urban area of the State to test the new data collection system.

The grant was awarded to the Department of Health and Senior Services (DHSS).

Role of Key Partners

- The grant established a Work Group—comprising staff from the Departments of Social Services, Mental Health, and other relevant agencies—to assist with project design, implementation, and evaluation. Each department representative was responsible for meeting with various consumer and advocacy groups and provider agencies to obtain input on the design of the QA system.

- The Health and Behavioral Risk Research Center at the University of Missouri's Columbia School of Medicine was contracted to conduct consumer surveys.

Major Accomplishments and Outcomes

- Grant staff and the Work Group evaluated existing state database systems, researched and reviewed client satisfaction survey tools, operationally defined "quality" and how it applies to DHSS clients, and worked with data systems personnel to determine the most efficient and effective way of collecting and entering information into a data system. It was determined that the unique characteristics of each database system made it impossible to have a single, statewide universal system, and that none of the existing systems could be used for the data collection and reporting of complaints.

- The Health and Behavioral Risk Research Center conducted a pilot survey with 30 DHSS program participants across the State, using the CMS Participant Experience Survey for the Elderly and Disabled, which led to some minor changes to the survey protocol before the full grant-funded survey was implemented. The surveys included participants in both Medicaid and state-funded programs, and, by the end of the grant, 9,000 surveys of DHSS clients receiving in-home services had been completed in two separate phases.

  Given the large sample size, the survey was conducted by telephone, which generated a greater response rate than that obtained in other states (one in two, as opposed to one in three, of those contacted). Survey interviewers identified several issues that had to be brought to the attention of the State's Elder Abuse Hotline as well as the need for referrals for services.

The survey data were used to compute performance indicators, and reports were generated for review by DHSS program managers.

Enduring Systems Change

As a result of research and analyses that grant staff conducted, DHSS determined that it was not feasible to have a single universal system incorporating all state agencies' systems for collecting and reporting complaint data for HCBS programs.

DHSS is in the process of developing an information technology (IT) system that incorporates an Adult Protective Services and provider complaint system that interfaces with the State's Medicaid agency, the Department of Social Services, and the Missouri HealthNet Division (MHD). MHD purchases and monitors health care services for Medicaid beneficiaries and ensures quality health care through development of service delivery systems, standards setting and enforcement, and education of providers and participants.

The new system will provide MHD with real time information for its monitoring activities. It will also incorporate a client satisfaction survey that will be conducted through the mail or as part of the QA on-site monitoring process. The survey data will be available to MHD for reporting to CMS.

Key Challenges

- The DHSS went through multiple reorganizations during the grant period, and a staff layoff necessitated workload reassignment and changes in staffing for grant activities (e.g., field staff were unable to collect survey information).
- The Governor, through executive order, transferred the Personal Care Attendant program from another department to the DHSS, which created additional work for already overburdened staff, such as the need for policy revisions and changes in the Code of State Regulations.
- Working with the Information Technology Department, the Institutional Review Board, and legal departments required much more time than anticipated.

Continuing Challenges

State government is in constant flux, and priorities often change, creating challenges in developing and implementing quality management systems.

Lessons Learned and Recommendations

- When attempting systems change, it is important to be both realistic and flexible in determining what needs to be accomplished and what *can* be accomplished. Change is often incremental, and it may be necessary to focus initially on one or two small changes.

- Several lessons were learned during the first phase of the consumer survey process.
  - One of the drawbacks of administering the survey by telephone was the inability to observe the client and anyone else in the home, making it difficult to know whether a client was being "coached" by a family member or caregiver.
  - The broad range of questions in the survey tool proved unwieldy for individuals who receive only a single service, like the Program of All-inclusive Care for the Elderly or home-delivered meals. Ideally, a shorter survey would be used for programs that provide only a few services.
  - The staff at some Residential Care Facilities were reluctant to let surveyors speak to the residents for various reasons, including concerns about the effect of survey results on the facility and concerns about client confidentiality.
  - Locating the clients' guardians was time consuming, and obtaining permission for their participation in the survey was often difficult.

  Before beginning the second round of surveys, it was decided to exclude individuals who were receiving only a single service, those in residential facilities, and those who have guardians, which resulted in a better response rate and a shorter time period to complete the survey.

Key Products

Reports

A report was produced for each of the two consumer survey periods: *Comprehensive Results of the 2006 Participant Experience Survey-Elderly & Disabled (PES E/D), March 2007* and *September 2007*. Each report presents participant responses for 33 performance indicator areas, which are grouped by one of four priority areas: Access to Care, Choices and Control, Respect/Dignity, and Community Integrations and Inclusion.

New York

Primary Purpose and Major Goals

The grant's primary purpose was to provide opportunities for participants to give feedback regarding their experience and/or concerns with the Traumatic Brain Injury (TBI) and the Long Term Home Health Care Program (LTHHCP) waivers to inform the State's quality assurance and quality improvement (QA/QI) activities. The grant had four major goals: (1) to develop improved methods of enlisting waiver participants and other involved community members in the QA/QI process for New York's home and community-based services (HCBS) waivers; (2) to obtain independent information from waiver participants and their families about the quality of services received and to use that information to increase service quality, respond to issues, eliminate problems, and identify areas of best practice; (3) to develop a comprehensive and systemic approach to monitoring the quality of services and the achievement of participants' valued outcomes; and (4) to maintain a service delivery system designed to meet participants' needs in a timely and cost-effective manner.

The grant was awarded to the Department of Health (hereafter, the Department), the single state Medicaid agency. Grant activities were managed by the Department's Bureau of Medicaid HCBS, which has responsibility for the two waivers mentioned above as well as for the new Nursing Home Transition and Diversion (NHTD) waiver.

Role of Key Partners

- The Brain Injury Association of New York State (BIANYS) was contracted to conduct regional forums with TBI waiver stakeholders and to establish a complaint hotline for TBI waiver participants.

- The Center for Excellence in Aging Services at the School of Social Welfare of the State University of New York at Albany was contracted to develop a QA strategy and to test the Participant Experience Survey (PES) for the LTHHCP waiver.

- The Center for Development of Human Services Research Foundation of the State University of New York at Buffalo State College was contracted to design a standardized training program for waiver service providers.

Major Accomplishments and Outcomes

- The Brain Injury Association of New York State convened 10 regional TBI forums to increase communication among the waiver's many stakeholders, including participants and caregivers, service providers, advocates, and administrative staff, and to identify systemic program challenges. More than two-thirds of the 334 attendees were waiver participants and family members. The Department's regional service coordinators worked with BIANYS to develop materials and strategies for outreach, which succeeded in reaching virtually every waiver participant in the State.

BIANYS summarized the forum findings in a final report, which was analyzed by waiver management staff who prioritized issues based on the urgency of the identified problem and the feasibility of solutions. Waiver program staff identified short-term critical goals such as addressing provider shortages and provider training, and long-term goals such as enhancing waiver services and developing a participant manual. In addition, BIANYS and waiver program staff prepared a joint letter outlining the recommendations submitted to the Department, which was sent to forum participants.

- The Center for Excellence in Aging Services administered the Participant Experience Survey to a representative population of LTHHCP waiver participants. A total of 606 interviews were completed, evaluated, and analyzed. Best practices were identified in a final report and have been evaluated for potential inclusion in an ongoing Quality Management process that will incorporate future in-home satisfaction surveys. One immediate benefit of the survey was the enhanced consumer awareness of available services.

Enduring Systems Change

- In response to stakeholder input from the regional forums, the Department initiated the following:
  - The TBI waiver program implemented a statewide across-the-board rate increase for providers and a NYC Metropolitan Area rate differential for select services.
  - Grant funds were used to develop four service-specific training programs and related materials for selected services provided by the TBI and NHTD waivers. The training, which will ensure consistency in provider knowledge of services with an emphasis on person-centered care, is to be used statewide to meet provider staff training requirements. The Department has begun to use the new curricula in the NHTD program.
  - Waiver program staff are developing user-friendly materials for participants that will explain waiver services, address waiver participants’ rights and responsibilities, offer guidance on how to effectively work with service providers, and furnish tools and resources to help participants successfully navigate the HCBS system.
- The Brain Injury Association of New York State was contracted to establish a TBI waiver complaint hotline for the sole purpose of giving participants the opportunity to officially register grievances with a neutral party. The Department’s waiver management staff worked closely with BIANYS to develop program guidelines and an outreach strategy for the dissemination of information to participants. The Department provided training for BIANYS complaint line staff to ensure a basic understanding of waiver operations and of protocols for responding to complaints, and also provided training for regional service coordination staff on the protocols.

  The line was fully operational in 2005, and by the end of the contract period a total of 245 complaints and concerns had been received, several of which required immediate intervention and for which solutions were found. An unexpected benefit of the complaint line was its usefulness as a mechanism to correct and/or prevent errors in Medicaid billing. Regional service coordinators were able to compare providers' billing statements with complaints regarding direct care staff no-shows and initiate prompt billing corrections where appropriate.

The TBI complaint line has become a part of the waiver's quality management program, adding an additional layer of protection for participants' safety by enhancing the ability of contract and Department staff to address and resolve issues in an appropriate and timely manner. It has also proven to be an extremely useful tool for uncovering deficiencies on the provider, regional, and state levels and for obtaining valuable information on individual and systemic issues.

Key Challenges

- Unanticipated turnover of experienced staff and emerging new long-term services and supports in state priorities required workload reassignments and staff training that delayed grant activities. Additionally, the state procurement process took longer than originally anticipated and was further delayed by the turnover in grant management staff. Together the two situations delayed implementation of grant activities that required competitive contracts.

- Department staff initiated development of a database that would integrate case management and service utilization information. The original QA/QI database design was not sufficiently robust to fulfill the Department's expectations for easy access to system-generated reports. However, its development allowed the State to identify several issues that will inform efforts to institute a more comprehensive database or other QA tracking efforts in the future; specifically, the need to address (1) labor-intensive data entry requirements, (2) questions of responsibility for system updates to ensure accuracy, (3) complexities and expense of cross-system connectivity, and (4) compliance with system security measures to accommodate access control for data input by local and contracted providers and waiver administrators.

- The lack of a single database containing contact and demographic information for all participants created recruitment problems for the Participant Experience Survey. This barrier was overcome through a range of strategies, including working with the LTHHCP provider nurses and case managers involved with participants, revising marketing materials sent to participants, and using bilingual staff to schedule interviews.

- The grant contractor experienced difficulty using the PES software to download individual survey results into a database. However, PES technical staff were helpful in identifying and correcting problems with software use.

- Some waiver participants were unable to attend the TBI forums, especially in larger, more rural regions, because of lack of transportation.

Continuing Challenges

Managing quality assurance activities across multiple waiver programs is a continuing challenge. The Department is actively working to address issues as they arise in a comprehensive manner as part of the ongoing effort to restructure the State's long-term services and supports system.

Lessons Learned and Recommendations

Regional Stakeholder Forums

- Conducting focus groups in different regions is a very effective way of obtaining information that is both specific and reflects regional needs and differences. Also, dividing the focus group into a participant group and a provider group allows both groups to speak freely and provide better insight into the different program issues.

- Conducting focus groups using an advocacy organization that is viewed as an unbiased, neutral, yet knowledgeable party enables participants and providers to freely express concerns and complaints. Also, since many waiver participants have difficulty expressing themselves because of their brain injury, the presence of facilitators who are skillful in conducting effective focus groups and communicating with people who have impaired speech or cognitive abilities is crucial.

Participant Experience Survey

- The PES provides ample aggregate-level outcome data that identify programmatic challenges in many service areas. However, the tool does not provide insight into the micro-level dynamics of a program. Taking this into account, the contractor developed supplemental field notes to compensate for the tool's limitation. CMS should amend the PES to add an option for field notes, which would facilitate the survey process.

- Over-sampling for a participant survey in less populated areas might result in a more comprehensive examination of the issues faced by rural counties where the provision of community-based care, participant characteristics, and the availability of kinship care make them dramatically different from more populous areas.

- Some waiver participants had trust issues and were unwilling to participate in interviews. A pre-survey educational outreach to service coordinators and providers can facilitate the survey process by allaying fears and improving collaboration and participation.

- For data to be meaningful for a diverse population, it is important to recruit participants from different ethnic groups so as to yield a representative sample. To facilitate this, the grant contractor sent outreach letters in several different languages and used bilingual schedulers to arrange interviews. The incorporation of cultural diversity training into the interview training curriculum would also teach proper etiquette and enhance sensitivity to cultural variations, which could improve interview results.

Key Products

Outreach Materials

- The Brain Injury Association of New York State developed TBI complaint line promotional materials, including informational brochures and refrigerator magnets, which were distributed to waiver participants through the regional service coordinators. The refrigerator magnets are highly visible and easily located, which is especially helpful to TBI participants with cognitive impairments.
- In collaboration with regional service coordinators and Department staff, the BIANYS developed flyers, invitations, and other outreach material for each of the 10 TBI forums.

Educational Materials

Grant funds were used to develop four training programs entitled Waiver Services, Home and Community Support Services, Independent Living Skills Training, and Service Coordination. Each program has a trainer and a participant component and provides the following: overview/agenda, trainer's notes, participant handouts, PowerPoint slides, and pre-course and post-course questionnaire.

Reports

- The *New York State Traumatic Brain Injury Waiver Regional Forums* final report summarizes the grant activities and major findings of the initiative to gather participant and provider input through regional forums.
- The *New York State Traumatic Brain Injury Waiver Complaint Line* final report summarizes the grant activities and major findings of the initiative to establish a TBI toll-free complaint line as a consumer-driven quality assurance measure.
- The *Long Term Home Health Care Program Participant Experience Survey* final report presents a summary evaluation of the initiative to measure the current level of participant satisfaction with the LTHHCP. The greatest number of concerns were voiced in the areas of access to care, the quality and reliability of transportation services, and the availability and consistency of personal care staff.

North Carolina

Primary Purpose and Major Goals

In response to North Carolina Session Law 2001-437, the State published *State Plan 2001: Blueprint for Change* (the first in a series updated annually), to set the direction for the continuing efforts to transform North Carolina's public mental health, developmental disabilities, and substance abuse services (MH/DD/SAS) system. The target audience for the plan was the state legislature and all stakeholders in the MH/DD/SAS system. *State Plan 2002* outlined the key policy issues that set the direction for reform, and *State Plan 2003* refined policy issues and set a course for developing some of the products and processes necessary to sustain the momentum. *State Plan 2004* provided details on the key tasks and issues that needed to be addressed during state fiscal year 2004–2005.

The grant's primary purpose was to support the development of quality improvement (QI) processes to facilitate progress toward the State's reform goals. The grant had six major goals: (1) to design a quality management (QM) plan for the state MH/DD/SAS system based on a philosophy of continuous quality improvement; (2) to implement and evaluate a demonstration of the QM plan, focused on individuals transitioning from institutions to community settings; (3) to develop and/or enhance tools, protocols, and systems for data collection and management to identify problems and successes in structures, processes, and participant outcomes for transitioning populations; (4) to develop and implement processes to review individual data, rectify immediate problems, and prevent future problems; (5) to implement structures and processes for continuous quality improvement; and (6) to develop a plan to expand the demonstration project to other populations with long-term services and supports needs.

The grant was awarded to the state Department of Health and Human Services (DHHS), Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (hereafter, the Division).

Role of Key Partners

- A project design committee—comprising Division staff, other state staff, service users, family members, and local stakeholders—developed the QM plan and provided guidance for all grant activities.
- The Center for Development and Learning (CDL) at the University of North Carolina (UNC) at Chapel Hill developed interview tools, hired and trained interviewers, and coordinated and implemented data collection for the grant's demonstration project.
- The Division's Advocacy and Client Customer Services Section collaborated with grant staff to develop the incident response and reporting protocol as part of the demonstration project.
- The Quality Management Team from the Division's Community Policy Management Section managed all aspects of the grant activities, including the demonstration project;

a statewide QM conference; and the development, dissemination, and review of quality reports.

Major Accomplishments and Outcomes

- The UNC Center for Development and Learning was contracted to gather information to inform the development of discovery, remediation, and improvement processes and structures, and to evaluate and improve the transition process. To obtain this information, CDL interviewed individuals discharged from psychiatric institutions and intermediate care facilities for persons with mental retardation to community settings. The Quality Management Team, with assistance from CDL, reviewed existing institutional discharge planning procedures and tools, developed questions for the interviews, and tested and refined interview tools and processes as needed.

  CDL staff recruited, hired, and trained a team of 31 interviewers—comprising 5 service users, 16 family members, and 10 persons with professional experience serving individuals with mental retardation or developmental disabilities (MR/DD)—to conduct face-to-face interviews with transitioning individuals. CDL planned to interview these individuals four times over the course of a year about the quality of community services and supports they were receiving, the transition process and any problems they had experienced, and progress toward their personal goals. By the end of the grant, 155 individuals had been interviewed post-discharge. Because of challenges in locating individuals who had moved, much smaller numbers participated in subsequent interviews: 96 at 3 months, 68 at 6 months, and 29 at 12 months.

- The Quality Management Team developed a database and protocols for data collection, review, and analysis; and adopted a process for identifying and responding to participant concerns. The Division's Incident Review Committee developed and oversaw the implementation of the remediation protocol into the participant incident response and reporting system.

- The grant implementation team and the CDL team produced three reports based on findings from individual questionnaires and concerns raised by interviewers for the transitioning population projects. Aggregate information was reviewed with the Incident Review Committee and with the Division staff responsible for the transitions so that they could improve their processes. Using the remediation protocol, issues identified in interviews were sent to the Division's Advocacy and Customer Services Section for investigation and responses to the problems identified in the reports.

- Grant staff held a statewide conference to train providers, local management entity (LME) representatives, and local consumer and family advisory committee (CFAC) members at the state and local levels about the philosophy, measures, and methods of continuous quality improvement. About 50 LME representatives, 50 providers, and 50 CFAC members and their advocates received training on the use of performance data for quality improvement.

Enduring Systems Change

- The Division designed and implemented a comprehensive quality management plan for the MH/DD/SAS system based on the CMS Quality Framework for home and community-based services. The plan includes mechanisms and activities that promote adherence to basic standards as well as improvements over time. Essential quality assurance monitoring activities will continue to the extent that they directly serve the goal of ensuring the viability of the system, safeguarding participants, and improving the quality of services; and ongoing QI activities have been developed and coordinated across all levels of the State to guide policy and practice.

  The QM plan is now Chapter 5 in the *State Plan 2005, Blueprint for Change*, the fifth annual update of the blueprint for change series. The update highlights accomplishments of the previous 4 years and elaborates on the fundamental areas of person-centered planning, quality management, cultural competence, and best practices. Furthermore, it focuses on tasks that are necessary for the upcoming fiscal year to continue the process of systems transformation. The plan has been implemented during the past several years and includes requirements for LME oversight and improvement of services, the involvement of state and local CFACs in QI activities, and quarterly reporting on the Division’s website of state and local measures of systems performance.

- The Division developed and refined the incident response and reporting system. Under the new system, the LMEs are required to review all serious incident reports submitted to them by service providers in their areas, and to report quarterly on trends and efforts to reduce incidents and respond to complaints. Procedures are in place to involve state agencies for the most serious incidents to ensure adequate backup. Also, new reporting processes and forms (e.g., the *DHHS Incident and Death Report*) were revised and implemented. The forms will be made available online with the implementation of the web-based incident reporting system, which has been delayed until July 2009 because of restructuring at the sister agency responsible for technology projects.

- The Division implemented structures and processes for continuous quality improvement through the establishment and training of local, divisional, and statewide QI committees. LMEs are now required to submit annually at least three QI reports that describe how they have used QI processes to address service delivery issues in such areas as building service capacity, ensuring continuity of care, and ensuring the use of evidence-based practices. The CFACs participate in the collection of information on participant experiences and system performance, provide input into policy decisions, and identify unmet service needs, emerging problems, and other concerns.

- The new QM system enables the Division to provide the following reports: (1) regular statewide performance reports to the Legislative Oversight Committee, (2) local performance reports on measures related to the CMS Quality Framework domains, (3) quarterly incident and complaint trend reports, and (4) LME annual reports on the QI projects that they have undertaken for the year as part of their performance contract with the Division.

- The QM structures and protocols implemented during the grant period for oversight of the local service system, the comprehensive response to complaints and incidents, and the coordination of institutional to community transitions will be used as the basis for planning the QM system for the State's new Money Follows the Person grant and for the Community Alternatives Program MR/DD waiver. Also, the State will incorporate DD measures into its Treatment and Outcomes Program Performance System: the Division's web-based outcomes tracking system that collects data on individuals with mental health and substance abuse problems who receive publicly funded services.

Key Challenges

- Because the State was developing multiple statewide systems reform projects, Division staff had to deal with competing priorities, which made it difficult to focus on specific grant goals. The QM system was in development at the same time, so the grant project expanded beyond the initial demonstration planned.

- LMEs were undergoing restructuring and services were being outsourced, which hampered the local staff's ability to focus on demonstration projects that were added to their changing responsibilities. In addition, a few LMEs stopped providing some services at the same time that private providers began direct billing for Medicaid services, which made it harder for LMEs to keep track of participants who had transitioned to community settings.

- The process for opening the project manager position and finding a qualified candidate took more time than anticipated.

- It was not possible to interview the number of individuals originally planned in the Transition to Community demonstration project for several reasons.

  - Obtaining consent from potential interviewees—in particular, those who had guardians—required a great deal of time.

  - Project participants, particularly those who moved into their own apartment, often moved again or had their phone disconnected. Staff asked case managers for contact details, but some were themselves unaware that an individual had moved and others did not return phone calls.

  - Scheduling interviews for demonstration participants who had moved to group homes or residential care facilities was very time consuming. In some instances, interviewers would arrive at the scheduled time and find that the interviewee was out for the day.

  In addition, even with assistance from CDL staff, many demonstration participants could not be located after the initial interview.

- Incident reports were not always sent to the Division or the LMEs in a timely fashion, thus delaying the process of review and remediation. Continued training and regular on-site reviews of provider agencies by LMEs helped to improve incident reporting.

Continuing Challenges

Finding natural and community supports for individuals transitioning from institutions into the community continues to be a challenge, especially for persons with developmental disabilities. The State and LMEs need to place more emphasis in their strategic plans on finding housing and employment so that individuals who transition from psychiatric institutions and developmental centers can be sustained in the community. The Division's State Strategic Plan for 2007–2010 has set goals to improve housing and employment outcomes for participants.

Lessons Learned and Recommendations

- Moving people from institutional to community settings proved to be more challenging than expected, in part due to the structure of funding mechanisms (fee-for-service), which made start-up difficult for private provider agencies. Funding for state institutions was still required, whereas start-up funds were needed before transitions could take place.

  Because individuals transitioning into the community require many different types of services, including housing, education, and employment, the State needs to adopt a coordinated, cross-agency approach to services to comprehensively address individuals' needs. State Plan goals for 2007–2010 address these issues. The State is moving to more flexible funding mechanisms, while trying to maintain service utilization data that can be used to ensure accountability, as well as to evaluate and improve services.

- Incorporating grant goals and objectives into the Division's long-term systems reform plan ensured that grant-related accomplishments would be sustained beyond the life of the grant. This was made possible largely because of the involvement of staff from the Division's Quality Management Team who had experience in both quality management and the Division's service delivery system. As the Quality Management Team Leader, the grant's principal investigator helped ensure that the comprehensive QM plan developed through the grant was included in the State's reform plan.

Key Products

Outreach and Educational Materials

The Division's Quality Management Team and other presenters produced numerous materials for a 2-day Quality Management Conference *(Sustainable Collaborations for Successful Outcomes)* to educate participants about ways of examining and assessing available multisource data and about ways in which innovative QM projects can be developed, implemented, and evaluated within specific systems of care.

Technical Materials

The Center for Development and Learning produced a range of materials for the Transition to Community demonstration project, including (1) job responsibilities of interviewers and job application form, (2) interviewer training curriculum and training evaluation form, (3) interview instructions with script for oral consent, (4) script to obtain approval to release information for individuals with guardians, (5) initial, 3-month, 6-month, and 12-month post-discharge interviews, and (6) initial guardian interview with authorization form.

Reports

- The Division's grant staff produced a report based on data from the Transition to Community demonstration project.
- The Center for Development and Learning produced a final report on the implementation of the data collection component of the Transition to Community demonstration project.

Ohio

Primary Purpose and Major Goals

The grant's primary purpose was to design and implement an information management system as a foundation for quality assurance and improvement in the delivery of services and supports to individuals with mental retardation and other developmental disabilities (MR/DD). The grant had two major goals: (1) to develop a statewide quality management framework as a foundation for quality assurance and improvement in the MR/DD service system; and (2) to develop and implement computerized tools to facilitate the collection, organization, analysis, and dissemination of quality data.

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

Role of Key Partners

- The Department contracted with the Kansas University Center on Developmental Disabilities to develop the overall quality management framework and to evaluate grant progress and outcomes.

- The Quality Management Advisory Council—comprising representatives of state agencies, county MR/DD boards, advocacy organizations, and provider associations—was convened to assist the Department in its design and implementation of the new quality management system. The Council had four work groups: Individual and Family Survey, Regional Council Design, Quality Management Administrative Rule, and Quality Management System Description.

- A Consumer Advisory Committee (service users and their families and advocates, staff from multiple state agencies, and service providers) provided a forum for individuals to provide input and share information about grant activities.

Major Accomplishments and Outcomes

- The Kansas University Center on Developmental Disabilities conducted 13 meetings/ focus groups in five counties with 171 consumers, state staff, and providers (107 unduplicated) to obtain input for the design of the quality management framework. A variety of tools were used to collect stakeholder ratings of priorities for indicators and performance measures as well as information about existing data sources (and others that could be developed) to provide data for the measures. Input was also solicited regarding wording for the description of the quality management system itself.

  The resulting Ohio Quality Management Framework, which is based on the CMS Quality Framework for home and community-based services and cross-referenced with the CMS waiver assurances, includes modified domains with additional outcomes, indicators, and performance measures. The framework is intended to help integrate all quality measures and quality assurance processes (critical incident reporting, county board accreditations, facility licensure, provider certification, consumer surveys, and compliance reviews) into one quality management system.

- Early in the grant period, the Department used grant funds to purchase and install computer hardware and software for the new information management system. Information technology (IT) staff built data marts and developed reports for client demographics, critical incidents, licensed facility review information, and waiver tracking and payment authorization. The Department piloted the system in five demonstration counties and incorporated user feedback to improve the system.

- The Individual and Family Survey Workgroup of the Quality Management Advisory Council engaged a consultant to review draft consumer survey questions, recommend changes as needed, establish the reliability and validity of its measures, ensure integration with the core indicators identified in the Quality Management Framework, and develop a final draft of the survey. The consultant trained volunteer and state staff interviewers, conducted 91 interviews across five counties using the test-retest method (participants completed the identical survey twice between 2 and 3 weeks apart), and produced a final report that included recommendations for revising the survey.

- The Department established a Quality Management 101 training curriculum and conducted training with 85 stakeholders, both internal and external to the Department, on the short- and long-term value of a quality systems approach for Ohio. All sessions were recorded for distribution on CD and for dissemination on the Department’s website.

Enduring Systems Change

- The Ohio Quality Management Framework developed through the grant project served as the foundation that aligned the State’s MR/DD system with the CMS Quality Framework and the waiver assurances. In the future, the Quality Management Framework will be incorporated into the processes that will be used to determine actions needed to improve quality, such as additional training or regulatory and other policy changes. The Department will systematically assess these processes over the next several years, addressing and/or modifying them as needed.

  The Department has identified the data sources needed to evaluate the Quality Management Framework’s outcomes, and IT staff are in the process of retrieving and transferring data to the data warehouse for report development. The Department has also established an Office of Quality Management, Planning, and Analysis, which is working with several state-supported stakeholder groups to carry on the work of improving the quality management system.

- The Department implemented the new information management system and its associated training activities in five pilot counties. The system will facilitate quality assurance and improvement activities by reducing redundancy in reviews conducted by different agencies, facilitating reporting, and enabling comparison with other reviews and with data from other units and state agencies. All of the tools needed to expand the new information management system were scheduled to be ready by the end of 2008, and statewide implementation was planned for 2009.

- The Quality Management Advisory Council completed its work and was disbanded at the end of the grant period. However, the Policy Leadership Roundtable, an Advisory Council developed by the Department as charged by the governor and the General Assembly, will pick up where the Council left off and will provide a forum for a wide range of stakeholders (state agencies, county MR/DD systems, advocacy organizations, provider associations) to provide ongoing review and input on quality management issues.

Key Challenges

- The new Quality Management Framework is centered on outcomes measurement, not compliance, and requires a different set of data to be gathered and reported. As a result, obtaining buy-in for the framework from the 88 county MR/DD boards was difficult in view of concerns about inadequate resources to train—or hire new—staff in order to modify data collection methods.

- Changes in state government, including a new governor, department director, and many new personnel, led to changes in departmental priorities, which prevented the accomplishment of some grant objectives. For example, work to establish regional quality councils and a new administrative rule for quality management was discontinued.

Continuing Challenges

Ohio's 88 counties face a wide range of technology challenges in regard to data transmission between county MR/DD boards and service providers and the Department. These challenges include lack of resources, staff, and technological capacity; that is, computer hardware and software.

Lessons Learned and Recommendations

- Prior to committing resources to quality assurance and improvement initiatives, states need to conduct an assessment to determine which activities have priority and ensure that all activities are aligned with existing or planned quality management initiatives. Enlist the support of top administrators, and secure the commitment of relevant leadership to ensure that resources will be committed to the initiative's systems change and that information about the changes will be communicated to those whose work will be affected.

- When undertaking systems change initiatives, it is essential to ensure broad, strategic representation of stakeholders with adequate authority and responsibility for the changes to participate on a variety of levels, from advisory groups to work groups to focus groups. Clarify what is expected of stakeholders, and, if their input is solicited, be prepared to respond to it.

- A grant should be handled like a project. Be very clear about the scope of work, design a work plan, and get buy-in from all stakeholders and sponsorship by those with the authority to ensure that it is implemented—and stick to it. Employ a good project manager to avoid scope creep or the need to fast track at the last minute. Be deliberate, so that the changes are not viewed as temporary, and be prepared for the iterative, continuous improvement process to take place over the long term (5 to 10 years at a minimum). Keep stakeholders informed at every stage of the work, and use subject matter experts as needed.

- All information regarding the quality management initiative, including written documents, multimedia materials, websites, and web-based services, should be fully accessible to individuals with disabilities.

- It is important to establish and maintain methods to acknowledge and celebrate accomplishments. Finding ways to identify high performers and to provide incentives for high performance will embed the new quality management system into professional practice in a way that simple compliance systems can never achieve. This goal will most likely require some creative work with providers, advocates, service users, and families to identify ways to recognize excellence.

Key Products

Educational Materials

Grant staff developed a Quality Management training curriculum targeted to a wide range of stakeholders, both internal and external to the Department, which is available on CD and the Department's website.

Technical Materials

- The grant contractor developed data work sheets for each performance measure in the Ohio Quality Management Framework to provide IT staff with the information needed to find and deploy the data required to report findings across time. Each work sheet was completed through a process of several meetings with internal stakeholders who had knowledge of Ohio's MR/DD system and its data sources. The initial drafts were bound into a document of data sources for use in the creation and implementation of the overall reporting system.

- A grant consultant partnered with a Quality Management Advisory Council work group to develop a statistically valid and reliable Individual and Family Survey format for the Department, which will become an additional source of data in the information management system.

Reports

- The Kansas University Center on Developmental Disabilities, in collaboration with the Department, completed two *Formative Evaluations* and one *Summative Evaluation* of the grant's strategies and processes, as well as progress on grant goals and objectives. The reports include summaries of focus group input and recommendations for prioritizing future work on quality assurance and improvement.

- The Kansas University Center also produced two final reports: *Developing a Performance Measurement Strategy for the Ohio Quality Assurance Systems Change Initiative* and *Developing a Quality Management Strategy for the Ohio Quality Assurance Systems Change Initiative*. Both reports include recommendations for future direction; for example, establishing feedback mechanisms with all key stakeholder groups, creating a regular evaluation process to maintain the responsiveness of quality data to the needs of stakeholders, and using quality data to identify service system and information system redesign issues.

- The Department engaged a consultant to advise and assist in the development of a marketing and communication plan for its quality initiative. The contractor prepared a report *(Marketing and Communication Planning Tool for the Quality Management Initiative)* that includes the identification of target audiences; proposed communication tools, products, and activities; the design for a continuous feedback loop; strategies for countering negative responses; and recommendations for branding/naming the quality management concept, including a logo.

- A grant consultant conducted a pilot survey and produced a final report *(Reliability and Validity of Ohio's Individual and Family Survey)* that included recommendations for revising the survey instrument.

Oregon

Primary Purpose and Major Goals

The grant's primary purpose was to improve the quality assurance systems for waiver participants self-directing their services, with a particular focus on health, safety, and service satisfaction. The grant had four major goals: (1) to develop and support a consumer/stakeholder group to provide grant oversight and to assist with grant implementation, (2) to develop tools and procedures to help ensure health and safety and manage risk for in-home services recipients, (3) to design system-wide data collection and reporting processes that permit trend analysis and systems evaluation, and (4) to develop a detailed plan for project sustainability.

The grant was awarded to the Department of Human Services, Seniors and People with Disabilities (SPD).

Role of Key Partners

- The grant convened a Stakeholder Group comprising individuals receiving in-home waiver services and advocacy organizations representing a broad range of perspectives: local senior services agencies, the Support Service Brokerages, the Developmental Disabilities (DD) Council, the DD Coalition, Douglas County DD Services, the Home Care Commission, and Self-Advocates as Leaders. The Stakeholder Group contributed to the design, implementation, oversight, and evaluation of the project.

- Local administrative, case management, and service brokerage agencies contributed time and staff resources to complete field tests and assist with the evaluation of grant products.

Major Accomplishments and Outcomes

- A grant contractor and the Stakeholder Group developed a set of 11 quality indicators applicable to self-directed, in-home services across three service populations: people with developmental disabilities, people with physical disabilities, and older adults. The indicators provide a common foundation for measuring and reporting service quality throughout SPD, despite separate service delivery, planning, and advocacy systems.

  Critical health and safety data already available in the State's current information systems were identified, mapped, and assessed for applicability relative to the quality indicators. With information on each of these quality indicators gathered over time, SPD management will become knowledgeable about service system quality, and will be able to focus its improvement activities efficiently and effectively on specific problem areas.

- A grant contractor worked with SPD staff and members of the Stakeholder Group to develop a consumer satisfaction survey for individuals being served through three waiver programs: the In-home Comprehensive Services program and the Support Services Brokerages program (both serving people with developmental disabilities), and the Client-Employed Provider program (serving older adults and people with physical disabilities).

The project team field-tested the survey to obtain feedback for improving both the instrument and the methodology before final recommendations were submitted to SPD. They also tested a user-friendly, web-based prototype of the survey, which clearly indicated the limitations and benefits of an online survey for each service population.

- A grant contractor completed an assessment of existing information systems and made recommendations for an add-on program that can be incorporated into larger information system projects currently under way at SPD.

Enduring Systems Change

- The grant enabled SPD to improve its quality monitoring system by developing a consumer survey that (1) measures overall participant satisfaction with services and also provides participant perspective on how well supports meet health and safety needs and preferences, and (2) can be used across three waiver programs. SPD will administer a single consumer survey every 2 years to a statistically valid random sample of individuals who receive self-directed in-home supports (people with developmental disabilities, older adults, and people with physical disabilities). Because participation in the survey is not mandatory, the sample size has been tripled to account for a high no-response rate.

- The grant developed a personal safety and emergency management (PSEM) planning tool that participants can use to review critical issues, focus on the most likely risks, and plan measures to lessen those risks. The tool was designed for individuals who self-direct in-home services to decrease risks without compromising their authority and independence. The tool uses participant-friendly, noninstitutional language to help participants, their families, and others who help them plan and arrange supports to understand common risks and their implications. This understanding informs decision making about service planning and the need for specific steps to reduce risks.

- Contracted grant staff, in consultation with the Stakeholder Group, submitted a sustainability plan for including the grant's quality improvement activities as part of SPD's quality management strategy for waiver services. The plan identifies critical infrastructure components such as organizational design, technology and systems needs, and additional training and technical assistance needs for key program staff, as well as timelines for integrating the new processes and resources developed by the grant.

  No new service contracts, administrative rules, or statutory changes are required to implement these quality improvement activities. Implementation of the PSEM tool is currently in process. The consumer satisfaction survey was conducted for people with developmental disabilities in 2007, and the survey was scheduled to be conducted for older adults and for people with physical disabilities in 2008.

Key Challenges

- Lack of state financial resources and insufficient field staff presented major challenges to implementing the grant as planned. Consequently, grant staff changed priorities and adapted procedures to reduce the impact of these constraints on the field tests of the consumer survey and the PSEM planning tool.

- An original grant goal was to develop a single information system solution that would allow SPD to integrate and report information about participant health and safety from information systems that were created when the three service populations were served by two different agencies. Soon after the grant project began, the Department of Human Services had the opportunity to replace its antiquated Medicaid Management Information System (MMIS) system, and all other cross-system work was shifted to a lower priority—both for budget/resource reasons and because solutions developed for the existing system would be moot when the MMIS project is completed.

  However, the grant project's mapping of the location of critical health, safety, and satisfaction data for three disability populations—and its identification of additional elements needed—will still serve as a valuable guide for designing features of either the new MMIS or supplementary systems compatible with the new MMIS.

- Identifying and working through perceived differences in the needs, preferences, and communication styles of each service population and service delivery system culture significantly slowed the development of the consumer satisfaction survey and the PSEM planning tool. Grant staff worked with the Stakeholder Group until agreement was achieved.

- Toward the end of the project, several major state initiatives competed for participants' and advocates' time, and it was difficult to maintain their participation in the grant's consumer/stakeholder group after the consumer satisfaction survey and the PSEM tool were developed.

Continuing Challenges

- Oregon is currently developing and implementing a new Medicaid Management Information System, which will not be completed for several years, owing to unavoidable delays.

- Accumulating and analyzing data from various systems continues to be a challenge, as does distributing that information to various stakeholders.

Lessons Learned and Recommendations

States seeking to implement a single Quality Management System for multiple service delivery systems serving different populations are well advised to spend the time needed to engage all stakeholders in establishing priorities for the project prior to submitting a request for funding. When representatives of different service populations could not agree about design and implementation features, to get them back on track, grant staff found it helpful to remind them of their initial agreement about priorities.

Key Products

Technical Materials

The grant project produced two tools that are being incorporated into SPD processes: the *Consumer Satisfaction Survey* and *Handling Emergencies: A Guide to Personal Safety and Emergency Management* (both described above under Enduring Systems Change). The second tool is available at http://www.hsri.org/docs/PSEM_Guide.PDF.

Reports

- *In-Home Quality Assurance Project: System Review and Initial Approach* is an analysis of information system needs and a description of the prototype suggested to manage the integration of existing and new information. Because much of the information system that existed at the initiation of the grant subsequently became part of an MMIS improvement project, the report is not applicable in several areas but will be used to help shape revisions to the MMIS.

- *SPD Consumer Survey for Use with Recipients of In-Home Services: Survey Development and Field Test Report* describes the development and field test of the consumer survey, and provides recommendations regarding the survey questions and administration.

- *Helping Individuals Prepare for Emergencies: Development and Testing of a Consumer Guide to Personal Safety and Emergency Management* describes the development of the PSEM planning instrument, the field-test process, and provides recommendations regarding its use.

- *Quality Assurance and Quality Improvement in Home and Community-Based Services: Final Report* summarizes the tasks and activities of the grant project completed between May 2004 and September 2006, and describes project accomplishments according to tasks associated with each work component.

Pennsylvania

Primary Purpose and Major Goals

The grant's primary purpose was to create a uniform and integrated quality management system for all Medicaid waiver services. The grant had three major goals: (1) to develop and test new quality management systems for participant-centered service planning and provision; (2) to develop coordinated data systems that support continuous quality improvement and system error corrections, as well as planning and policy decisions; and (3) to develop methods to evaluate the new quality assurance/quality improvement (QA/QI) systems after full implementation.

The grant was awarded to the Governor's Office of Health Care Reform.

Role of Key Partners

- The Center for Survey Research at Penn State Harrisburg developed standardized survey instruments and a uniform assessment process to measure participant satisfaction with home and community-based services (HCBS).
- The Paraprofessional Healthcare Institute developed and piloted training modules for providers on quality assurance and direct care worker recruitment and retention strategies.
- The grant's Advisory Committee was composed of service users and their advocates, service providers and their associations, Centers for Independent Living, Developmental Disabilities Councils, and state agency staff. The Committee provided input on and oversight of grant activities, and helped to develop the cross-waiver quality management strategy.
- The Brain Injury Association of Pennsylvania worked with grant staff to develop educational materials.

Major Accomplishments and Outcomes

- To obtain information about the current long-term services and supports system, grant staff held focus groups, meetings, and face-to-face interviews with participants, support coordinators, and providers regarding all aspects of waiver services, including quality, satisfaction, adequacy, issues, and problems. They also asked for suggestions to address issues.
- The Paraprofessional Healthcare Institute developed and piloted training modules on quality assurance and recruitment and retention strategies for direct care workers. Approximately 500 service providers attended the trainings, which were conducted regionally across the State; providers will continue to use the curriculum and materials.

- The project manager and a team of stakeholders—including providers, service users, and family members—developed the outline for an educational DVD to promote a broader understanding of the support, treatment, and essential services and programs needed by people with brain injuries. The DVD's intent is to help participants of the CommCare waiver and other brain injury programs to make informed decisions about services and to increase the number of service providers for individuals with brain injuries.

- The project manager developed a backup system for individuals experiencing service breakdowns, which is available statewide 24 hours a day. The system includes a help line for participants and a worker call-in system that provides computerized alerts to service coordinators if call-in does not occur. The State had originally considered piloting the system through a service assurance contract but instead began planning to implement a rate increase for health care agencies that use service assurance systems.

- During the grant period, the Bureau of Home and Community Based Services piloted an incident management system through a Referral Tracking System that is expected to standardize incident management across waiver programs and provide a vehicle for quality improvement. Grant staff worked with the Bureau to ensure that the Referral Tracking System—once it is implemented statewide—will be expanded to include the Aging waiver.

- Grant staff began exploring a new policy to use accreditation in lieu of some aspects of annual monitoring of HCBS service providers. The Community Health Accreditation Program, Inc. (CHAP), is an independent nonprofit accrediting body, whose goal is to improve the quality of community-based health care services nationally. Because CHAP accreditation standards are very high, accreditation of HCBS providers could reduce state monitoring costs. A Center for Independent Living, which is also an HCBS provider, is participating in a pilot to determine CHAP's applicability and usefulness for quality assurance and improvement in Pennsylvania's waiver programs.

- Representatives of the State's different data collection systems, both for quality assurance and other purposes, worked together on solving the problem of how to feed data into one central location. As a result, the State's data warehouse is now being updated to provide the information the State needs to create reports that will be used for quality improvement. Reports using quality indicators to identify service issues needing remediation have been developed, and data coordination will continue as additional data fields for quality management are added.

- Grant staff began developing a complaint system, which will be used for all disability and age groups.

Enduring Systems Change

- Grant staff developed a three-tiered quality management system, which was included in two waiver renewal applications and approved by CMS. Funding has been secured through the Financial Years 07/08 Governor's budget, which included $1,115,550 to implement the three-tiered system, provider report cards, information technology systems changes, a training institute, a public relations campaign, and the management of a quality council. The State anticipates that all new systems improvements will be reviewed and evaluated for further improvement.

- In consultation with state staff and various stakeholders, the Center for Survey Research at Penn State Harrisburg developed two standardized survey instruments—with add-on modules for each specific HCBS waiver, the Program of All-inclusive Care for the Elderly (PACE), and non-Medicaid programs—to assess participant satisfaction levels with services, processes, and providers' responsiveness. The first survey instrument is an intake survey for newly enrolled participants and the second an annual satisfaction survey.

  The Center also developed benchmarking and longitudinal tracking templates and data analysis procedures. The instruments and survey administration processes are intended for use statewide with all programs administered by the Office of Long Term Living, including eight waivers, and two state programs: LIFE (a PACE program) and the Attendant Care Act 150 program.

- The reorganization of the long-term services and supports sections of the Office of Medical Assistance Programs, the Office of Social Programs, and sections of the Department of Aging into the Office of Long Term Living (OLTL) is providing the basis for implementing the quality improvement activities that have been piloted through the grant. The creation of the Division of Quality Management, Metrics, and Analytics has focused energy, resources, and efforts on quality management for OLTL programs, and the establishment of the Division's five regional offices will provide quality management and support across the State for all long-term services and supports programs.

Key Challenges

Pennsylvania's long-term services and supports delivery system was spread across two cabinet-level departments, with several layers of bureaucracy and no centralized authority; funding priorities did not support quality assurance activities across the systems. Therefore, the grant's quality improvement activities were difficult to coordinate and frequently broke down mid-process. Even the terminology used by different programs was a barrier, particularly for standardizing the language used in consumer satisfaction surveys, program forms, and monitoring tools.

Continuing Challenges

- New Medicaid regulations will require major changes in how the State pays for case management services. Surmounting the administrative obstacles and obtaining buy-in from case management providers will pose a major challenge.

- The State spends about 20 percent of its annual budget on long-term services and supports. Because Medicaid coverage of nursing facility services is an entitlement, convincing the State’s budget office each year to spend money on HCBS waivers and infrastructure also presents a major challenge.

- Reconfiguring and standardizing several data management systems to fit with the single organizational structure that now manages the eight waiver programs will be a significant challenge.

Lessons Learned and Recommendations

The establishment of one office responsible for all long-term services and supports programs—including nursing facility services and waiver services—has been critical to developing and implementing an integrated approach to quality assurance and improvement.

Key Products

Educational Materials

- The project manager and a team of stakeholders developed an outline for an educational DVD, *Recovering from Brain Injury,* that will provide consumers with information about the state system of services in order to promote choice, identify other resources, and educate providers and workers about the impact of brain injury.

- The Paraprofessional Healthcare Institute produced PowerPoint presentations on Quality Assurance and Direct Care Worker Recruitment and Retention Strategies as well as two workbooks: *12 Steps for Creating a Culture of Retention: A Workbook for Home and Community Based Long Term Care Providers*, which features best practices for worker recruitment and workplace culture; and *Sustaining and Nourishing Peer Mentoring Programs*, which describes the components needed to ensure the success of a peer mentoring program for direct care workers.

Technical Materials

- The Center for Survey Research at Penn State at Harrisburg developed two core surveys (intake and annual), and benchmarking and longitudinal tracking templates and data analysis procedures. Each survey instrument contains universal core questions as well as variable question modules tailored for specific programs.

- The Paraprofessional Healthcare Institute produced a *Caregiver Assessment Guide*, a set of tools to assist employers in assessing the suitability of candidates for direct caregiver positions in long-term services and supports facilities. Materials include (1) a job application form, (2) a guide for assessing applications and conducting interviews, (3) a basic skills assessment test, (4) organizing/prioritizing skills tests and job skills/ problem-solving abilities tests for experienced and inexperienced candidates, and (5) a chart for assessing inexperienced candidates based on their performance on the tests.

- The State’s Waiver Monitoring Unit developed a guide for waiver programs to help staff complete the new CMS waiver application (Version 3.4), but with the introduction of Version 3.5, it is no longer used.

- The project manager developed a draft *Quality Assurance/Quality Improvement Monitoring Guide* to monitor Area Agencies on Aging, county government, and administrative entities in regard to person-centered service planning.

Reports

The Center for Survey Research at Penn State Harrisburg produced a project report, *Home and Community Based Services Standardized Satisfaction Surveys,* that describes the processes and outcomes associated with the development of survey instruments and a uniform assessment process to measure participant satisfaction levels with home and community-based services.

South Carolina

Primary Purpose and Major Goals

The grant's primary purpose was to assess the validity and reliability of the State's quality assurance and quality improvement (QA/QI) programs that use an external Peer Review Organization (PRO), now called a Quality Improvement Organization (QIO). The grant had two major goals: (1) to review the State's current Quality Review Program to assess its effectiveness in addressing all aspects of the CMS Quality Framework for home and community-based services (HCBS) waivers, and to implement any needed enhancements for the program; and (2) to provide recommendations to CMS related to the use of a QIO to fulfill waiver oversight requirements in lieu of CMS regional office reviews.

The grant was awarded to the South Carolina Department of Disabilities and Special Needs (hereafter, the Department). The National Association of State Directors of Developmental Disability Services (NASDDDS), in partnership with the University of Minnesota Research and Training Center on Community Living Institute and the Center for Disability Resources at the University of South Carolina, was contracted to implement the grant along with staff from the Department.

Role of Key Partners

The grant's Stakeholder Advisory Group—comprising service users; family members; Disabilities Board Executive Directors; an advocacy organization; and staff from local provider agencies, the Medicaid agency, and the Department—provided input and guidance on initial project direction and design, served as key informants on specific grant topics, and interpreted study findings.

Major Accomplishments and Outcomes

- The Department's Quality Review Program was developed in collaboration with its contracted QIO, First Health Services of South Carolina (hereafter, First Health). Assessment domains include providers' licensing, quality assurance reviews, risk management, personal outcome measures, and consumer satisfaction. First Health is contracted to perform the scope of work using quality indicators that relate to clients' health, safety, dignity, personal choice, community participation, and goal attainment.

  First Health conducts approximately 400 face-to-face interviews annually with clients of all ages diagnosed with mental retardation and/or related disabilities, using the National Core Indicators survey tool. The University of Minnesota drafted a report on the relationship between the Quality Review Program's quality assurance measures and the National Core Indicators survey, based on quantitative data from First Health, to help the State understand which process measures increased the likelihood of achieving a particular outcome.

- The grant's Quality Evaluation Team assessed the Quality Review Program's effectiveness in addressing two Quality Framework domains: participant safeguards and participant-centered service planning and delivery. As part of the assessment, NASDDDS drafted a preliminary findings report on QA/QI data collected through both the internal licensing process and the external quality assurance reviews conducted by First Health. In addition, the Team conducted interviews with Department staff, statewide Disabilities Board Executive Directors, and other key stakeholders to identify the strengths and weaknesses of the Quality Review Program and to identify key issues and trends.

The program evaluation methodology was based on the CMS HCBS Quality Framework, assessing reliability and validity with respect to the functions of design, discovery, remediation, and continuous quality improvement. NASDDDS produced a second report that presented themes from the interviews and recommended ways to enhance the use of QA/QI data as well as changes that could be made in QA/QI processes to improve outcomes and communication among all stakeholders.

Based on the findings of the two NASDDDS reports, the Department revised current policies, procedures, standards, and the quality assurance review process to incorporate measures of compliance needed to achieve the intent of the seven domains in the CMS Quality Framework. NASDDDS evaluated the revised system and repeated the review, revision, and evaluation activities to assess the Quality Review Program's effectiveness in addressing the remaining five domains of the Quality Framework.

- The University of South Carolina arranged, conducted, and reported on eight focus groups that included state Medicaid staff, Disabilities Board Executive Directors, service coordinators, consumer groups, family member groups, and direct support staff. The purpose of the focus groups was to gather information on the Department's quality assurance review and licensing processes. Questions for the focus groups were designed based on the CMS Quality Framework, and the information gathered was a key component of the overall evaluation of the Quality Review Program.

- The Department and the University of South Carolina arranged for the Human Services Research Institute to train survey team members and policy staff about how to conduct consumer interviews, using a train-the-trainer process; and to assist the Department in developing a Quality Management process for ongoing continuous quality improvement, which the State implemented.

- The Department and the University of South Carolina used grant funds to plan and implement a Quality Conference to disseminate the results of the Quality Review Program's evaluation, and to provide information on issues relating to the State's quality assessment and improvement efforts. The Conference provided a forum for service providers, members of the Stakeholders' Advisory Group, and family members to discuss local, state, and national perspectives on quality.

- NASDDDS conducted an end-stage assessment to determine the use and applicability of the Quality Review Program's revised model in addressing the original goals set forth by the Quality Framework. It also developed recommendations for possible use in fulfilling CMS oversight reviews of HCBS waivers.

Enduring Systems Change

The State revised policies, procedures, and standards in its Quality Review Program.

Key Challenges

- As a result of lack of response, the original request for proposals for an external research entity was recalled in March 2004, revised, and released in September 2004. The contract was finally awarded in January 2005, delaying grant implementation by 15 months.
- The Department and the contractors were unable to complete grant activities because CMS would not extend the grant longer than 18 months. The State authorized and appropriated funds to continue paying the contractors until their work was completed.

Continuing Challenges

Combining monitoring for regulatory compliance with outcome measurement is a continuing challenge.

Lessons Learned and Recommendations

- Reporting quality data can create problems if the public does not know how to interpret the data. When data are misinterpreted and used against providers they could be reluctant to provide data in the future.
- CMS should shift its primary quality management focus from emphasizing regulatory compliance to measuring outcomes—or at least achieve a better balance between the two.
- To help states ensure that the data they collect are in accord with the CMS Quality Framework and the waiver assurances, CMS should clarify that the assurances differ from the domains in the Quality Framework, even though some appear to be the same (e.g., service planning).
- Contracting with Quality Improvement Organizations to conduct quality management activities assures the public that the reviews will be objective. Another advantage is that CMS provides a 75 percent federal match for approved QIOs.

Key Products

Reports

- NASDDDS developed two reports: *Preliminary Themes from Interviews on Quality Assurance Information Flow at SCDDSN* and *Themes from Interviews on Quality Assurance Information Flow at SCDDSN: Key Findings and Recommendations on Processing QA/QI Reports and Information*.

- The University of South Carolina completed the Report on *Interviews with SCDDSN Board Staff: Views on First Health and SCDDSN Licensing Review Processes*.
- The University of Minnesota completed *Quantitative Data from First Health Services (FHS) on the Relationship between South Carolina Quality Assurance Measures and the National Core Indicators Survey*.

Tennessee

Primary Purpose and Major Goals

The grant's primary purpose was to create the foundation of a quality assurance and quality improvement (QA/QI) system that results in timely remediation and system-wide quality improvement. The grant had five major goals: (1) to design a participant satisfaction instrument, and recruit and train interviewers to interview service users and their families; (2) to collect and analyze data from the participant satisfaction surveys and establish a single, functional database that generates useful and timely reports of findings; (3) to design and implement systems' improvements using the data reports; (4) to establish a mechanism to respond to urgent and nonurgent needs for remediation within the State's QA/QI system, with monitoring and follow-up to ensure remediation action; and (5) to develop and initiate the implementation of a sustainability plan that will continue the cycle of listening, recording, remediation, and systems improvement.

The grant was awarded to the Department of Finance and Administration, Division of Mental Retardation Services (DMRS), and contracted to the Arc of Tennessee for implementation.

Role of Key Partners

- Consumers provided feedback on proposed policies and procedures, made introductory calls to agencies, assisted in creating the interview process, and conducted interviews.
- The Arc of Tennessee formed the Tennessee Quality Services Committee, comprising service users and their families, to help with the recommendations process for remediation and quality improvement and to create a sustainability plan for the inclusion of participant satisfaction surveys in the QA/QI system.
- The Arc of Williamson, Arc of Mid South, and Arc of Washington, and the Jackson Center for Independent Living provided office space for training and interviewing when needed.

Major Accomplishments and Outcomes

- Grant staff recruited 20 individuals to work as interviewers across the State in the nine DMRS district areas. Teams in each district consisted of two members, one being an individual with a disability (often a developmental disability) and the other a family member of someone with a disability. The teams interviewed participants using the CMS-approved Participant Experience Survey (PES). Grant staff modified the survey instrument and related processes based on findings from the first year's activities.

  Respondents were chosen randomly in each region through a computer-generated statistical selection method. Respondents included individuals receiving services from waivers and/or state-funded programs. The teams completed 2,144 surveys, with a decline rate of only 7.5 percent. The Grantee exceeded the project's specific goal of interviewing in at least 75 percent of Tennessee's 95 counties, by conducting interviews in 77 counties (81 percent).

As a result of the interview process, respondents increased their knowledge of the availability of services, job opportunities, and self-determination principles. In addition, interviewers found some possibly precarious situations and—with the respondent's permission—were able to enlist an Arc advocate to help solve various problems. A few cases of abuse were also found and addressed.

- The Arc of Tennessee staff developed and implemented an information management system accessible within all nine DMRS regions to receive, enter, maintain, protect, utilize, and report data collected through the participant surveys. All analysis was completed by the Arc of Tennessee for the 3 years of surveys, and findings were reported to DMRS and to TennCare, the state Medicaid Agency.

Enduring Systems Change

- The State has committed funds to conduct annual participant satisfaction surveys using peer interviewers, and the new policies and procedures manual developed by the grant is being used as training material for the interviewers.

- The grant project solicited participant and family input through the participant survey initiative on ways to improve the long-term services and supports system in several areas, including identification of critical incidents and remediation efforts. In response to their recommendations, DMRS has made a number of changes as follows.

  - Prior to 2004, DMRS' definitions of abuse, neglect, and exploitation were extremely complex, making it difficult to understand what and when to report. The DMRS investigative Protection from Harm Unit held many meetings with all stakeholders to establish definitions of abuse, neglect, and exploitation that would be more easily understood. Although the new definitions are clear and concise, if in doubt, program participants can report questionable incidents to DMRS staff, who will determine whether the definitions have been met.

  - The Protection from Harm Unit made changes in operational procedures to ensure that participants' legal representative and/or designated family member are informed about allegations of abuse, neglect, or exploitation, and understand the investigative process.

  - Grant staff developed a new communication system for reporting incidents. Formerly, information was furnished only in aggregated form, which did not provide all of the information needed to enable Adult Protective Services and the Protection from Harm Unit to follow up; the new system requires that reports provide more detailed information about each incident.

Key Challenges

- The goal to develop and support the Tennessee Quality Services Committee, which was run by families and self-advocates, could not be completed because of lack of funding. The Committee met several times before budget cuts halted activity. However, DMRS provides funding for a statewide Advisory Council composed of DMRS personnel, service users, family members, guardians, and advocates. The group meets once a month in day-long sessions, working on a variety of topics such as systems change and policy development.

- A major obstacle to implementing the grant program was the high turnover of interviewing staff (the project is still experiencing about a 47 percent turnover rate). Reasons for the high turnover include (1) some individuals never having held a job and not understanding the responsibilities it entailed, (2) family caregiving responsibilities, and (3) illness. Also, some interviewers moved, some left without providing a reason, and two found better jobs as a result of their grant project experience.
- The PES was difficult to use, with many questions repetitive and unclear. It was expensive to correct data entry and other errors, and data were missing on several items, which complicated the analyses. Grant staff obtained technical assistance to help them address these issues.
- It was very challenging to find some respondents, given the lack of—or inaccurate—information. Many respondents had moved or passed away. Locating a respondent and setting up an interview required an average of eight phone calls.
- Initially, the provider agencies did not know about the PES, but as more interviews were completed, the provider agencies were more helpful in arranging interviews for the individuals they serve.

Continuing Challenges

The grant successfully dealt with all challenges to achieving our grant's goals. Finding the resources to expand services and fund new initiatives is always a challenge.

Lessons Learned and Recommendations

- The most important recommendation is to include service users and families in any effort to improve quality assurance programs. Much has been learned about the system by talking directly to those receiving services, and programs should hire people with disabilities to survey their peers. Individuals who are being interviewed feel more comfortable talking to someone with similar issues, which resulted in an extremely high response rate.
- States that are considering implementing a program that uses peers to conduct participant satisfaction surveys should consult with others that have experience with such programs. Many of the problems grant staff encountered would have been minimized if they had spoken first to those with experience.
- The Mental Retardation waiver should be expanded to cover individuals with developmental disabilities other than mental retardation.
- The State should fund the development of a new mental retardation/developmental disabilities supports waiver to provide limited services for individuals with developmental

disabilities other than mental retardation, which would reduce their time on the waiting list for waiver services.

- The State should adopt policies to reduce work disincentives for people with disabilities.
- The State needs to update its Information Technology system to make communication more efficient and timely and to reduce paperwork.
- The State should standardize training on the implementation of Individual Service Plans and fund more training for providers. The State should also fund more training for professional staff, direct care providers, and individuals with disabilities on reporting abuse, neglect, and exploitation.

Key Products

Outreach Materials

Grant staff developed a brochure about the participant survey.

Educational and Technical Materials

Grant staff developed a policies and procedures manual, which is being used to train interviewers.

Reports

Report Year Two: People Talking to People is a report on the surveys conducted under the grant from October 2004 to September 2005. The report includes recommendations for program and systems change.

Texas

Primary Purpose and Major Goals

The grant's primary purpose was to develop and implement sustainable measures for improving the quality assurance and quality improvement (QA/QI) system in the Department of Aging and Disability Services waiver programs. The grant had four major goals: (1) to develop a methodology or tool that accurately reflects waiver participants' experiences, and measures whether they have achieved their goals; (2) to develop a uniform and automated critical incident reporting process; (3) to establish a centralized system for agency-wide data collection, analysis, and reporting; and (4) to conduct and analyze participant experience surveys with a statistically significant random sample of participants in all the Department's waiver programs and in the Intermediate Care Facility for Persons with Mental Retardation (ICF/MR) program.

The grant was awarded to the Texas Department of Mental Health and Mental Retardation, which is now the Department of Aging and Disability Services (hereafter, the Department).

Role of Key Participating Partners

- The Department convened a QA/QI Task Force to assist in implementing grant activities. In addition to self-advocates and family members, the Task Force included representatives from The Arc of Texas, Advocacy, Inc., Texas Council for Developmental Disabilities, Texas Council of Community Mental Health and Mental Retardation Centers, and the Private Providers Association of Texas.

  Department staff and representatives of the Texas Health and Human Services Commission also contributed as subject-matter resources to the Task Force. Task Force members provided insight and guidance on grant activities; program participants' input, in particular, informed the State's selection of a consumer satisfaction survey tool.

- Nurse Aide Competency Evaluation Services (NACES Plus Foundation, Inc.) recruited interviewers and conducted annual face-to-face interviews and mail surveys for waiver participants and residents of ICFs/MR.

- The University of North Texas conducted telephone surveys of people receiving Primary Home Care services.

Major Accomplishments and Outcomes

- As part of the grant's outreach strategy, the Department collaborated with Advocacy Inc., and the Texas Council for Developmental Disabilities to sponsor and organize a workshop for people with disabilities who were interested in learning about self-determination. More than 200 people attended the 1-day workshop, one third of whom were persons with disabilities and their family members. During one workshop session, attendees who volunteered participated in a pilot test of the consumer survey.

- Grant staff and Task Force members developed six questions related to self-determination to be added to the National Core Indicators (NCI) consumer survey. The NCI project developer gave permission and provided assistance to pilot the additional questions. The NCI is currently considering whether to include the additional questions in the next survey revision.

- Grant staff and contractors provided interviewer training to 44 registered nurses who had been hired to conduct face-to-face consumer surveys statewide. The training took place over 1 day and included disability etiquette instruction as well as training on the process for reporting suspected instances of abuse, neglect, and exploitation. Self-advocate Task Force members attended the training to provide insight on self-determination and to participate in practice interviews, which were videotaped for subsequent trainings.

- In 2005, 1,980 interviews were completed with persons aged 18 or older who receive waiver services or ICF/MR program services. Values for quality indicators were calculated based on survey responses, and a report of the findings was published.

- A mail survey was also conducted in 2005, using the NCI Children/Family Survey tool. A total of 2,060 surveys were mailed to all children under 18 years of age who live at home and receive services in four waiver programs, and to all families with children in the Medically Dependent Children Program (up to 21 years of age). The findings were published in a report.

- In 2006, the Department conducted 2,600 adult face-to-face interviews, 800 children/family mail surveys, and 450 telephone surveys for people receiving Primary Home Care services, an attendant care services program under the Medicaid State Plan.

- The QA/QI Task Force developed some new definitions for “critical incidents” and defined a set of minimum data elements to be collected by private and public providers when a critical incident occurs. The Task Force recommended that the Department adopt them. The Department has not yet revised the definitions but is reviewing other activities of the critical incident reporting system.

- The Task Force drafted a facility closure report with recommendations for processes and procedures to use during voluntary and involuntary facility closures, which informed the Department’s closure process. The purpose of the policies and procedures is to ensure timely and accurate communication with residents, family members, guardians, and other stakeholders about the closure process.

Enduring Systems Change

- The Department implemented a Quality Assurance and Improvement (QAI) Data Mart to draw existing data from the Department’s disparate automated systems. The Data Mart will also provide data for quality measures based on the Home and Community-Based Services (HCBS) Quality Framework. The State has started using the Data Mart to generate reports to help identify the current state of program effectiveness, and help management set goals for improvement by measuring the impact of new policy on program performance. The Data Mart will also enable the analysis of participant outcomes and fulfill evidentiary report requirements mandated by CMS for waiver renewal.

- Texas is conducting face-to-face and mailed surveys annually as one critical component of the comprehensive quality management plan that spans agency programs. This enables the Department to conduct analysis, to identify areas for improvement, and to develop improvement strategies.

  The first consumer survey, which was funded by the grant, established a baseline of quality indicator data that is used as a mechanism to measure program quality. For example, quality indicators can be compared for people receiving services who use the self-direction option and those who do not, and additional quality measures can be implemented based on those results. Stakeholders will continue to be partners in identifying areas that need improvement and in assisting the Department in developing intervention strategies to improve services.

- The Quality Assurance and Improvement Unit is charged with continuing the activities of the grant, including conducting annual surveys and continued development of the QAI Data Mart as a tool for collecting and reporting operational data. Principles that were put into practice by the grant task force include implementing quality measures based on the HCBS Quality Framework and maintaining a commitment to providing quality services and supports.

Key Challenges

- The most significant challenge faced during the grant period resulted from a legislatively mandated consolidation of 12 health and human services agencies into 4 new departments under an umbrella agency: the Texas Health and Human Services Commission. During this period, several key staff were redirected from the grant, causing a redistribution of efforts in order to balance consolidation activities with daily business. The merger with other agencies also increased the number of disparate computer systems using different software and hardware platforms that were used in developing the Data Mart.

  The grant was originally awarded to the Texas Department of Mental Health and Mental Retardation for use in its mental retardation programs. The consolidation merged the MR programs with the Department of Human Services' long-term services and supports programs and all of the functions of the Department on Aging. This shift created some changes in personnel and administration of the grant. However, it also allowed the Department the opportunity to expand the scope of the programs to examine, thereby ensuring that a greater number of people would benefit from the grant's quality assurance initiatives.

- Another challenge was keeping self-advocates involved in grant activities through monthly meetings. Although they received a stipend for attending the meetings, lack of transportation often prevented their attendances.

Continuing Challenges

- Competing information technology projects have limited the participation of state technical staff and the amount of work that can be completed within requested time frames.
- Finding resources to update outdated computer systems is an ongoing challenge.
- Continued funding for the QAI unit's activities, as with all programs, is based on agency appropriations, which can vary.

Lessons Learned and Recommendations

- Reasonably limit the number of objectives to those that are attainable within resource and time constraints.
- Maintain constant communication with executive management on all aspects of the project, and make information about grant activities available to internal and external stakeholders.
- Establish mechanisms to inform key agency program staff about quality-related initiatives pertaining to their respective programs and to solicit their feedback.

Key Products

Outreach Materials

- A video about self-determination and participant control was developed. Advocates and others use the video at workshops and conferences and provide it to anyone interested in learning more about self-determination.
- The QA/QI Task Force created a Values and Supports statement that describes the Task Force's vision and mission for promoting quality initiatives in HCBS programs for people with disabilities. The statement was published in brochure and poster formats, which were distributed and posted at various provider agencies.
- Grant staff created a website for the QA/QI grant that includes information about the Task Force's goals and activities.

Educational Materials

During the annual interviewer training, a video tape of the training sessions was produced for use in training additional interviewers.

Technical Materials

As part of the design and development of the QAI Data Mart, several deliverables were created, including (1) a diagram depicting the Department's conceptual Data Mart architecture, (2) a Software Requirements Specification, (3) a System Design Description of the system architecture and design, and (4) a Conceptual Reports and Queries document outlining the various reports and information available from the QAI Data Mart.

Reports

QAI staff published reports of two surveys' findings:

- *Measuring Quality Using Experience Surveys: Adult Face-to-Face Survey Results 2005,* which was distributed to internal and external stakeholders and can be found on the Department website in English and Spanish under Long Term Services and Supports Quality Review (www.dads.state.tx.us/news_info/publications/legislative/index.html).
- *Measuring Quality Using Experience Surveys: Children/Family Mail Out Survey Results 2005.* Also available on the Department's website (use URL above).

West Virginia

Primary Purpose and Major Goals

The grant's primary purpose was to develop, implement, and support a quality assurance (QA) process and quality improvement (QI) infrastructure for the Developmental Disabilities (MR/DD) and Aged and Disabled (A/D) waiver programs. The grant had five major goals: (1) to define and expand core quality measurement sets for the waiver programs; (2) to develop and implement a data collection strategy of real-time and retrospective information for assessing waiver program performance; (3) to select, design, and implement QA/QI strategies; (4) to develop and implement a QA/QI system that involves program participants, their families, and advocates in active roles; and (5) to evaluate and upgrade the State's direct care service management and data collection system.

The grant was awarded to the Department of Health and Human Resources, Bureau for Medical Services, which is the state Medicaid agency. The Grantee contracted with the West Virginia University Center for Excellence in Disabilities to implement the grant.

Role of Key Partners

Grant staff established a Quality Improvement Team, which comprised staff from the Bureau for Medical Services, the Bureau of Senior Services, and the Bureau for Behavioral Health and Health Facilities; and the chairperson from each waiver's Quality Assurance and Improvement Advisory Council. The Quality Improvement Team provided oversight of the grant project and was involved in key grant activities, including data mapping, incident management, contracts between Medicaid and the waiver programs, and implementing the Participant Experience Survey (PES) for the A/D waiver. The Team will continue to provide coordination and oversight for the quality initiatives of both waiver programs.

Major Accomplishments and Outcomes

- In the first year of the grant, a Quality Assurance and Improvement Advisory Council was established for each waiver to provide advice on waiver operation, to monitor quality initiatives, and to promote networking and partnerships among stakeholders. Each Advisory Council is composed of 15 members, 5 of whom must be current or former service recipients, the other 10 being family members, advocates, and providers. The Advisory Councils meet quarterly and provide an opportunity for nonmembers to provide input on issues of concern.

- Annual retreats were held for the Advisory Councils and waiver staff to provide an opportunity for training and information sharing about common issues. (The State will continue to hold these retreats annually.) At the first retreat, grant staff provided basic information about the grant project, and staff from the Muskie School of Public Service presented information on the CMS Quality Framework for home and community-based services (HCBS) and methods to improve HCBS quality. Grant staff developed a Resource Manual containing these materials, which was distributed to members of the Quality Improvement Team and the Advisory Councils. Subsequent annual trainings focused on principles of self-direction, data utilization, and quality indicators, and the Resource Manual was updated in 2007.

- During the annual retreats, grant staff helped waiver staff and Advisory Council members to develop Quality Management Work Plans that prioritized quality issues of concern and identified strategies to address them. Each Advisory Council established work groups, which included Council members, state staff, and ad hoc members to ensure appropriate stakeholder representation, to address the areas for improvement identified in the Work Plans.

  Quality concerns and issues were also identified and compiled for each waiver through public forums, open comment periods at Advisory Council meetings, and ongoing provider monitoring. Many of these issues and concerns were incorporated into the Quality Management Work Plans and addressed during the grant period through policy and/or procedure changes. For example, the A/D waiver revised the initial certification process for providers and developed a recertification process that examines compliance with the basic standards on an annual basis.

  In addition, each Advisory Council implemented an annual Quality Improvement Project to address a priority issue. For example, the A/D Quality Improvement Project addressed the issue of loss of Medicaid eligibility because level-of-care assessments were not conducted in a timely manner. With assistance from the Muskie School staff, the work group conducted a Root Cause Analysis of the issue and solicited additional data to further clarify the concern. At the end of the grant period, the work group developed recommendations to address the problem, and the State has since implemented them.

- Advisory Council work groups for each waiver completed a comprehensive data mapping initiative to assess whether existing data could be used to provide evidence for the CMS waiver assurances. The data mapping process identified numerous information “gaps” in both waiver programs. Grant staff and the Advisory Councils’ work groups developed specific recommendations to address them.

- Grant staff helped waiver staff to develop quality indicators to support the evidentiary requirements for CMS’s six waiver assurances. In addition, Muskie School staff produced a preliminary assessment of the capacity of major data sources within each waiver program to support measurement of the indicators, and an early draft of potential measures. This initial phase of work provides a foundation for the development of quality improvement indicators and measures that extend beyond the minimum requirements of the CMS waiver assurances.

- Grant staff proposed a number of changes regarding quality management roles and responsibilities that were incorporated into the contracts between the state Medicaid agency and the agencies that administer the waivers. These changes include commitments to stakeholder involvement through the Advisory Councils, the ongoing development of quality indicators that exceed CMS requirements, and the annual retreat process of training and Quality Management Work Plan development.

- The A/D waiver's standardized curriculum work group surveyed 150 service providers to assess the training materials currently being used, drafted recommended content areas to be addressed in required training areas, and drafted curriculum recommendations. A lending system was established to make the training materials available to providers and, as of December 2007, 120 agencies had requested the materials. The curriculum also includes the mandatory training for independent workers of individuals who choose to self-direct a portion of their services.

- The A/D waiver's incident management work group developed policies with broad input from a range of stakeholders. Tracking of abuse and neglect is now part of the incident reporting template, and training in abuse and neglect was added to the required provider training. Also, a brochure on abuse, neglect, and exploitation was developed to increase clients' awareness of the issues. Clients now receive the brochure when they have the initial assessment for waiver services and again at the annual reassessment.

  As the incident management system was being developed for the A/D waiver, the MR/DD incident management work group was developing a web-based data system that tracks critical incidents and produces mandatory reports to Adult Protective Services. A/D waiver staff were involved in the development of this data system, which has the same structure for both waiver programs. Provider testing by region was conducted during the grant period, and the web-based system was fully implemented in 2008.

- An A/D work group surveyed 985 stakeholders (service providers, family members, participants, and advocates) to determine preferences for providing feedback and input. Strategies for accommodating stakeholder preferences were developed (e.g., the State has implemented a toll-free complaint line for A/D waiver participants).

- Staff of the MR/DD waiver drafted a template for quality management reports that incorporates data on services and budgets, quality indicators, and quality improvement projects. A/D waiver staff modified the MR/DD template to meet its needs, and each waiver is now using its report template to compile and organize data and to generate reports for waiver staff and Advisory Council members.

- The A/D waiver's Participant Experience Survey work group modified the survey tool to capture the experiences of participants who self-direct a portion of their services. A contractor assisted the work group throughout the development of the survey tool and provided onsite training to waiver staff surveyors. Grant staff developed an electronic version of the modified tool and developed the reporting capability of the database. The PES has been incorporated into the annual provider monitoring process.

- Grant staff worked with A/D waiver staff to revise the automated provider monitoring tools and process to ensure that necessary quality management data are collected. Quality reviews are now entered directly into electronic forms, which are merged into a centralized database. The information collected is more readily available and easier to use for quality monitoring.

- The MR/DD Advisory Council formed a work group to revise the waiver's *Policy Manual*. The Council gathered extensive statewide stakeholder feedback and comment on the initial drafts. Because of the volume of public comment received, the Advisory Council developed a template to record and respond to public comments, which will be used for all future public comments.

Enduring Systems Change

The grant was successful in implementing a system-wide approach to quality management in both the MR/DD and A/D waiver programs. An infrastructure was built for the state Medicaid agency and the two agencies administering the waivers to identify and prioritize quality concerns and to implement and evaluate quality improvement projects. All parties have formalized agreements to continue working with the Quality Improvement Team and with the Quality Assurance and Improvement Advisory Councils for each waiver, and to continue using the quality report template and the automated incident reporting systems.

The State now has formalized monitoring procedures and a set of quality indicators for each waiver, an annual consumer survey for the A/D waiver, procedures for soliciting stakeholder input, a training curriculum for providers, and a web-based incident management system. The system-wide infrastructure established through the grant will enable the State to continue improving the quality of services. (The components of the infrastructure are described in the Major Accomplishments section, above.)

Key Challenges

No major challenges were encountered during grant implementation. In general, the grant worked well because communication was good among the many stakeholders. Many challenges that could have arisen were avoided by constructing the initial quality management plan, which focused the grant activities on the infrastructure for a new quality management system. One challenge was that some policies needed to be changed as a result of the quality improvement projects, and changing Medicaid policy is a time-consuming process.

Continuing Challenges

None related to the grant's goals. Staff turnover in the waiver administrating agencies is a challenge.

Lessons Learned and Recommendations

- The involvement of all stakeholder groups in the waiver Advisory Councils helped to promote systems change. However, to provide helpful input, stakeholders must be knowledgeable. Education and training was needed for everyone to understand quality management principles and CMS expectations.

- Having a work plan at the outset helped the stakeholders to focus on the grant's ultimate goals, and having the Medicaid agency and the two agencies that administer the waivers constantly at the same table was critical in reaching agreement.

Key Products

Educational Materials

- The brochure produced for A/D waiver participants *(How to Report Abuse and Neglect)* will continue to be distributed annually to each client. Also, a waiver service eligibility information packet has been made available in alternative formats.

- The A/D waiver training curriculum for service providers will continue to be utilized, as will the *Participant Experience Training Guide and Survey: West Virginia*, which is available at http://www.hcbs.org/moreInfo.php/doc/1714.

- The *Quality Management Resource Manual* produced by grant staff will continue to be updated and used by both the A/D and the MR/DD waiver staff and Advisory Councils.

Technical Materials

- *Procedures Handbooks* for each waiver program will continue to be used by each of the Advisory Councils as well as an *Incident Management System User Manual* and *Provider Guidelines and Responsibilities for Management of Incidents*, and various incident reporting and tracking forms.

- The electronic forms and database developed for the A/D waiver's quality monitoring process will continue to be used as part of the waiver agency's primary discovery process. The *AD Waiver Monitoring Nurse Tools and Database—West Virginia* is available at http://www.hcbs.org/moreInfo.php/doc/1210.

Reports

- Grant staff produced reports detailing the results of the data mapping process for each waiver, and detailing comments from the public forums for both waiver renewals.

- The Muskie School staff produced a report that assessed the State's data collection capacity in terms of expanded quality indicators: *Preliminary Quality Indicators, Measures and Data Sources for WV HCBS AD and MRDD Waiver Programs*.

Wisconsin

Primary Purpose and Major Goals

The grant's primary purpose was to design a coherent and comprehensive quality management (QM) system for home and community-based services (HCBS) programs, which incorporates the CMS Quality Framework and meets federal, state, and local requirements. The grant had three major goals: (1) to increase the focus on participant outcomes by identifying and adopting key experience, functional, and clinical outcomes and measuring them comparably across all waiver programs; (2) to develop and implement tools, training, and technical assistance that incorporate a participant focus and participant outcomes into care management; and (3) to review and revise the State's quality management systems for HCBS programs to enable, support, and empower more effective local quality management systems.

The grant was awarded to the Department of Health and Family Services (DHFS), Division of Disability and Elder Services (DDES). The State contracted with two firms, APS Healthcare (APS) and The Management Group (TMG), to help staff the grant project.

Role of Key Partners

- The grant's Local Advisory Panel—comprising state staff with QM responsibilities, local staff responsible for quality management in each of the managed care organizations (MCOs) and in county HCBS waiver programs, and External Quality Review Organization representatives—provided input and responded to draft recommendations developed by grant staff. Members also participated in a series of work groups focusing on specific aspects of the QM system, such as quality indicators, and participant outcomes measurement.

- The grant's Stakeholder Committee, comprising long-term services and supports providers and self-advocate leaders of advocacy groups, provided input during meetings of the Wisconsin Council on Long-term Care Reform and its Executive Committee, and through individual interviews.

- The Center for Health Systems Research and Analysis, University of Wisconsin-Madison was contracted to conduct a comparative assessment of outcomes measurement systems and their use in quality indicators.

Major Accomplishments and Outcomes

- Grant staff reviewed departmental requirements and protocols for local QM programs to identify areas for improvement and to increase their focus on participant outcomes. They also created a "Cross-unit Quality Management Team" of Department staff from QM sections within the DHFS to share information on QM practices and to develop QM policy recommendations.

- A grant contractor assessed several methods for measuring participant experience outcomes currently used in Wisconsin's various long-term services and supports programs. In addition, the contractor examined the outcome measures in (1) the Participant Experience Survey, which was tested for use in Wisconsin with grant funds; (2) the Recovery Oriented Systems Analysis used in Wisconsin's mental health waiver; (3) the Dementia Quality of Life Outcomes Care Planning Tool, developed for use in Wisconsin; and (4) the National Core Indicator survey.

- The Grantee established a clinical and functional indicator quality work group, which included grant staff, representatives from DHFS, local waiver program administrators, and Family Care and Partnership counties. The work group examined more than 850 program outcomes and indicators from about 20 sources, including the National Committee for Quality Assurance, Agency for Healthcare Research and Quality, the National Core Indicators, the Group Participant Experience Surveys, and Wisconsin's DHFS, among others. The original list was narrowed to include only those outcomes/indicators relevant to clinical and functional well-being. Work is currently under way with DHFS analysts to establish a work plan to collect and report data on the indicators twice a year, beginning with the managed care HCBS programs.

Enduring Systems Change

- The grant activities and products have improved the QM systems used by both state and local HCBS programs, and have improved the extent to which state and local HCBS officials and staff perceive the value, understand the purpose and methods, and are committed to the practice of evidence-based quality management. Many of the activities begun during this project have informed activities under the Comprehensive Systems Reform grant and are being implemented in the managed long-term services and supports expansion effort currently under way in the State. Examples include the following:

  - Grant staff developed a preliminary design for an integrated QM system that has given HCBS professionals a shared vocabulary for discussing and thinking about QM processes. The final report has guided the development of contract requirements and certification standards for the expanding managed care system, which will help to ensure that local agencies fulfill QM requirements.

  - Grant staff created a comprehensive quality assurance plan for Wisconsin's Functional Screen system, which is used to determine eligibility for long-term services and supports programs, for rate setting, and other purposes. This plan includes activities to enable the DHFS to determine whether the screen is working as intended, to correct deficiencies, and to continually improve it. Responsibility for tasks has been assigned to existing staff, and additional funding has been committed for two new positions to carry out the Functional Screen QM system.

  - Grant staff developed a program of QM training and technical assistance for local care managers, agency managers, and QM staff. The training was delivered to 95 participants statewide in June 2007 through a webcast and has received more viewings since then. The webcast includes most of the basic concepts and material developed during the grant project, and will continue to be used during the State's expansion of managed care for home and community-based long-term services and supports programs.

- The DHFS adopted a set of 12 participant experience outcomes to be used in all HCBS programs serving adults with physical or developmental disabilities or frail elderly persons. This enabled the completion of a standardized outcomes-based individual service plan (ISP) form for the State's fee-for-service waivers, and of a web-based program in basic training for creating outcomes-based plans, which is now active and available to all HCBS care managers in the State.

  The new ISP contains elements designed to gather information that had not heretofore been collected, such as personal discretionary funds available to the participant, and a field to record the total waiver program start-up and/or one-time costs. Also new to the ISP is a companion document, the ISP-Individual Outcomes form, which provides a means to identify and document participants' desired individual outcomes that the service plan will address. The form will enable the care manager/supports and services coordinator to monitor and document the achievement of participant outcomes.

  The set of 12 participant experience outcomes will form the basis for the development of a reliable and valid measurement tool for the State's HCBS managed-care programs. The tool will be used by both care managers (during assessments) and quality reviewers (during site visits and quality reviews), so that their assessment findings will be more useful to one another.

- The Quality Management Council (the sustainable version of the grant project's Local Advisory Panel) continues to provide a forum in which (1) local quality managers educate one another about successful QM practices and provide guidance to the State on how it can best support local QM programs, and (2) the State and the External Quality Review Organization can provide efficient training and guidance on QM requirements. The DHFS has charged the group with providing guidance to the Department, the counties, and MCOs on QM policy, practices, and benchmarks, and will financially support its ongoing meetings.

- The Cross-unit Quality Management Team of department staff from QM sections within DHFS is now a unit within the Department and continues to be a focal point for sharing information on QM practices and for developing QM policy recommendations.

- The Stakeholders Participation Committee formed during the grant is now a permanent subcommittee of the Statewide Long-term Care Reform Council, and is training and supporting consumers to serve on local boards and committees.

Key Challenges

- Lack of a common understanding of what "quality management" is—among HCBS officials and staff at all levels statewide—presented a continuous challenge, which was addressed through intensive communication and education. The most frequent misconception was that the grant project—or any project with “quality” in its title—should make recommendations regarding best practices for service delivery itself, rather than about how to objectively determine the quality of services and move the system ahead to remediation and improvement.

It was necessary to train people continually about quality management as a discrete and unique managerial function, and to defend it as legitimate (e.g., explain that although quality indicators *alone* will not directly improve quality, they are still worth creating and monitoring).

- More time and staff resources were needed to implement many of the new practices developed through the grant (e.g., some standardized statewide participant satisfaction questions).

Continuing Challenges

- Many of the challenges discussed above have continued since the grant ended. The field of QA/QI is not as well developed in home and community-based services as it is in primary and acute health care, so the state and local HCBS agencies have to develop QA/QI methods and indicators specific to HCBS waivers. Professionals in the long-term services and supports system have traditionally addressed quality issues on a case-by-case basis. Incorporating a systems approach into their assumptions and expectations regarding quality assurance can be very difficult.

- Reaching consensus on the development and the use of quality indicators can be challenging because some stakeholders, including staff and managers, do not understand the appropriate use of indicators in quality management. Only a few understand that indicators by design seldom do more than *indicate*; they are not intended to serve as a direct justification for action but as a pointer to areas for more in-depth discovery.

Lessons Learned and Recommendations

- Web-based communication among stakeholders is useful to facilitate sharing documents and ongoing discussion of key topics in between face-to-face meetings.

- Before changes in QM systems can be made, time and resources are needed to achieve buy-in from key stakeholders and to convince them to adopt new ideas and approaches.

- Consistent reinforcement of a systems approach to QM is needed for and from all professionals who shape the HCBS system: state management and staff and national and regional CMS staff. Continuing education is needed to ensure that all these professionals, including CMS regional staff who review and approve waiver applications and those who conduct periodic reviews of waiver programs, thoroughly understand the concepts and requirements of a systems approach to QA/QI. Doing so will help the system as a whole to implement effective systems approaches to quality management.

Key Products

Educational Materials

The webcast training in the basic components of quality management for HCBS programs will be expanded as the components are incorporated in the expansion of managed long-term services and supports. The webcast can be accessed at http://dhfs.wisconsin.gov/managedltc/grantees/webcasts/060606.htm.

Technical Materials

- *Quality Close to Home: A Preliminary Design for an Integrated Quality Management System* is intended to serve as guidance, a basis for communication, and a reference for all the professionals, advocates, and participants who will help develop the specifications for and implement QM practices for the emerging statewide system of managed long-term services and supports. The report is available at http://dhfs.wisconsin.gov/LTCare/%0bResearchReports/qctreport.htm.

- The Long Term Care Functional Screen (LTC FS) is a key element of Wisconsin's HCBS programs. It is a web-based application that collects information about an individual's functional status, health, and need for assistance for various programs. A QM system must recognize that the administration of the LTC FS relies on both local and state knowledge, effort, and resources and depends on the skills of hundreds of screeners across the State. *Design Elements for a Quality Management System for Long-Term Care Functional Screening* describes an approach to LTC FS quality management that builds on and enhances current efforts while incorporating new QM activities. Although this report primarily addresses the LTC FS, many of the recommendations would also be applicable to the Children's Functional Screen and the Mental Health Functional Screen. The report is available at http://www.hcbs.org/moreInfo.php/doc/1354.

- *Assuring Quality in Wisconsin's Functional Screen System* provides a comprehensive framework for quality assurance and is organized according to the CMS Quality Framework for HCBS. Activities related to Functional Screen design come first, followed by operation, discovery, remediation, and improvement strategies in six key areas: Functional Screen change procedures, training of screeners, ensuring clinical integrity, communications, local-level quality assurance plans, and eligibility decisions. The report is available at http://www.hcbs.org/moreInfo.php/doc/1859.

Reports

- As part of an ongoing process to provide an overview of the existing QM system for HCBS programs and to develop recommendations for improving this system, a series of interviews was conducted with key local informants responsible for QM activities for the Community Integration Program, the Community Options Program, Wisconsin Pace/Partnership Program, and Wisconsin Family Care. The report *Quality Close to Home: Local Quality Management Practices* summarizes common themes, best practices, and suggestions for improved quality management at the local and state levels that emerged from the interviews.

- *Issues and Options in the Development of a Unified Approach to Outcomes Measurement in Wisconsin's Medicaid Waiver Programs* assesses different approaches to outcomes measurement as used by a variety of Medicaid waiver programs in Wisconsin and provides an extensive discussion of the current approaches, options for a uniform approach, the relationship between outcomes measurement and care management, and some possible uses of outcome measures to address CMS requirements.

Part 5

Family to Family Health Care Information and Education Center Grantees

Exhibits

Section One. Overview

Children and youth with special health care needs (CYSHCN) are individuals under the age of 18 “who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Their needs range from early and ongoing screening, diagnosis, and routine treatment and monitoring to extensive ongoing specialty care, medical equipment, therapies, and long-term services and supports. Nationally, 12.8 percent of children (9.4 million) have a special health care need, affecting one in five U.S. households with children.

Parents often lack knowledge about the wide range of services and supports for CYSHCN and have little experience dealing with the health and long-term services and supports systems and the health insurance bureaucracy. Family to Family Health Information Centers (hereafter, FHICs) provide a critically important service by educating parents about available services and helping them navigate complex systems and bureaucracies. In addition to helping families make informed choices about health care in order to improve their children’s health and functional outcomes, FHICs also promote the philosophy of family-centered care, individual- and family-directed supports, and the adoption of the medical home concept through education and training initiatives targeted to health care and other service providers.[10]

In 2001, as part of the federal New Freedom Initiative to promote community living for persons with disabilities, federal agencies were instructed to work together to eliminate barriers to community living. In response, the Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB), and CMS established grant programs to help develop FHICs. Funding for these centers was approved as part of the Family Opportunity Act (FOA), which was signed into law in 2006 as part of the Deficit Reduction Act of 2005. As of June 2008, 41 states/territories had FOA-funded FHICs with primary funding support from the MCHB, which also funds the national organization Family Voices, and the National Center for Family/Professional Partnerships to provide technical assistance to these 41 FHICs. It is anticipated that all states and the District of Columbia will have FOA-funded FHICs by 2009.

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[10] In a medical home, a pediatric clinician works in partnership with the family and/or patient to ensure that all medical and non-medical needs are met. Through this partnership, the pediatric clinician can help the family and patient obtain and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the patient and family. See http://www.medicalhomeinfo.org/ for more information.

In FY 2003, CMS awarded grants to organizations in nine states to develop Family to Family Health Information Centers (see Exhibit 5-1)

Exhibit 5-1. FY 2003 Family to Family Grantees

Alaska—*Stone Soup Group*
Colorado—*Family Voices Colorado*
Indiana—*About Special Kids*
Maryland—*The Parents' Place of Maryland*
Montana—*Parents, Let's Unite for Kids*
New Jersey—*Statewide Parent Advocacy Network, Inc.*
Nevada—*Family TIES of Nevada, Inc.*
South Dakota—*South Dakota Parent Connection, Inc.*
Wisconsin—*Family Voices of Wisconsin*

The amounts of the awards to the Family to Family Health Care Information and Education Center (FTF) Grantees were less than those given to other Systems Change Grantees, reflecting the narrower scope of their goals (i.e., not to bring about systems change but to establish a Family to Family Health Information Center).

Results

All of the Grantees established a Family to Family Health Information Center as part of their existing organizational structure. For many of the organizations that received FTF grants, developing an FHIC required an expansion of their original mission. For example, the Parents' Place of Maryland (PPMD) is a nonprofit family-centered organization, which was established in 1991 to enhance the ability of CYSHCN to participate as fully as possible in home, school, and community life by providing education, information and referral, and support for them and their families. Prior to receiving an FTF grant, PPMD had focused on providing support and training for families on their rights in special education. The grant enabled PPMD to expand its mission and its staff's capacity to help families access health care.

Once established, partnerships with other organizations are critical to FHICs' ability to achieve their goals, to avoid duplication of efforts, and to sustain their work. Most FHICs are partnering with other nonprofit and community-based organizations and their states' Title V programs to provide information and referral services or to ensure that the family perspective is represented in policy decisions. FHICs also collaborate with state and local agencies and programs, managed care organizations, hospitals and medical practices, tribal organizations, universities, and public school districts.

Many of the Grantees established partnerships with other organizations that serve CYSHCN. For example, the Grantee in New Jersey, the Statewide Parent Advocacy Network, Inc. (SPAN), is a family education and advocacy agency. The new FHIC enabled its staff and volunteer Resource Parents to develop partnerships with hospitals, clinics, mental health facilities, family support organizations, immigrant networks, and other organizations, thereby facilitating the dissemination of information and support for families statewide.

Once the South Dakota Parent Connection, Inc. (SDPC), established an FHIC, FHIC staff established partnerships and working relationships with health care providers, the two major hospital systems in South Dakota, and state agencies. Establishing the FHIC expanded SDPC's focus to include providing information, training, and other resources in the area of health care for CYSHCN.

The Alaskan FHIC established strong collaborative relationships with many organizations and agencies concerned with children's health, including The Governor's Council on Disabilities and Special Education, The Children's Hospital at Providence Hospital, The Disability Law Center of Alaska, the University of Alaska Center for Human Development, Anchorage School District, the Alaska Autism Resource Center, the Alaska Youth and Family Network, and many others.

Once established, the new FHICs engaged in a wide range of activities that assisted thousands of CYSHCN and their families as well as the health care professionals that serve them. These activities are discussed below.

Providing Information and Referral Services

Grantees provided extensive one-on-one information and referral services to thousands of families and hundreds of professionals during the grant period. For example, program staff and volunteers in Alaska directly or indirectly assisted 1,741 parents and 221 professionals. The information provided has empowered parents and caregivers to make more informed decisions regarding the most appropriate care and treatment for their child. FHIC staff in Maryland assisted 2,902 families through phone calls, e-mails, and in-person meetings.

Issues, problems, or concerns that spurred family contact with FHIC staff included a need for information about public benefits, eligibility for services, funding for medical services, and access to appropriate services and nonmedical services. Staff advised families, made referrals, or helped them with the referral process, and attended meetings with parents and agencies or providers. The Grantee conducted a survey in which about 96 percent of parents reported that the information and assistance they received from FHIC staff made them more knowledgeable about how to work with providers; and about 84 percent of parents reported that their child received more appropriate services.

Developing Informational Materials

Grantees developed a range of print and web-based materials, including newsletters, brochures, information packets, fact sheets, resource notebooks, and care notebooks, to provide a system to organize information about a child's medical history, daily activities, appointments, and medical expenses. To meet the needs of non-English-speaking families, many FHICs translate their materials into languages common in their states, such as Spanish, Portuguese, and Chinese.

To address the statewide need for information, FHICs are disseminating materials in various formats, including CDs and DVDs, as well as on the Internet. Websites and electronic mailing lists have been particularly useful in reaching families who have computer access in rural and frontier areas. Partner organizations, including other nonprofit and community-based organizations, state chapters of the American Academy of Pediatrics, the Title V program, and individual pediatricians and case managers, also assist with dissemination by printing and distributing FHIC materials.

Providing Education and Training

Grantees provided in-depth education in workshops and at conferences, and some facilitated family participation by providing modest subsidies for travel expenses and respite care. Sample topics covered include Medicaid eligibility and benefits and transitioning from child health and support services to the adult service system. To serve families who were unable to attend trainings in person, many FHICs used technology such as web-based conferences, teleconferences, and videoconferences. To reach the greatest number of families possible, they also employed train-the-trainer educational approaches, so those participating could share what they had learned with other families in their communities.

In addition to providing education and training for families, FHICs also provide programs for health professionals, including physicians, nurses, and social workers, and for medical and nursing students. Some of the workshops and seminars have been approved for continuing education credits.

Improving Programs and Informing Policies

Policy makers and program administrators may not understand how specific policies and program provisions affect service delivery. Consequently, educating policy makers and other stakeholders about the needs of CYSHCN and the challenges their families face is critical to ensuring the quality and timely receipt of services. Several Grantees engaged in activities to educate policy makers about program and policy issues important to families of CYSHCN.

For example, in collaboration with the Survival Coalition of Wisconsin, Family Voices of Wisconsin developed a series of proposals for the FY 2007–FY 2009 biennial state budget that included funding to address waiting lists for children's long-term services and supports and to develop the infrastructure to provide information, assistance, and advocacy services for children with disabilities and special health care needs. Their efforts resulted in the inclusion of $4.7 million to address waiting lists in Year 1 and $4.8 million in Year 2, which was the first significant increase in funding for children's long-term services and supports in 12 years. Federal sponsorship of the FHICs has helped them to play a meaningful role in the policy process by increasing their visibility and perceived legitimacy.

In sum, the FTF Grantees' accomplishments are impressive, particularly given their modest grant funding. They have creatively extended this funding through the formation of strategic partnerships, the use of technology, by recruiting volunteers, and to some extent, by developing community and regional networks throughout their states.

The purpose of the FTF grants was to provide seed money to help establish a Family to Family Health Information Center. Grantees had to develop plans to sustain the new FHIC after the grants ended. The national organization Family Voices, funded by CMS to furnish technical assistance to the FTF Grantees, provided sustainability tool kits and organized conference calls to discuss approaches and options. Grantees pursued several strategies, including applying for new grants, alone or in partnership with other organizations, and several received a grant from the federal Maternal and Child Health Bureau.

Continued funding is needed for family-driven organizations to do grassroots information and advocacy work. Congress has recognized the value of these organizations by authorizing funds to establish FHICs in every state. However, grants are time limited and not intended to provide ongoing support. These highly effective organizations require a stable source of funding to sustain outreach and referral services, information dissemination, and education and training initiatives.

Lessons Learned

Grantees cited a number of lessons learned throughout the grant period that may be helpful to organizations seeking to aid CYSHCN and their families, generally, and to develop and operate FHICs, specifically.

- It is difficult to get families and professionals to attend in-person trainings on public funding for services for CYSHCN (e.g., Medicaid waivers) despite their expressed interest in the topic and the availability of financial assistance to support attendance. This is likely due to professionals' very busy schedules and families' caregiving and work responsibilities. Using technology and web-based activities for providing information, education, and training can help reach families and professionals who cannot attend in-person meetings.

- Prioritizing the development of leadership skills for parents and families of CYSHCN is a key strategy for bringing about systems change. Training develops parent leadership: first to advocate for their own child, then to support and advocate for other children and families, and then to participate in systems change activities.

- Developing a dedicated and well-informed parent trainer network requires a significant level of support and nurturing. Because of the complexity of both the health care system for children with disabilities and of insurance coverage issues, family educators may require extensive training and mentoring to gain the expertise needed to support other families. Active mentoring is essential for parents conducting outreach with unfamiliar communities.

- Using focus groups is an effective strategy for identifying the needs and strengths of families from diverse backgrounds in order to develop supports and services to address their needs and to build on their strengths. Using cultural brokers to work with families from diverse cultures and creating partnerships with community-based, immigrant, and other organizations can maximize outreach and effectiveness.

- Bringing state agencies together to address issues strategically and share scarce resources is essential to increase access to and the availability of services for CYSHCN. Children's disabilities and health care needs have an impact on many other areas, such as mental health and education, and the needs of families of CYSHCN also span many areas, including housing, employment, and public benefits.

  No organizations or agencies have all the resources and expertise needed to address issues in all of these areas for families statewide. Collaboration is key, and working together has much more impact than working individually. Collaborative relationships with organizations and entities with similar goals can leverage resources, reduce duplication of efforts, and develop effective shared strategies for providing information on services and supports to families of CYSHCN.

- When beginning systems change activities, involving the people who are directly affected—particularly those with least access to services and supports, such as low-income ethnic minorities—is essential to identify what is and is not working and why; to determine how to address problems and barriers; and to develop, implement, and evaluate solutions. Involving stakeholders from the beginning and conducting outreach in communities are essential components of building a Family to Family Health Information Center.

- Although it is important to provide data to bring about changes in policies affecting CYSHCN, providing personal information about individuals who need services is also a very powerful and effective educational approach. For example, when advocating for an increase in waiver slots, FHIC staff produced a booklet that showed children who had been on the waiver waiting list for as long as 6 years, along with a short story about them.

Recommendations

Grantees made several recommendations for states to better meet the needs of CYSHCN and their families. Although their recommendations were aimed at their own states, they are relevant for other states as well.

Policy Issues

- The state should streamline the Medicaid and Children's Health Insurance Program eligibility process for all presumptively eligible categories of children. Streamlining the process and using other means to identify children in low-income categories (such as through the free and reduced school lunch programs) can help children access health services.

- A significant number of South Dakota's CYSHCN are uninsured and underinsured—higher than the national average. A Medicaid buy-in option would help working families who have private insurance but whose coverage does not meet their child's health needs. Enacting the Family Opportunity Act in South Dakota would help families whose income fluctuates or is slightly over the income guidelines for the State Children's Health Insurance Program and Medicaid, by establishing a sliding scale for eligibility.

- Medicaid policy focuses on the individual receiving the services, which leads to a lack of flexibility in meeting the needs of CYSHCN living with their families, particularly to support the health of family members and their ability to care for their child at home. Medicaid policy should allow families of children under 18 with significant disabilities to be reimbursed for providing personal care and other expenses incurred to care for their child.

- One state has converted most of its state programs serving CYSHCN to Medicaid waiver programs in order to secure federal matching funds. However, many individuals who need services are ineligible because they do not meet the waiver program's level-of-care criteria. To meet their needs, the state should increase service funding for non-Medicaid eligible individuals and should decrease the stringency of the waiver level-of-care criteria.

- To correct the continued institutional bias in Medicaid and state policies, home and community-based services should be mandatory—and waivers should be required for *institutional* services.

Services and Supports

- As Wisconsin continues to expand Aging and Disability Resource Centers, the disparity between resources dedicated to adults with disabilities and CYSHCN has become more apparent. The Department of Health and Family Services has made a commitment to end waiting lists for community-based services and supports for adults of all ages with disabilities, but no such commitment has been made to children and their families. The State needs a single point of entry coupled with high-quality information in the system that serves CYSHCN.

- The state should provide incentives to create a Durable Medical Equipment recycle program for children, as well as incentives to provide a cash-and-carry process for transitioning youth to become independent after completing Vocational Rehabilitation and transition programs. A cash-and-carry process would allow individuals to take services and equipment to their place of employment through an agreement between departments serving the transitioning population.

- The state and the federal government should increase access to and the availability of services through public programs for CYSHCN, and a comprehensive range of services should be available statewide.
- Parents are a critical partner in the "workforce" that supports CYSHCN yet often do not have access to the information they need to support their child/young adult's needs. Parents need access to high-quality training and information to be effective advocates, partners, and allies with the professionals with whom they work. This training, support, and leadership development needs to be an integral component of the infrastructure of state systems.

Section Two. Individual FTF Grant Summaries

Alaska

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Information Center (FHIC) to (1) serve as a statewide information clearinghouse for families of children and youth from birth to age 22 with special health care needs (CYSHCN); (2) create an interactive, statewide peer-to-peer network and support forum for families caring for CYSHCN; and (3) develop sustainable funding for the ongoing operation of the FHIC.

The grant was awarded to the Stone Soup Group, an Anchorage-based nonprofit organization that provides information and training for parents of CYSHCN. The Center for Human Development at the University of Alaska Anchorage and the Governor's Council on Disabilities and Special Education were subcontractors on the grant.

Results

- Grant staff developed training programs and workshops to provide parents with information on services available for CYSHCN and how to navigate the state and federal service systems. Throughout the grant period, 233 community trainings, workshops, and meetings were conducted with 3,858 participants.

- The Grantee created a statewide advisory group of parents and professionals to serve as a resource to families of CYSHCN. Members of this advisory group educate providers and other parents about the need for a family-centered perspective when caring for CYSHCN. The advisory group also developed a funding sustainability plan, which describes approaches for sustaining the FHIC beyond the grant period.

- The Grantee established a fully operational Family to Family Health Information Center and created a statewide information clearinghouse to provide printed and digital information on resources for families of CYSHCN. The FHIC now has an established base of parent volunteers who work directly with Alaskan families as a parent-to-parent network of support. During the grant period, program staff and volunteers directly or indirectly assisted 1,741 parents and 221 professionals. The information provided has empowered parents and caregivers to make more informed decisions regarding the most appropriate care and treatment for their child.

- The FHIC developed strong collaborations with many organizations and agencies concerned with children's health, including The Governor's Council on Disabilities and Special Education, The Children's Hospital at Providence Hospital, The Disability Law Center of Alaska, the University of Alaska Center for Human Development, Anchorage School District, the Alaska Autism Resource Center, the Alaska Youth and Family Network, and many others. These continuing partnerships will significantly benefit CYSHCN across Alaska. Stone Soup Group's website was updated to include additional collaborating agency links and resource information for CYSHCN. (See http://www.stonesoupgroup.org/index.cfm?section=Links&page=Overview.)

- As a result of collaboration in statewide advocacy efforts by grant staff, the State has increased the number of Medicaid waiver slots available for children, youth, and adults with developmental disabilities. The increase has reduced the number of individuals waiting for Medicaid services from about 1,400 to 900. The State plans to further reduce the number on the waiting list.

- The Stone Soup Group secured annual funding of $108,000 for 2 years from the Alaskan Mental Health Trust Authority to expand a peer-to-peer network targeting rural Alaskan communities.

Lessons Learned and Recommendations

- Stakeholders should use collaborative relationships to leverage resources and reduce duplication of efforts, and to develop effective shared strategies for providing information on available services and supports to families.

- The State has converted most state programs serving CYSHCN to Medicaid waiver programs in order to secure federal matching funds. Many individuals who need services are ineligible because they do not meet the required level-of-care criteria for waiver eligibility. To meet their needs, the State should increase service funding for non-Medicaid eligible individuals and also decrease the stringency of the waiver level-of-care criteria.

Products

Outreach Materials

- Grant staff produced a brochure entitled *Alaska Statewide Parent-to-Parent Support Network*, and the *Stone Soup Group Agency Brochure* to increase awareness of the FHIC among parents of CYSHCN.

- Grant staff developed *Soup of the Week*, a web-based newsletter offering information on current community and statewide trainings, programs, and ongoing policy updates. The newsletter is distributed to 1,592 subscribers.

Educational Materials

Grant staff created Disability Resource Packets on 22 individual topics, and developed an FHIC Resource lending library with 678 titles available in digital and print format.

Colorado

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center (FHIC) and establish a statewide network of parent professionals who will (1) improve access to information about health care systems and community resources, and help other parents to effectively navigate these systems and use these resources;
(2) disseminate new and current information to families of children and youth with special health care needs (CYSHCN), service providers, and advocates; and (3) evaluate access to, use of, and satisfaction with the quality of health systems information.

The grant was awarded to Family Voices Colorado, which is a chapter of the national, grassroots organization whose primary goal is to ensure that children's health is addressed when changes are made in public and private health care systems. Colorado's Health Care Program (HCP) for Children with Special Needs was a subcontractor on the grant.

Results

- Family Voices Colorado established a Family to Family Health Care Information and Education Center as a part of its operating structure. During the grant period, staff conducted outreach and provided information to more than 2,300 families of CYSHCN through a toll-free phone line and via e-mail, and distributed more than 6,000 pieces of informational materials. They also created a hotline for providers to call for information on resources for CYSHCN.

- The FHIC staff, in collaboration with Colorado's Health Care Program, trained 14 parent leaders in the State's 14 HCP regions to conduct trainings with about 1,200 providers, professionals, and families on issues affecting CYSHCN. They also provided support for other parents, and conducted Medical Home outreach by serving as a resource for providers regarding service and health coverage issues affecting CYSHCN. A process is now in place for outreach throughout Colorado, in particular, to Spanish-speaking populations, for whom materials and trainings have been translated.

- Trained parent leaders became members of several decision-making bodies that address the needs of CYSHCN to ensure that their views are heard and their children's needs addressed. One parent has been appointed to a State Health Reform Commission.

- A statewide FHIC-conducted needs assessment survey of CYSHCN provided information that has helped influence policy decisions affecting CYSHCN. For example, when the state tobacco tax was passed, FHIC staff provided information and education to the legislators about the need for more home and community-based services waiver slots for CYSHCN, which led to the addition of 630 slots.

Lessons Learned and Recommendations

- Although data are necessary for bringing about changes in policies that affect CYSHCN, providing personal information about individuals who need services can be a very powerful and effective approach. When advocating for an increase in waiver slots, FHIC staff produced a booklet that showed children with their waiver waiting list number—some had been on the list for 5 or 6 years—and a short story about them.
- Continued funding is needed for family-driven organizations to do grassroots information and advocacy work.
- Increased funding is needed to provide home and community-based services for ventilator-dependent children who are currently residing in hospitals at much greater cost.
- The State should provide incentives to create a Durable Medical Equipment recycle program for children, as well as incentives to provide a cash-and-carry process for transitioning youth to become independent after completing Vocational Rehabilitation and transition programs. A cash-and-carry process would allow individuals to take services and equipment to their place of employment through an agreement between departments serving the transitional population.
- The State should streamline the Medicaid and Children’s Health Insurance Program eligibility process for all presumptively eligible categories of children. Streamlining the process and using other means to identify children in low-income categories (such as through the free and reduced school lunch programs) can help children access health services.

Products

Outreach Materials

Grant staff developed and distributed outreach materials that contain information about the FHIC, including the services offered and a toll-free number.

Educational Materials

FHIC staff produced training DVDs covering a variety of topics, including self-determination, advocacy and leadership, building medical homes, and navigating health care systems. FHIC staff collaborated with several partners to develop brochures to answer frequently asked questions and other materials on topics such as Medicaid, EPSDT, managed care plans, and SSI. They also developed several forms to help parents and paid caregivers manage and coordinate care for CYSHCN, such as a *Medication Schedule Template*.

Reports

Grant staff prepared a paper based on a Dual Diagnosis Summit convened in January 2007. The document highlights the need for service delivery systems to coordinate services, funding, eligibility, and appeals processes to assist individuals who need services from more than one system simultaneously.

Indiana

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Education and Information Center with the goal of improving the ability of (1) no fewer than 100 families in two regions of the State to care for their children with special health care needs (CSHCN) in the community; and (2) at least 20 health care professionals to provide a medical home for at least 50 families of CSHCN.

The grant was awarded to About Special Kids (ASK), formerly the Indiana Parent Information Network, Inc. ASK implemented the Indiana Parent Education Project in 1990, thus laying the foundation for a statewide network of parents trained as Parent Liaisons to provide information, peer support, and training to other families.

Results

- The Advisory Council for the Family to Family Health Care Education and Information Center—comprising parents and several key professionals from various agencies, organizations, and state offices—provided a forum in which to address issues affecting CSHCN, such as the quality of Medicaid waiver case management, implementation of Medicaid managed care, and training of state education professionals about Medicaid waivers.

- Over the course of the project, grant staff provided families of CSHCN with information about Medicaid services, special education services, and other community resources for CSHCN. They conducted 21 Public Health Care Financing trainings with 165 attendees and provided ongoing support via in-person contact, telephone, and/or e-mail to 427 families of CSHCN, surpassing the goal of reaching 100 families.

  Staff also contacted 301 health care professionals who work with CSHCN to educate them about community resources, financing for services, and the medical home concept by using one-on-one conversations, mailed written materials, and the online resource directory.

- Grant staff developed and disseminated 426 packets of information to families and professionals and developed an e-newsletter, which is distributed to 1,841 recipients.

- The grant project led to greater name recognition and awareness of the services offered by ASK and the Family to Family Health Care Education and Information Center. For example, social workers and discharge planners from Kosairs Children's Hospital now frequently consult with an ASK Parent Liaison in that region before a child with special health care needs is discharged home, and include an ASK brochure in the discharge information packet.

- The Grantee developed a new website (http://www.aboutspecialkids.org), and the web-based resource directory of family supports was enhanced and updated.

- The Family to Family Health Care Education and Information Center is being sustained through a grant from the federal Maternal and Child Health Bureau. The grant has also enabled ASK to expand its services throughout the State by funding three part-time Parent Liaisons in three regions.

Lessons Learned and Recommendations

It is difficult to get families and professionals to attend in-person trainings on public funding for services for CSHCN (e.g., Medicaid waivers) despite their expressed interest in the topic and the availability of financial assistance to support attendance. This is likely due to professionals' very busy schedules and families' caregiving and work responsibilities. The use of technology and web-based activities for the provision of information, education, and training can reach families and professionals who cannot attend in-person meetings. Therefore, grant staff recommended that anyone interested in providing similar training opportunities develop a web-based curriculum.

Products

Educational Materials

The Family to Family Health Care Education and Information Center Advisory Committee developed a one-page information sheet for educators and school personnel who interact with students with significant disabilities and their families during annual special education case conference meetings. The information sheet provides information about the State's five Medicaid home and community-based services waivers, using a concise and easily understood format: why educators need to know about Medicaid waivers, who might qualify for services, where to apply, and why it is their responsibility to refer families. The Committee developed a statewide version and a regional version representing the regions served by Family to Family Health Care Education and Information Center staff. The information sheet is used by the entire ASK staff in all regions of the State.

Technical Materials

A comprehensive *Guide to Health Insurance* was developed to educate families of CSHCN about services available to their children through private insurance, Medicaid, Children's Special Health Care Services, and Social Security.

Maryland

Primary Purpose

The grant's primary purpose was to ensure that families of children with special health care needs (CSHCN)—including those from minority populations and those with mental and behavioral health disorders—have access to accurate, timely, and culturally appropriate information to enable them to make wise health care decisions.

The grant was awarded to The Parents' Place of Maryland (PPMD), a nonprofit family-centered organization, which was established in 1991 to enhance the ability of CSHCN to participate as fully as possible in home, school, and community life. It provides these families with education, information and referral, technical assistance, and support.

Results

- The Grantee established a Family to Family Heath Care Information and Education Center (FHIC) by expanding its mission and its staff's capacity to assist families with access to health care. Previously, PPMD had focused on providing support and training for families on their rights in special education. To better understand access issues related to health care plans and the public and private health care systems, staff conducted focus groups with parents throughout the State. They established a toll-free number for parents to obtain information on health care options, and eight parent educators employed by PPMD were trained to respond to requests for information and support on health care issues.

- FHIC staff assisted 2,902 families over the grant period through phone calls, e-mails, and in-person meetings. Issues, problems, or concerns that spurred family contact with FHIC staff included a need for information about public benefits, eligibility for services, funding for medical services, and access to appropriate services and nonmedical services. Staff advised families, made referrals, or helped them with the referral process, and attended meetings with parents and agencies or providers.

  The Grantee conducted a survey in which about 96 percent of parents reported that the information and assistance they received from FHIC staff made them more knowledgeable about how to work with providers; and about 84 percent of parents reported that their child received more appropriate services.

- In response to data collected during the first year of the project, staff focused on increasing supports to ethnically diverse populations in Maryland, assisting significantly more minority families each year (in the first year of the grant, 25 percent more than in previous years, and 43 percent more in the grant's final year). In addition to broadening outreach to diverse communities, the project also focused on reaching out to families with children who had a range of disabilities and special health care needs.

- Project staff conducted outreach to pediatricians, hospitals, and clinics; provided information to community-based family resource centers, school-based health clinics, homeless shelters, and Head Start programs; and provided training to many agencies and state or community-based organizations in order to increase their skills in effectively assisting families of CSHCN. More than 7,850 contacts with providers were documented during the grant period.

- Project staff developed and conducted an annual Health Leaders training program each year of the grant for 80 parents and family members of CSHCN. The curriculum included information on private health plans and public health programs, enrollment processes, appeals processes, and how to utilize benefits. Graduates of this training program are participating on the Medicaid Advisory Board, several state-level committees, and several community-based policy-making committees. Others have been hired as "Family Navigators" to help families navigate the mental health service system.

- Project staff developed 10 workshops (6 in Spanish) and conducted 160 workshops with more than 3,000 families and providers across the State. They also worked with a web designer to update the PPMD website, published an Email Newsletter that is disseminated to more than 1,500 subscribers monthly, and developed various health fact sheets, brochures, and resource guides for each region of the State.

- Grant activities around the "medical home" model included the creation of a Maryland State Plan for Medical Home Implementation, co-sponsorship of a statewide medical home work group looking at issues in Maryland, creating more opportunities for parental input at the system level, and production of the *Extreme Medical Home Makeover* training series for pediatric practices.

- As a result of the enhanced partnerships with state agencies, providers, and other advocacy groups developed through the grant project, PPMD is taking the lead on creating a broad statewide Children and Youth with Special Health Care Needs Consortium. The Grantee is continuing and expanding activities begun under this grant as part of another 3-year Family to Family grant funded by the Maternal and Child Health Bureau.

Lessons Learned and Recommendations

- Involving stakeholders from the beginning and conducting outreach in communities are essential components for building a family-to-family health care information and education center. Funds and other resources are also required.

- Because of the complexity of the health care system for children with disabilities and of insurance coverage issues in general, family educators required extensive training and mentoring in order to gain the expertise needed to support other families. Active mentoring is essential for parents conducting outreach with unfamiliar communities.

- The State and the federal government should increase access to and the availability of services through public programs for CSHCN, and a comprehensive range of services should be available statewide.

- Medicaid needs to be expanded to cover children with disabilities whose family incomes are above the Federal Poverty Level. States should fully implement the portions of the Family Opportunity Act that permit families of children with disabilities to buy in to Medicaid.

Products

- PPMD staff developed a video describing FHIC services, which can be played in the waiting room of clinics and at health fairs, conferences, and trainings. They also introduced health care topics into several special education workshops in order to expand outreach, especially to minority communities (using school partners as translators).

- PPMD staff worked with the Department of Health and Mental Hygiene (DHMH) to create a series of brochures on public insurance programs, which are being distributed to parents and partner organizations. The series is also available on the DHMH website.

- PPMD staff worked with Maryland's Medicaid agency to develop a series of brochures for parents explaining Medicaid services.

- Project staff created the workshop *Show Me the Money,* to assist families in finding ways to finance care for children, and an interactive workshop called *Managing the Maze*, to teach families how to organize medical records for CYSHCN to improve quality of care. Other workshops developed through the grant include the following:

  - *Finding Community Resources*, which addresses the specific needs of the participants and matches those needs to local resources.

  - *Choosing a Health Care Plan*, which offers practical step-by-step information to help families of children with disabilities and special health care needs sort through their health care plan options.

  - *Getting Needed Services from Your Managed Care Plan*, which explains how managed care health plans work, and takes participants through the steps of referrals, authorizations, and other service barriers.

  - *Appealing Insurance Denials* covers the appeal process available to families and teaches strategies that can make appeals successful.

All materials and resources, which are an integral part of PPMD outreach and information dissemination to both parents and providers, will be made available on the website (http://www.ppmd.org/index.asp). Workshops are presented throughout the State and are provided free of charge to parents of children with disabilities. Fees for professionals vary by workshop.

Montana

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center to (1) increase the capacity of the Parent Training and Information Center's existing infrastructure in order to provide health care information and education to parents of children with special health care needs (CSHCN) that will enable the children to live in the most integrated setting with appropriate supports, (2) increase collaboration among public and private entities to ensure that families with CSHCN receive accurate and timely information from their peers, (3) strengthen statewide support of CSHCN by increasing the presence of family advocates within the health care system, and (4) facilitate the sustainability of family-to-family activities by providing a means for ongoing education and support for families with CSHCN.

The grant was awarded to Parents, Let's Unite for Kids (PLUK), the State's Parent Training and Information Center, which parents of CSHCN in Montana formed in 1984 to provide information, support, training, and assistance to ensure that their children have access to high-quality educational, medical, and rehabilitation services. PLUK uses a statewide team of well-trained volunteers who provide support and skill building for positive interactions with the education system (http://www.pluk.org).

Results

- The grant enabled PLUK to become a Family to Family Health Care Information and Education Center by expanding its services to include providing information and assistance related to health care issues for families of CSHCN. All of PLUK's staff and parent training and publications now include information about health care for CSHCN.

- In the final year of the grant, staff and volunteers handled nearly 10,000 direct contacts with families, professionals, and individuals and provided individual assistance to more than 2,000 families. They also developed a CD library of materials to cost-effectively provide a large amount of information to families.

- PLUK developed and implemented an outreach plan to provide training and to disseminate information throughout the State, including its most remote regions and Indian Reservations. Outreach activities helped to increase awareness about the services available to families of CSHCN and how to obtain them; outreach has been among the most successful activities begun by the project and will be continued and expanded.

- PLUK staff and/or peer trainers trained volunteer parents throughout the State to be CSHCN advisors. The trainings were provided in-person locally and on a statewide basis through videoconferencing and Internet streaming. Training announcements are made in the bimonthly newsletter and by mail and e-mail.

- The grant facilitated the development of a statewide, self-sustaining peer network project using the associate board concept. Seventeen associate boards—including Native

American—with advisory board functions were established and moved beyond their initial peer support role to look at additional needs in their communities.

- PLUK established a contractual relationship with Montana's Children's Special Health Services. Initial collaborative activities have been minor—developing publications for parents—but they are the first steps in an ongoing relationship that will increase the ability of the Family to Family Health Care Information and Education Center to provide information and referral services to families.

Lessons Learned and Recommendations

- Children's disabilities and health care needs do not occur in a vacuum. They affect many other areas, such as mental health and education, and the needs of families of CSHCN also span many areas, including housing, employment, and public benefits. Although resources to meet these children's and families' needs are inadequate, the real challenge to increasing access to and the availability of services for CSHCN is bringing state agencies together to address issues strategically and share resources. No organizations or agencies have all the resources and expertise needed to address issues in all of these areas for families statewide. Collaboration is key to success, and working together has much more impact than working individually.

- The peer network of associate boards is perhaps the most powerful tool for giving communities a voice and for leveraging the network to address issues strategically.

Products

- PLUK STAFF developed a *Health Care Resources Handbook* and *Health Care Transition Handbook* in collaboration with Montana's Children's Special Health Services for use by PLUK's Family Support Consultants who provide individual assistance to families. The Handbooks are in the final stages of preparation and will be printed soon.

- PLUK staff also contributed to the development of *Montana Parent's Handbook on Transition: Adult Living* to answer questions that parents frequently ask about the transition process from childhood to adulthood.

Nevada

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center (FHIC) to (1) increase the understanding and use of appropriate health care resources for children and youth with special health care needs (CYSHCN), and (2) promote family-centered and self-directed health care services and supports.

The grant was awarded to Family TIES of Nevada, Inc., a consumer-run organization whose mission is to provide training, information, emotional support, and advocacy to increase the hope, confidence, and independence of people of all ages with disabilities or chronic health conditions. Family TIES is an affiliate of Family Voices, a national organization that speaks on behalf of CYSHCN and is the designated state Parent to Parent organization.

Results

- The Grantee expanded its mission by establishing a Family to Family Health Care Information and Education Center, which is run by its staff and volunteers.

- Grant staff established a Family TIES website and an online Resource Directory, which is a searchable database of resources and services for people with disabilities (available at http://www.familytiesnv.org). The Resource Directory will be continually updated. Grant staff also developed training materials specific to the needs of families of CYSHCN.

- With additional funding from a Champions for Progress Incentive Award, grant staff created a training curriculum and hosted a 1-day workshop (Nevada Youth Health Care Transition Training) to educate youth, family members, and medical professionals about transitioning youth with special health care needs from pediatric to adult services. The workshop was adapted to be available on the Family TIES website, and other online training options will be added.

- Grant staff developed a series of conference calls to help educate families and providers. Topics included state health care financing for CYSHCN, Medicaid services, advocating for private insurance coverage, Part C early intervention regulations, and caring for caregivers. The last topic was recorded and uploaded on the website. The 1-hour call-in format is a successful method for providing information, and Family TIES plans to continue offering the calls and to expand the topics covered.

- Grant staff developed another workshop (How to Toot Your Own Horn) to help similar organizations serving families of CYSHCN to identify practical strategies to promote their organization and services through the media. The training was presented originally at the Family Voices National Conference in Washington, DC, in 2006 and was revised for a 2007 family leadership workshop in Honolulu, Hawaii.

  Elements of the training have been and will continue to be used in the Nevada Partners in Policymaking training. Grant staff also developed a training module and corresponding study guide, entitled Building Connections Between Families, Schools and Communities, to help families of CYSHCN learn how to create a supportive community for themselves and their children. This training is available on DVD.

- To address the needs of the State's growing Hispanic population, grant staff assisted with the ongoing operations of Hidden Miracles, a support group in Las Vegas for Hispanic families who have CYSHCN. They translated Family TIES' newsletters and handouts into Spanish, offered a number of the conference calls in Spanish, disseminated existing materials and information in Spanish, and referred Hispanic families to community resources.

- The Grantee received additional funding for the FHIC through the Human Resources Services Agency, which will enable a more comprehensive evaluation of the FHIC to be undertaken.

Lessons Learned and Recommendations

- A significant number of the State's CYSHCN are uninsured and underinsured—higher than the national average. A Medicaid buy-in option would help working families who have private insurance but whose coverage does not meet their child's health care needs. (The legislature failed to enact a Medicaid buy-in option in the last session.)

- Partnering with the other Systems Change Grantees in Nevada was very beneficial. By working together, each project was strengthened. Additionally, Grantees forged new partnerships with state agencies that have a shared interest in CYSHCN, which prevented a duplication of systems change efforts.

Products

Outreach Materials

Grant staff produced an organizational brochure and developed a website to promote Family TIES and the Family to Family Health Care Information and Education Center. They also produced a newsletter and a flyer promoting the online Resource Directory. Issues of the newsletter are archived on the website to be used as handouts.

Educational Materials

Grant staff developed several courses for professionals and families of CYSHCN, some of which are now available on the Family TIES website. They also developed an online Resource Directory that contains information about resources and training opportunities available to families of CYSHCN.

New Jersey

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Information and Resource Center (FHIC), whose objective is to provide the information and support that families of children and youth with special health care needs (CYSHCN) must have to partner effectively in decision making to ensure the availability of appropriate community-based systems of services.

The grant was awarded to the Statewide Parent Advocacy Network, Inc. (SPAN), a family education and advocacy agency in New Jersey. SPAN's foremost commitment is to children and families with the greatest need due to disability; poverty; discrimination based on race, sex, language, immigrant, or homeless status; involvement in the foster care, child welfare, or juvenile justice systems; geographic location; or other special circumstances.

Results

- SPAN established a Family to Family Health Information and Resource Center, which allowed its staff and volunteer Resource Parents to develop partnerships with hospitals, clinics, mental health facilities, family support organizations, immigrant networks, and other organizations, thereby facilitating the dissemination of information and support for families statewide.

- Project staff and volunteers facilitated 24 focus groups with families of CYSHCN, as well as with youth and professionals, to gather information to determine best approaches to reach diverse families of CYSHCN, and to shape project activities and bring about systems change. For example, feedback about service quality and gaps in services was shared with the New Jersey Departments of Children and Families, Health, and Human Services, and these agencies are using the information to improve quality and fill gaps.

- During the grant period, staff and volunteers provided information and technical assistance via phone and e-mail to 102,700 families and professionals, as well as in person to more than 4,200 families. An additional 144,095 families and professionals obtained information from the Family to Family section of SPAN's website, including 29,390 who accessed the website's Spanish language section.

- Project staff built families' leadership capacity by facilitating a number of parent leadership trainings and developing a Statewide Family Council (15 of the 20 parents are African-American or Latino) to advise the Commissioner of the Department of Children and Families on family support, child welfare, and child behavioral health services. Staff also helped to develop a Kids as Self-Advocates chapter, which brings the views of youth with special health care needs into the policy-making processes that affect their lives.

- About 400 parent volunteers participated in trainings in how to provide emotional support and/or information to other parents and families of CYSHCN.

- During a full-day workshop, project staff trained 340 medical students who were in their third-year pediatric rotation at the State's medical school; each medical student also spent an evening with a family of a child with special health care needs. The training focused on the importance of providing coordinated, ongoing, comprehensive care within a "medical home" and on strategies to effectively serve CYSHCN.

- The Family to Family Health Information and Resource Center is fully operational, and families have access to support through the FHIC main office and 15 satellite offices. The offices are located in hospitals, mental health agencies, community-based organizations, Special Child Health Services (Title V) Case Management Units, and other sites, which are staffed by employees and/or trained volunteers in different regions of the State. Since the grant ended, the FHIC is funded through a grant from the Federal Maternal Child Health Bureau and the New Jersey Department of Health and Senior Services' Title V Program.

- Project staff gathered information from families to share with the legislature, which helped bring about key legislative changes: (1) significant increases in funding for family support and health services; (2) a new State Children's Health Insurance Program (SCHIP) buy-in, even for families with incomes above 350 percent of the federal poverty level (FPL); (3) wraparound prescription coverage for children dually eligible for Medicaid and Medicare; (4) eliminating proposed Medicaid copays; (5) increasing Medicaid's specialty care reimbursement rates; (6) increasing funding for early intervention; (7) maintaining early intervention services at no cost to families at up to 350 percent of the FPL; (8) requiring cultural competence training for health care professionals; and (9) requiring the State to apply for Medicaid waivers for children's services.

Lessons Learned and Recommendations

- Prioritizing the development of leadership skills for parents and families of CYSHCN is a key strategy in bringing about systems change. Training develops parent leadership, first to advocate for their own child, then to support and advocate for other children and families, and then to participate in systems change activities.

- When beginning systems change activities, involving people who are directly affected—particularly those with least access to services and supports (e.g., people of color, low-income, non-English speaking)—it is essential to identify what is and is not working and why; to determine how to address problems and barriers; and to develop, implement, and evaluate improvements.

- Using focus groups is an effective strategy to identify the needs and strengths of families from diverse backgrounds, and to develop supports and services to address those needs and build on those strengths. Also, using cultural brokers to work with families from diverse cultures and creating partnerships with community-based, immigrant, and other organizations can maximize reach and effectiveness.

- To correct the continued institutional bias in Medicaid and state policies, the provision of home and community-based services should be mandatory, and waivers should be required for institutional services.

Products

Outreach Materials

Grant staff developed outreach materials targeted to families of CYSHCN in English, Spanish, Chinese, and Haitian-Creole. Additional outreach materials were developed in collaboration with the State's Early Hearing Detection project for families of children with deafness/hearing loss. They also developed population-specific outreach materials for Latino organizations to help them identify, refer, and support families of CYSHCN.

Educational Materials

- Project staff and volunteers developed multiple materials for families of CYSHCN and professionals, including an interactive *Transition to Adult Life* CD-ROM of resources for youth; transition resources for health practitioners; a CD-ROM of resources on including young children with special health care needs in early childhood programs; an information packet in English and Spanish of resources for families of children who are deaf or hard of hearing, and for professionals who provide services to this population (a brochure, parent information packet, and CD); and a Medicaid managed care fact sheet series.

- Project staff also developed various training curricula for early intervention providers, service coordinators, and families; curricula for early intervention parent leadership development and for Statewide Family Council leadership development; curricula on family involvement in systems change; intensive health advocacy curriculum; an online training course for Child Care Resource and Referral agencies to inform them of the rights of young CSHCN and their families, and about resources to support and strategies to work more effectively with those families; and a workshop on the child behavioral health system and services in New Jersey.

Technical Materials

- Grant staff developed a guide for school districts to help them secure additional funds to educate students with significant needs in their communities and in more inclusive settings.

- Grant staff worked with the chair of the state Senate Health Committee to develop a user-friendly one-page application for SCHIP.

Reports

Grant staff developed a report based on the focus group findings on barriers to health care access for CYSHCN and also on family support needs. The findings were shared with the state Departments of Health, Human Services, and Children and Families, as well as with the Association for Children of New Jersey, the New Jersey Council on Developmental

Disabilities, the New Jersey Immigration Policy Network, the Governor's office, and numerous legislators. The report can be obtained by e-mailing Diana.autin@spannj.org.

South Dakota

Primary Purpose

The grant's primary purpose was to expand the capabilities of the State's Parent Training and Information Center by creating a Family to Family Health Care Information and Education Center (FHIC) that will (1) provide information, referrals, and education about health care and home and community-based services statewide to those caring for children with special health care needs (CSHCN); (2) connect those caring for CSHCN with local training opportunities, information, services, advocacy, and other parents of CSHCN; (3) provide culturally competent training and information for the Native American and Spanish-speaking families of CSHCN; and (4) collaborate with existing FHICs to promote the philosophy of individualized, family-directed support.

The grant was awarded to South Dakota Parent Connection, Inc. (SDPC), which is the State's only Parent Training and Information Center.

Results

- The Grantee established the Family to Family Health Care Information and Education Center, which will operate within SDPC. The FHIC staff established partnerships and working relationships with health care providers, the two major hospital systems in South Dakota, and state agencies. The establishment of the FHIC expanded SDPC's focus to include the provision of information, training, and other resources in the area of health care for CHSCN. SDPC staff provided information and assistance to families in the following areas: Medical Home information (2,438 requests), Mental Health (879 requests), Respite Care (424 requests), Transition (556 requests), and referrals to community resources (3,543 requests).

- Grant staff developed training materials for families and professionals and presented 275 workshops attended by 2,390 parents and 3,372 professionals, approximately 11 percent of whom were minorities. They also promoted training and disseminated information through newsletters and websites. When families needed to travel out of state for health or medical services, grant staff were able to link them with families in those states to provide support and help them connect with services.

- Grant staff provided training for social workers who work with families caring for CSHCN on the following topics: Navigating the Health Care Maze, Patients'/Parents' Bill of Rights, Health Care Resources in South Dakota, and Child Abuse and Reporting.

- SDPC staff, in collaboration with other agencies, developed a Folder of Information and Life Experiences (FILE), a record-keeping system for families of children with disabilities and CSHCN, and mailed or distributed 500 copies to assist families in maintaining their children's educational and medical records.

- Grant staff developed a database of more than 400 parents and families of CSHCN who are interested in working with other families, and conducted training using several formats, including small group settings, one-on-one, and self-learning using a CD either in the SDPC office or at home. All training materials and information resources developed by the Grantee are available to families and professionals in electronic format on the SDPC website (http://www.sdparent.org/), which contains an FHIC web page.

- SDPC-FHIC staff developed Parent Tips and Fact Sheets on several topics, including *Grandparenting*, *Working with Doctors*, *Autism, Fatherhood, Attention Deficit Disorder/Hyperactive Disorder*, *Stress Reduction*, and *Mental Health.* They also developed a *Health Care Resource Guide* that will be distributed through clinics and community health centers and on the SDPC website.

Lessons Learned and Recommendations

- Because families caring for CSHCN have limited time, it is important to provide opportunities for education and training at convenient times and places. Using technology and web-based activities makes it possible to reach families who cannot attend in-person meetings.

- Enacting the Family Opportunity Act in South Dakota would help families whose income fluctuates or is slightly above the income guidelines for SCHIP and Medicaid eligibility, by establishing a sliding scale.

Products

Outreach Materials

Grant staff produced a brochure with basic information on services and supports for families of CSHCN and professionals who work with families, which is available on the SDPC website.

Educational Materials

Grant staff developed workshop curricula for SDPC staff and volunteer Parent Trainers to work with families and health care professionals. The curricula included the following topics: Navigating the Health Care Maze, Patients'/Parents' Bill of Rights, Health Care Resources in South Dakota, and Child Abuse and Reporting. The workshop handouts are available in English and Spanish, and interpreters are available for Hispanic families.

Technical Materials

SDPC staff served on the revisions and reprint committee for the Folder of Information and Life Experiences, a family record-keeping system. Their participation ensured that health care information relevant for families of CSHCN was included in the FILE. The system has 10 folders to help families sort and find papers related to the following: Family Records, Developmental History, Medical, Therapies, Individual Family Service Plan/Individual Education Plan, Letters/Contact Info, Evaluations/Consents, Respite Care/Child Care, Transition, and Legal & Life Planning.

Wisconsin

Primary Purpose

The grant's primary purpose was to develop a training curriculum and sustainable methods for delivering it so that parents of children with disabilities and special health care needs (CDSHCN), including those in under-represented segments of the community, can be knowledgeable and effective navigators of their child's system of care. Other grant objectives were to increase coordination among existing, state-funded information and assistance activities, to increase the availability of health and community resources for CDSHCN, and to support parent involvement to shape these resources and develop the infrastructure for a sustainable Family to Family Health Care Information and Education Center (FHIC).

The grant was awarded to Family Voices of Wisconsin (hereafter, Family Voices), a nonprofit organization that is part of the national Family Voices network, which promotes a system of comprehensive health and community supports based on fundamental principles that ensure the health and well-being of CDSHCN and their families. The role of Family Voices is to advocate for the inclusion of these principles in the design, implementation, and delivery of services and supports throughout Wisconsin (see http://www.wfv.org/fv/aboutfvwi.html).

Results

- Family Voices convened a statewide planning group over a period of 18 months to explore how Information, Assistance and Advocacy (IA&A) services could be provided most effectively to people with disabilities. The group inventoried the State's current capacity to serve individuals, its database technology, and options for sharing databases. The inventory was formatted into an easily understandable brochure and was also formatted for easy navigation on the Family Voices website.

- The Grantee developed a logic model, a mission statement, and guiding principles to inform the organizational structure of the FHIC, which is administered by Family Voices. The FHIC now has two co-directors and a training and outreach coordinator and has developed a brochure, listserv, newsletter, and website. Parent trainers are paid as consultants based on the number of trainings they are able to provide ($250 per session). Each trainer is expected to provide the training at least twice annually in his or her region of the State.

  Additional funding for the FHIC has been secured through a grant from the federal Maternal and Child Health Bureau and through a contractual arrangement with the Title V program to build and support a statewide network of parents who can present their views on policy, quality improvement, and program development. This contract will complement the activities of the CMS grant and sustain the parent training network beginning in 2009. Family Voices is also meeting with several counties and the United Way to discuss future work together, and continues to seek opportunities and funding to broaden its base and to provide greater organizational stability.

- To increase the availability of information to families to help them obtain health and community-based services and supports for CDSHCN, grant staff devised two strategies: a five-part (10-hour) face-to-face training and an e-mail listserv. The training modules provide information on the following topics: Parents and Partners on a Journey, Public Support Systems, Private Insurance and Your Doctor, Medicaid, and Advocating for Change. Extensive materials were compiled or developed for each module to support the presentations. Training is presented in single- or multi-session formats depending on the audience and collaborating partners. Although the training has been designed for families, county agencies increasingly are requesting portions of it for their staff involved with early intervention, social work, and children's long-term support.

  Parents from across the State were recruited to participate in a train-the-trainers program, resulting in a statewide network of 25 parent trainers who are supported to provide the face-to-face training to families and providers. The parent training network meets bimonthly via conference call and annually for a 2-day event. The conference calls provide additional content information on elements of the training and the annual meeting enables the parent trainers to refresh their skills, to acquire more information, and to network with other parent trainers. Individual calls are also used to provide one-to-one support to trainers on a personal level.

  Grant staff paid particular attention to the recruitment of minority parents, and unique versions of the curriculum were developed for Native American families in collaboration with the Great Lakes Intertribal Council, for African American families in collaboration with FACETS, and for Latino families in collaboration with Family Support 360. The curriculum was also translated into Spanish. As of July 2008, more than 500 parents and providers had participated in training offered in 38 locations around the State. An evaluation of the trainings demonstrated very high participant satisfaction.

- Family Voices staff participated in Department of Health and Family Services work groups that developed recommendations for (1) policy changes in the Family Support Program "First Come First Serve" to require all counties to develop policies to serve urgent or crisis situations and allocate funding accordingly; and (2) the allocation of new funding to address waiting lists, urgent needs, and youth in transition; and drafted an easily understandable document explaining the shift from identifying services to outcomes-based planning with families.

- In collaboration with the Survival Coalition of Wisconsin, Family Voices developed a series of proposals for the FY 2007–FY 2009 biennial state budget that included funding to address waiting lists, an investment in an infrastructure to provide IA&A services for CDSHCN, and funding to pilot principles of managed care for CDSHCN. (Materials outlining these proposals can be found at http://www.wfv.org/fv/statebudget.html.) This effort resulted in the inclusion of $4.7 million to address waiting lists for Children's Long-Term Supports in Year 1 and $4.8 million in Year 2, which was the first significant increase in funding for children's long-term supports in 12 years.

Lessons Learned and Recommendations

- Parents are a critical partner in the "workforce" that supports CDSHCN yet often do not have access to the high-quality training and information they need to support their child/young adult's needs and to be effective advocates and allies with the professionals they work with. This training, support, and leadership development must be an integral component of the infrastructure of state systems.

- The development of a dedicated and well-informed parent trainer network requires a significant level of support and nurturing.

- Overall, the parent trainers expressed a high degree of preference for face-to-face trainings. They found the bimonthly conference calls less effective because of the frequency of the calls and personal scheduling issues. Many of the parent trainers stressed that a limited number of conference calls each year—two to four times—would be useful for planning events or to provide critical updates on programmatic or other issues.

- The Department of Health and Family Services has made a commitment to end waiting lists for community-based services and supports for adults of all ages with disabilities, but no such commitment has been made to children and their families. As Wisconsin continues to expand Aging and Disability Resource Centers, the disparity between resources dedicated to adults with disabilities and CDSHCN becomes more apparent. The need for a single point of entry coupled with high-quality information remains an essential but unrealized element of the children's system. Family Voices will attempt to engage government, advocacy, and family partners to again make the case for a well-funded initiative in this area.

- Medicaid policy focuses on the individual receiving services, which leads to a lack of flexibility in meeting the needs of CDSHCN living with their families, particularly to support the health of family members and their ability to care for their child at home. Medicaid policy should allow families with children under 18 with significant disabilities to be reimbursed for personal care and other expenses specific to caring for their child.

Products

Outreach and Educational Materials

- The Grantee, in collaboration with Disability Rights Wisconsin, the Waisman Center, and the Wisconsin CDSHCN network, produced the booklet *Information, Assistance & Advocacy Resources for People with Disabilities in Wisconsin*, which is an inventory of IA&A agencies with a statewide or multiregional presence whose primary missions are to provide information, assistance, and/or advocacy to CDSHCN and their families and to adults with disabilities. The booklet was produced in print and electronic media, and is also available at http://www.wfv.org/fv/ir/.

- Family Voices developed a five-module curriculum for parents in English and Spanish: Did You Know? Now You Know! The modules provide a comprehensive, fundamental overview of health care access, coverage, and community supports for CDSHCN from birth through young adulthood. The training can be offered in a variety of time formats (e.g., two half-day sessions or five 2-hour evening sessions), and Family Voices can customize the training to meet local needs.

- Additional resources developed for the Family Voices website cover information on policy issues and on communicating with your legislator, on accessing and using Medicaid and private insurance (http://www.wfv.org/fv/docs.html), and include a listing of statewide resources by topic (http://www.wfv.org/fv/topic.html).

Reports

Grant staff produced a report for Wisconsin's Title V program—*Strategies to Increase Minority Parent Participation in Decision Making Roles on Behalf of CDSHCN*—to assist in engaging minority families.

Part 6

Feasibility Study and Development Grants

Exhibits

Overview of Respite for Adults and Children Grants

Whether caring for a minor child or an aging parent, caring for a family member with a disability or long-term illness can be highly stressful and time consuming. In addition to the physical and emotional stress of providing care—sometimes 24 hours a day, 7 days a week—caregivers can experience financial difficulties due to loss of employment as well as marital and family difficulties. Because respite care can significantly reduce caregiver stress, it is the service most often requested by family caregivers to enable them to continue caring for a family member with a disability or long-term illness at home to prevent or delay an out-of-home placement.

Currently, respite services can be covered by Medicaid only when provided under HCBS waiver programs, many of which have waiting lists. In FY 2003, CMS funded two types of Respite grants through the Systems Change Grants Program: Respite for Adults and Respite for Children. Respite for Adults grants were awarded to four states as listed in Exhibit 6-1.

Exhibit 6-1. FY 2003 RFA Grantees

California	Ohio
New York	Rhode Island

Respite for Children grants were awarded to six states as listed in Exhibit 6-2.

Exhibit 6-2. FY 2003 RFC Grantees

Alabama	Michigan
Arkansas	Oregon
Maryland	Rhode Island

The purpose of the Respite grants was to enable states to conduct studies to assess the feasibility of developing respite services for caregivers of a specific target group—such as elderly persons or children with developmental disabilities—through a Medicaid program or using other funding sources. In addition to conducting feasibility studies, Grantees were permitted to develop projects that could lead to a future Medicaid respite program.

The remainder of this section provides brief summaries for each of the Respite Grantees, focused on the results of their study, their lessons learned, and their recommendations.

Individual Respite for Adults Grant Summaries

California

Primary Purpose

The grant's primary purpose was to (1) develop recommendations for approaches the State can use to implement and evaluate a new respite benefit under Medi-Cal (the state Medicaid program) for informal caregivers of individuals with adult-onset cognitive impairment; and (2) to develop and disseminate a policy framework for ensuring that family caregivers are involved in the development of policies that affect them so that their needs will be recognized and addressed.

The grant was awarded to the California Department of Mental Health, which subcontracted with the Family Caregiver Alliance to implement the grant. (Contractor staff are called grant staff.)

Results

The feasibility study, entitled The California Study on a New Respite Benefit for Caregivers of Adults with Cognitive Impairment, included a review of national Medicaid data on respite programs; a comprehensive analysis of California's Medicaid-funded respite programs; and a literature review and interviews with experts on ethics, policy, and caregiving. This study informed the development of recommendations for expanding respite services throughout the State.

Although the feasibility study included 15 recommendations, the 4 key policy recommendations that could be applicable in many states are the following:

- Amend the State's HCBS waivers to include respite services.
- Improve information and data collection systems to enable them to collect the data needed to conduct a risk assessment of caregivers of persons with adult onset, cognitive impairments. The Health and Human Services Agency should require all appropriate state departments to commit to using a uniform, systematic data collection method when they are updating strategic or other internal plans.
- Cover respite service, and conduct a risk assessment of family caregivers in all nursing home diversion projects.
- Urge CMS to review Medicaid regulations to determine whether it is possible to increase states' flexibility to support caregivers of Medicaid participants.

Grant staff also developed a public policy framework to support family caregivers. They convened a small group of technical experts to discuss ethics and public policy related to family caregiving, and developed a policy framework for dissemination to policy makers, relevant state departments and advisory committees, advocates, and family caregivers.

Lessons Learned and Recommendations

- Family caregivers must be included as key stakeholders in all long-term services and supports policy and planning discussions at the state level.

- More uniform protocols for operating respite programs should be adopted, addressing service definitions, data collection, eligibility, and triggers for receiving service. Currently, they vary across Medicaid waiver programs.

Products

The Family Caregiver Alliance produced a final grant project report, *The California Study on a New Respite Benefit for Caregivers of Adults with Cognitive Impairment*, which includes 15 recommendations for specific changes to state policies.

In addition, the Department of Mental Health produced *A Policy Framework to Support California's Family Caregivers*, which contains a set of principles and values to guide public policy development and implementation. Both reports will serve as a starting point for discussions about increasing support for family caregivers, in particular, increasing the availability of respite service. The reports can be obtained from the California Department of Mental Health, 1600 9th Street, Room 151, Sacramento CA 95814; (916) 654-3890; e-mail: dmh.dmh@dmh.ca.gov; website: http://www.dmh.cahwnet.gov/.

New York

Primary Purpose

The grant's primary purpose was to determine the feasibility of developing and implementing a model of respite care for caregivers of adults that supports both Medicaid eligible and non-Medicaid eligible individuals' ability to remain in the community by lessening the emotional and physical hardships of their caregivers.

The grant was awarded to the New York State Department of Health, which subcontracted with Navigant Consulting, Inc., to conduct the grant's research activities. (This summary refers to Department and contractor staff as grant staff.)

Results

Grant staff conducted a comprehensive feasibility study to identify potential service delivery models for respite for adults. The study included review and analyses of current state policies, respite models in other states (including direct payment/voucher models), state statutes and regulations, and other relevant materials. They also facilitated five regional town hall meetings across the State for consumers, caregivers, providers, and government entities involved in providing long-term services and supports to obtain input on their concerns about respite care and the need for respite care across New York State. Grant staff also prepared a survey of consumers and caregivers to gather information regarding their needs, and 245 surveys were completed and returned.

The final report recommended several self-directed respite service models, including an individual budget option, that warrant further evaluation. Department staff will assess operational policy considerations specific to New York that would need to be taken into account in developing and implementing any future respite initiatives.

Lessons Learned and Recommendations

Any discussion of new initiatives in long-term services and supports requires input from the broadest possible range of stakeholders to ensure a balance of opinions, preferences, and recommendations. Rather than seeking stakeholder input on a general topic, presenting a specific model or multiple models to stakeholders for their consideration will help to obtain more targeted and constructive input.

Products

Navigant Consulting, Inc., prepared a report that analyzes the current availability of respite care for caregivers of adults in New York and discusses respite care models to meet anticipated caregiver needs. The report also contains recommendations for the State regarding new respite programs. The State will use the information presented in this report to inform efforts to balance the State's long-term services and supports system.

Ohio

Primary Purpose

The grant's primary purpose was to determine the feasibility of restructuring the State's Medicaid waiver program for seniors—Pre-Admission Screening System Providing Options and Resources Today (PASSPORT)—to provide respite services for caregivers. The grant was awarded to the Ohio Department of Aging and was subcontracted to SCRIPPS Gerontology Center of Miami University for implementation. (Contractor staff will be referred to as grant staff.)

Results

The feasibility study found that although the PASSPORT waiver does not include a specific respite service, case managers have a respite strategy that they use when establishing service plans (i.e., they take into account how much informal support participants are receiving and increase services accordingly based on the informal caregiver's unavailability for specific periods). For example, if a caregiver is unavailable for a week or more, the participant could use adult day services during this period.

Because the majority of PASSPORT participants have at least one active caregiver and the average cost of serving a waiver participant is less than that of a nursing home, the study concluded that any additional investment in the respite strategy would save the State money, and proposed a plan to ensure the provision of respite in the program. The study report recommended several approaches, including (1) continuing the current "de facto" strategy but ensuring that it is used consistently so that all participants have access to services when their caregivers are unavailable; (2) providing institutional respite as a specific service; and (3) providing a flexible funding mechanism so participants can purchase what they need, including increased services when their regular caregiver is unavailable.

When the Passport waiver was being renewed, the Grantee conducted focus groups to determine what service participants and their families would like added to the waiver. At that time, the State was considering adding institutional respite (i.e., authorizing a stay in a nursing home for a specific period when a caregiver is unavailable). However, focus groups revealed that participants placed a higher priority on nonmedical transportation and nursing facility transition services. They also wanted the State to raise the asset limit above the current $1,500 threshold. Based on this feedback, the State decided not to add institutional respite to the waiver, but instead added a service called "community transitions" (basically "goods and services") that is restricted to individuals leaving nursing facilities who will be receiving waiver services.

The State also decided to provide more training to case managers about the waiver's de facto respite strategy, that is, ensuring that all case managers adopt an approach to service planning that involves informal caregivers, documents the hours of care they are providing, and includes provision for increased services during periods when informal caregivers are unavailable. The State's goal is to ensure that case managers use a consistent approach so that participants receive comparable services. This de facto respite strategy can help to prevent institutionalization because many waiver participants—particularly those with extensive needs—would be unable to live in their homes without informal caregivers.

The State continues to use vouchers for small amounts (e.g., $200) in its Alzheimer's Respite Program (funded with state funds), and counties use vouchers in their respite programs (funded through county property tax levies).

Lessons Learned and Recommendations

Conducting focus groups prior to waiver renewal to obtain participant and family input on the changes they would like to see provided the State with valuable insights about the services they value.

Products

The SCRIPPS Gerontology Center of Miami University completed a study entitled *Real Choices: A Caregiver Respite Strategy for the State of Ohio*. The report outlines options for adding respite services to the PASSPORT program. The report is available at http://www.units.muohio.edu/scripps/research/publications/Real_Choices.html.

Rhode Island

Primary Purpose

The grant's primary purpose was to conduct a feasibility study to determine the most effective and efficient methods for providing respite care in the State's waiver programs. Respite services are defined as short-term services that provide relief to allow the informal primary caregiver to continue at-home care for the recipient.

The grant was awarded to the Department of Human Services, Center for Adult Health, and was subcontracted to Affiliated Computer Services, Inc., a company that provides health care management and administrative support to Rhode Island's Department of Human Services Medicaid Program. (This summary refers to contractor staff as grant staff.)

Results

Grant staff conducted a comprehensive study of respite care to identify service needs, gaps, and barriers. The study included a literature review, data analysis, and the results of focus groups with program participants, their families, and other stakeholders (e.g., service providers, advocates, consumer advisory councils, and state policy makers).

Grant staff and consultants determined the best ways to coordinate public and private resources to provide respite services. Although specific Medicaid savings could not be calculated, the focus group members confirmed unanimously that respite will enable them to continue caring for their family members at home.

The Rhode Island Medicaid Department designed a respite care benefit and developed implementation tools (e.g., credentialing process, provider agreements).

As a result of these activities, the Department of Elderly Affairs added respite as a new service in the Elderly waiver when it was renewed in June 2007. The Department also developed and implemented a quality monitoring function for respite as part of the waiver quality review process, and added website capacity to enable participants who direct their services to recruit workers.

Lessons Learned and Recommendations

Input from program participants and family caregivers provided important information and guidance for developing respite services in Rhode Island. Eight individuals participated in a focus group. Because caregivers often had difficulty attending focus group meetings, grant staff also conducted in-person interviews with 12 individuals in their homes. Although this was costly, the results were well worth the investment because input from program participants and family caregivers is critical to the success of a respite program.

Products

Grant staff produced a comprehensive report on the grant project that describes the feasibility of expanding respite services for Medicaid-eligible elderly persons and younger adults with physical disabilities. The report includes a summary of research on other states' programs. The report has been shared with state policy makers and will be used to improve access to respite services in the State's Section 1915(c) waiver.

Individual Respite for Children Grant Summaries

Alabama

Primary Purpose

The grant's primary purpose was to determine the feasibility of developing and implementing a statewide respite care system for children with serious emotional disturbance (SED) and their families. The grant was awarded to the Alabama Department of Mental Health and Mental Retardation (hereafter, the Department). Alabama Family Ties, a nonprofit group, was a sub-Grantee.

Results

Alabama Family Ties and the Department collected information from consumers on their need for respite care. Results showed that 62 percent of families indicated they needed and would use respite care. In response, the Department drafted a definition of respite, developed criteria and billing rates for coverage of respite services, and made recommendations for certification standards.

The Department implemented four pilot sites in the State for respite delivery through community mental health centers. Standards for training were established and approved, a training and certification system for respite care providers was developed, and the providers in the pilot sites were trained. The pilot sites are currently funded by the Department to serve a minimum of 15 children per year per site and are being monitored by the Respite Care Task Force through the evaluation process to determine the effectiveness of services. Staff from the Medicaid agency are members of the Respite Care Task Force, but the Agency has not yet amended the Medicaid State Plan to cover respite services.

Lessons Learned and Recommendations

- Family members were a driving force in maintaining momentum for the project. To encourage family participation, states should pay for their time to attend task force meetings in addition to providing a mileage and meal stipend.

- The State should permanently expand the provision of children's respite services by amending the Medicaid State Plan to include respite as a reimbursable service.

Products

- The Department collaborated with the Department of Human Resources to design a comprehensive training for respite care providers based on established practices, with the addition of specialized components in SED training, as well as a segment on developing support groups for families.

- A Needs Assessment instrument was developed to survey the families and parents of children with serious emotional disturbance in Alabama.

- Grant staff prepared a report using statewide case management data to determine the number of residential treatments, in-home treatments, and outpatients, as well as costs of services by county and community mental health center.

Arkansas

Primary Purpose

The grant's primary purpose was to determine the feasibility of expanding the number of participants in Arkansas's Title V Children's Services respite program for children with special health care needs (CSHCN) from 132 to 275, and to increase self-reported consumer satisfaction with the program. The grant was awarded to the Arkansas Department of Human Services. The University of Arkansas for Medical Sciences/Partners for Inclusive Communities was a subcontractor on the grant.

Results

In the first year of the project, 2003, Medicaid funding for respite care through the Arkansas Title V Children's Services program was sufficient to serve 275 families of CSHCN. However, because of multiple access barriers, only 132 families were served.

Grant staff assessed the need for respite care and barriers to obtaining respite services by reviewing data from the Title V Respite program, conducting surveys and focus groups with families of CSHCN, and interviewing respite program administrators. Based on these activities, they recommended revised policies and procedures; developed projected use rates, cost projections, and cost savings resulting from program revisions; developed recommendations for further modifications based on an evaluation of the project; and identified funding sources for providing respite services.

The State's Nurse Practice Act, which required families to have a Registered Nurse (R.N.) approve all respite plans—whether or not medical care was needed—was identified as the chief barrier to participation in respite programs. As a result of the study's conclusions and the efforts of other agencies, the legislature amended the Nurse Practice Act to allow families to delegate the care they provide to a person of their choosing without the need for R.N. approval.

A complicated application process was identified as another barrier. By reducing the volume of paperwork required to apply for respite service and to document expenditures, more families were able to participate in the program. The number of families receiving services increased to 310 in 2007, with applications climbing markedly from 140 to 3,750.

In response to families' expressed needs, the program was expanded to include a broader range of family supports, allowing families to purchase additional services, such as equipment needed to care for the child at home, or to have the child or siblings attend summer camp or to take a family trip, thus helping the family to continue supporting the child in the family setting. Expanding the program in this manner increased satisfaction with the respite program.

After the grant project's first year, the Arkansas Medicaid program decided to eliminate funding for the Title V Respite program. However, the Title V Children's Services director viewed the respite program as important to families and used Title V funds to continue funding the program at the same level. Although continued funding is not guaranteed, the program is strongly committed to offering the service.

Funding is clearly inadequate to meet the demand of 3,750 applications for 310 slots, and several families have expressed a need for more than $1,000 for respite/family support in a given year. The current level of support may be inadequate for many families to continue providing care in their homes.

Lessons Learned and Recommendations

- As the Title V program increased options for participants to direct respite care and family supports, both participation in and satisfaction with the program increased.
- Funding should be increased to allow more families to receive respite services.
- The supply of respite care providers with skills necessary to manage special health care needs is inadequate. Many families have difficulty finding respite caregivers with whom they are comfortable leaving their child. As a result, some families did not participate in the program, and others did not use their full allotment of care. The State should address the shortage of care providers by making respite care a service under the Medicaid State Plan and developing recruitment and training programs for respite workers.

Products

Grant staff developed a *Resource Manual for Arkansas Respite* that is designed for respite planners and includes a caregiver checklist as well as descriptions of programs in other states and contact information for the program directors. The manual is available from Partners for Inclusive Communities by calling (800) 342-2923.

Maryland

Primary Purpose

The grant's primary purpose was to conduct a feasibility study to inform the development of a model of respite care for Medicaid-eligible children under 18 with special health care needs, using a Medicaid-type delivery model. The grant was awarded to the Maryland Department of Health and Mental Hygiene, Mental Hygiene Administration. The Center for Health Program Development and Management at the University of Maryland, Baltimore County, was subcontracted to conduct the feasibility study.

Results

As part of the feasibility study, a review of state regulations that govern the provision of respite services was conducted, and a comprehensive listing of various Titles and Chapters that describe respite, as contained in the Code of Maryland Regulations (COMAR), was compiled and analyzed. Separate surveys polled providers of respite services and families of children with disabilities. The findings demonstrated a shortage of respite care resources for the State's families. Available resources were fragmented—covered by several separate state and federal funding sources that have differing models, regulatory requirements, and eligibility criteria.

A work group, composed of Maryland Caregivers Support Coordinating Council members and many other stakeholders and advocates knowledgeable about children's respite services in Maryland, used the findings to develop a model that could be used as a basis for a demonstration project. Although children with serious emotional disturbance were the model's target group, the model was designed to be expanded and/or replicated to cover all children with disabilities.

In reviewing the regulations and designing a system that would meet the needs of a diverse target population, it became clear that services are often difficult to access because of multiple eligibility and statutory requirements. The model that was developed attempts to address some of the current challenges in the service delivery system by not only showing ways it could become more streamlined, but also by putting a greater emphasis on caregiver needs and outcomes.

The model includes a system of levels based on the severity of disability, the cost of service delivery, and the potential for expanding the group that could be served if other financial options became available. The model assumes that a portion of the existing state respite funds will be used as the state match for a Medicaid waiver program and a smaller portion for individuals not eligible for the waiver program.[11] The goal of the model is to create a

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[11] The grant objective to develop a model as if it were a Medicaid service was a challenge because respite services were viewed as a support service rather than a therapeutic intervention and therefore not a stand-alone benefit allowable under the Medicaid State Plan. Although respite may be offered as a waiver service, waiver participants must meet institutional level-of-care eligibility criteria.

statewide program for respite services with a single point of entry for all eligible children with a disability. If the model were to be implemented, it would need to be further developed, and the State would need to address funding and sustainability, data management (including developing tools and measures that can be used across agencies), and system-level issues.

Lessons Learned and Recommendations

- Although it slows the process, it is essential that there be as much input and buy-in into efforts to bring about systems change as possible. Being inclusive promotes a greater awareness of the need for respite across systems and disability groups, a more concerted effort to support respite as a priority service, and avoidance of duplication of effort.

- Under current regulations, Medicaid services must be directed solely at the eligible recipient. At the time the study was conducted, technical assistance providers and funding sources informed grant staff that because respite is primarily a support service to families, rather than a treatment service for children, it could not be billed through the Medicaid State Plan. This issue needs to be resolved because respite services benefit both program participants and their family caregivers.

- The State should consider amending the Medicaid State Plan—as permitted under the Deficit Reduction Act of 2005—to offer home and community-based services, including respite, as a State Plan benefit. Although this option covers *only* individuals with incomes at or below 150 percent of the federal poverty level, it does permit states to provide services to individuals who do not meet the institutional level of care provided in a hospital, nursing home, or ICF-MR. However, the requirements outlined under the DRA for the content of the State Plan are complex, and the service cannot be limited to children.

Products

The Center for Health Program Development and Management prepared a report (Real Choice Systems Change Grants for Community Living: A Feasibility Study to Consider Respite Services for Children with Disabilities in Maryland) summarizing the findings and workings of the planning process that resulted in the demonstration model, while also making key recommendations for implementation. Complete reports of the regulation analysis and surveys, as well as documents supporting development of the model, are included in the report, which is available at http://www.dhr.state.md.us/oas/pdf/06feas.pdf.

Michigan

Primary Purpose

The grant's primary purpose was to support the increase of Medicaid-funded respite care for children with developmental disabilities or serious emotional disturbance by (1) examining the feasibility of providing respite services as a Medicaid-covered mental health service, and (2) providing an implementation plan to phase in an array of respite services in Community Mental Health Service programs.

The grant was awarded to the Michigan Department of Community Health, Division of Mental Health Services for Children and Families. Michigan Public Health Institute was a subcontractor on the grant.

Results

Grant staff conducted a needs assessment using surveys, interviews, and case studies to identify the options needed to provide a choice of respite services to families. Community Mental Health Service program administrators assisted them in researching the types and costs of respite services in various geographic locations in the State. Grant staff also identified needed modifications to the state data collection system to classify children with developmental disabilities as a specific population, and established processes for measuring caregiver well-being and children's satisfaction with respite.

The results of the needs assessment survey identified a level of need for respite services that far exceeds the ability of the Community Mental Health Service programs to meet them. However, because of Michigan's ongoing fiscal crisis, the cost analysis and the recommendations developed through the needs assessment cannot be used effectively at this time to garner support for increasing resources for respite services.

Nevertheless, although not a direct result of grant activity, respite is now a Medicaid-covered mental health service in Michigan as a Section 1915(b)(3) waiver service—when medically necessary and identified through a person-centered planning process.

Lessons Learned and Recommendations

- The involvement of a stakeholder body that includes service users, advocacy organizations, and community mental health providers can greatly aid the creation of relevant, quality products that promote the use of respite services.

- The Centers for Medicare & Medicaid Services should promote respite as a Medicaid-covered service through the provision of information and technical assistance.

Products

- Grant staff produced *A Family Guide to Respite*, which provides information on the different types of respite care, how to obtain respite as a mental health service, and how to address health and safety issues with the respite care provider. A printed version of the *Guide* was disseminated to agencies providing services to children with serious emotional disturbance and developmental disabilities; the *Guide* is also available on the Michigan Department of Community Health website (http://www.michigan.gov/documents/A_Family_Guide_to_Respite_139866_7.pdf).

- The Family Support Workgroup of the Developmental Disabilities Council collaborated with grant staff to produce and distribute a respite brochure for service users that explains changes in funding for respite services. *Respite Care for You and Your Family* is available on the Family Support Workgroup website (http://www.bridges4kids.org/fswg/index.htm).

- Grant staff developed a *Field Guide to Respite* as a tool to assist community mental health service providers in assessing and developing a quality respite program that meets the needs of the community.

Oregon

Primary Purpose

The grant's primary purpose was to conduct a feasibility study to determine whether Medicaid funding could be used to expand and improve existing respite care services for children with developmental disabilities. The grant was awarded to the Oregon Department of Human Services (DHS), Division of Seniors and People with Disabilities (SPD). The Human Services Research Institute (HSRI) was subcontracted to implement the grant.

Results

As part of the feasibility study, grant staff undertook activities that included (1) a review of state and national written materials, state and county data, and Oregon Administrative Rules; (2) family forums and face-to-face and telephone interviews with developmental disabilities program staff and case managers; (3) a statewide e-mail survey of organizations that serve children with developmental disabilities; and (4) a roundtable discussion with stakeholders and two structured discussion meetings with DHS and SPD staff.

As the study progressed, it became apparent that it was difficult to examine respite services without considering them in the larger context of family support programs. As a result, study efforts broadened to consider larger issues pertaining to the Family Support and Lifespan Respite programs—and the role that Medicaid could play in helping to finance these programs—and to Oregon's two Medicaid Model waivers: the Children's Intensive In-home Supports waiver and the Medically Fragile Children's waiver.[12]

As a result of the study's findings and recommendations, which are included in a final report prepared by HSRI, state executive and administrative staff agreed to (1) implement policy changes to increase access to respite and other in-home support services; (2) increase the capacity of counties and regional offices to provide respite; and (3) increase training and technical assistance for—as well as oversight of—service coordinators working with families whose children are enrolled in family support services.

The State reviewed the option under the Deficit Reduction Act of 2005 to list respite services as a permitted service in the Medicaid State Plan but decided not to use this option because obtaining a third Model waiver would best meet the State's needs at this time. The State has received CMS approval for a Model waiver to support children who have intensive physical health needs but are not technology dependent, including children who were already enrolled in family support and receiving substantial state resources. The Model waiver now serves these children with Medicaid funds which, combined with other budget

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[12] These waivers provide intensive supports to children who are technology dependent or require intensive behavioral supports, respectively; the federal match for services provided through these waivers is about 60 percent. However, each waiver is limited to serving only 200 children at any one time and has strict eligibility criteria that screen out all but those with the most intensive service needs. Also, neither waiver supports children who have intensive physical health needs unless they also are technology dependent.

strategies and a modification of Oregon Administrative Rules, has enabled the State to reach more children and families with the limited funds available for respite care.

Lessons Learned and Recommendations

The willingness to adapt grant activities to respond to changes in federal and state policy during the grant period resulted in a more successful project and a greater commitment to future changes.

Products

The Human Services Research Institute prepared a formal report, *In Support of Children with Developmental Disabilities and Their Families: Policy Options and Recommendations*, that documents the activities, findings, and recommendations associated with the grant project. The report is available on the Home and Community-Based Services Clearinghouse website (http://www.hcbs.org/moreInfo.php/doc/1934).

Rhode Island

Primary Purpose

The grant's primary purpose was to examine how Rhode Island could extend its current provision of respite services to children with developmental and other disabilities to a wider population of Children with Special Health Care Needs (CSHCN) and their caregivers. The grant was awarded to the Rhode Island Department of Human Services.

Results

Grant staff conducted a comprehensive needs assessment to determine the nature, scope, and magnitude of the need for respite care for families of CSHCN. The assessment included (1) a survey of parents currently receiving respite services under an existing Mental Retardation/Developmental Disabilities (MR/DD) waiver and through a state-funded respite program; and (2) a series of stakeholder meetings with advocates, families, and professionals to gather information both on the unmet need for respite and on what worked and did not work in the existing provision of respite services.

Grant staff also assessed the current provision of respite services by public and private agencies, identified state legislation and Medicaid State Plan amendments or waivers needed to implement a broader respite care program, and drafted an implementation and evaluation plan. It was determined that the best strategy for providing respite as a Medicaid service was through a Section 1915(c) waiver.

The Grantee submitted three Respite for Children waiver requests, which CMS approved in May 2007. Three separate waiver requests were submitted to meet CMS guidelines stipulating that waivers must be an alternative to a specific type of institution. The three waivers included one for children who needed a hospital or nursing home level of care, one for children who needed a psychiatric hospital level of care, and one for children who needed a level of care provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR).

Each of these waivers provides a single service: respite. Once a child is enrolled in one of the three, the process and procedures for receiving respite are the same, and so the three waivers together are considered to constitute a single respite program. (A small number of children continue to receive respite under the MR/DD waiver.) Once enrolled, the child's parent/guardian is assessed for the amount of respite needed by one of the four certified Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Reevaluation (CEDARR) Family Centers.

Previously, only about 100 families of CSHCN had been approved to receive state-funded respite care, and no new families could be added because of state budget constraints. Through the three waivers, the new respite care program can serve up to 400 children at any time.

Grant staff developed respite care agency certification standards, and five agencies had been certified by the end of the grant period. Because waiver quality assurance and safety requirements are included in the certification standards, quality has been significantly improved in the new respite program. All respite services are provided under the terms of an approved Respite Service and Safety Plan, which is developed by the family and the certified respite agency. The new program also features an online worker registry that can assist families in identifying and recruiting respite workers.

To create a pool of respite workers to support families in their recruitment efforts, the respite agencies are required to undertake specific recruitment activities, which include the following: public relations efforts that increase the visibility of the need for respite; and specific targeted recruitment efforts to groups such as retired teachers, retired state employees trained to work with CSHCN, currently employed individuals trained to work with CSHCN who may want part-time work, classroom aides already employed in school systems; parents of disabled children who might be willing to offer support to other families, or parents whose children with special needs are now older and living independently; and college students. The new program features an online worker registry that can assist families in identifying and recruiting respite workers.

The Grantee partnered with an existing multistate online Direct Support Worker registry (http://www.rewardingwork.org/) to support families in locating trained respite workers as well as to develop materials to recruit potential respite workers. These materials included brochures and posters describing Direct Support work in general, and Respite Care specifically, and directed interested parties to the Rewarding Work website in order to register as available workers.

Because respite is designed to maximize the control and choice families have over the specifics of service delivery, the program uses a participant-directed approach, which assumes that the family is able to take on the primary responsibility of identifying a respite worker, developing a plan for use of the family’s allocated respite hours, providing child-specific and home-specific training to the respite worker, and managing the paperwork to ensure that the worker is paid. The Department of Human Services conducted trainings for both the newly certified respite agencies and for the CEDARR Family Centers to assist families in learning about and applying for the program.

Lessons Learned and Recommendations

- Respite should also be provided as a non-waiver service to enable families whose children do not meet the waiver requirement of an institutional level of care to be approved to receive respite services. (The state-funded respite program has ended.)

- If resources allow and it is demonstrated that the provision of respite can help prevent the need for more expensive services such as short-term institutional care or outpatient services, the Rhode Island Department of Human Services would recommend that the State consider adding respite as a Medicaid State Plan service, subject to appropriate oversight and monitoring.

Products

Grant staff produced brochures and posters on the workplace registry, and developed training materials for families, respite agencies, and CEDARR Family Centers. They also developed respite agency certification standards, which are available on the Department's website (http://www.dhs.ri.gov/dhs/famchild/respite_cert_standards.pdf).

Overview of Community-Based Treatment Alternatives for Children Grants

Medicaid provides inpatient psychiatric services for individuals under age 21 in hospitals and extends this benefit to children in Psychiatric Residential Treatment Facilities (PRTFs). PRTFs are defined in 42 CFR Section (§) 483.452 as "a facility other than a hospital that provides psychiatric services to individuals under age 21, in an inpatient setting." Over the last decade, PRTFs have become the primary providers for children with serious emotional disturbance (SED) requiring an institutional level of care.

However, PRTFs are not recognized as institutions under §1915(c) of the Social Security Act, as are hospitals, nursing facilities, and intermediate care facilities for persons with mental retardation. Thus, states cannot offer §1915(c) waiver services as an alternative to PRTFs, which would enable children to remain at home with their families. Currently, federal policy allows home and community-based services to be provided as an alternative to PRTFs only under a §1115 research and demonstration waiver.

In 2002, CMS considered proposing a statutory change to §1915(c) of the Social Security Act to designate PRTFs as institutions. When the change was not made, CMS then considered creating a demonstration program that would allow states to offer §1915(c) waiver services as an alternative to PRTFs, which also did not happen.

Consequently, in FY 2003, CMS decided to fund Community-Based Treatment Alternatives for Children (CTAC) grants through the Systems Change Grants Program. The primary purpose of the grants was to help states determine whether it would be feasible to operate a §1915(c) waiver program *if* PRTFs were considered institutions (i.e., to determine whether states would have the infrastructure and services needed to make such programs work and be able to meet cost neutrality requirements).

In addition to conducting feasibility studies, grants could be used to develop infrastructure for any future projects providing community-based treatment alternatives for children with SED who would otherwise require care in a PRTF. Grants were awarded to six states as listed in Exhibit 6-3.

Exhibit 6-3. FY 2003 CTAC Grantees

Illinois	Mississippi
Maryland	Missouri
Massachusetts	Texas

In 2005—during the CTAC grants' second year—Congress passed the Deficit Reduction Act, which authorized the Community Alternatives to Psychiatric Residential Treatment Facilities Demonstration Grant Program to help states provide community-based service alternatives to PRTFs for children. In response, several of the CTAC Grantees used their grants to help them develop applications for a Community Alternatives to PRTF demonstration grant. In 2006, CMS awarded $218 million in demonstration grants to 10 states, including 2 of the CTAC Grantees: Maryland and Mississippi.

The PRTF grants will be used to develop demonstration programs that provide services under a §1915(c) waiver as alternatives to PRTFs. For purposes of the demonstration, PRTFs will be deemed to be facilities specified in §1915(c) of the Social Security Act. The demonstration may target individuals who are not otherwise eligible for any Medicaid-funded, community-based services or supports. At the conclusion of the demonstration programs, states will have the option of continuing to provide home and community-based alternatives to PRTFs for participants in the demonstration under a §1915(c) waiver until these children and youth are discharged.

These 5-year demonstration grants will assist states in their efforts to adopt strategic approaches for improving quality as they work to maintain and improve each child's functional level in the community. The demonstration will also test the cost-effectiveness of providing home and community-based care as compared with the cost of institutional care.

The remainder of this section provides brief summaries for each of the CTAC Grantees, focused on the results of their study, their lessons learned, and their recommendations.

Individual CTAC Grant Summaries

Illinois

Primary Purpose

The grant's primary purpose was to examine the feasibility of developing a Medicaid Section (§) 1915(c) home and community-based services waiver program as an alternative to residential treatment currently funded under the State's Individual Care Grant (ICG) program, which supports care for children with serious emotional disturbance (SED). The grant was awarded to the Illinois Department of Human Services.

Results

Because psychiatric residential treatment facilities are not considered institutions for the purpose of providing home and community-based services for children with SED as an alternative through a §1915(c) waiver, the State analyzed whether a §1915(c) waiver could serve as an alternative to inpatient psychiatric hospital services. In Illinois, the annual cost for youth with psychiatric diagnoses severe enough to qualify them for an Individual Care Grant is $34,595. Given that inpatient hospital stays in Illinois are generally short, and longer-term institutionalization occurs in residential treatment facilities, the State concluded that it would not be possible to meet the cost-neutrality requirements of a §1915(c) waiver.

The State considered applying for a psychiatric residential treatment facility (PRTF) demonstration grant, but the grant program required that only PRTFs be used to satisfy the cost-neutrality requirement of the demonstration grant. Because Illinois serves children with serious emotional disturbance in facilities without the PRTF certification, the State was unable to apply for a grant.

Even though the State was unable to use a §1915(c) waiver to serve children with SED, the knowledge it gained through the Community-based Treatments Alternatives for Children (CTAC) grant activities informed several recommendations for strengthening the State's ICG program for children with SED, all of which were enacted. For example, a case coordinator is now available for every family with an Individual Care Grant to help them obtain supports for their child. Additionally, the ICG program now covers the costs of a therapeutic recreation program for youth in residential placements who are on weekend home passes, allowing for better reintegration into community-based care.

Recommendation

Congress should amend §1915(c) of the Social Security Act to allow residential treatment facilities for children with serious emotional disturbance and psychiatric residential treatment facilities to be considered institutions so that children with SED can be served in §1915(c) waiver programs.

Products

The CTAC governance council produced a report describing the grant's activities and the results of the feasibility study.

Maryland

Primary Purpose

The grant's primary purpose was to examine the feasibility of developing a wraparound model of home and community-based services (HCBS) that could be funded through Medicaid, to provide a level of care for children with serious emotional disturbance (SED) comparable to that provided in psychiatric residential treatment facilities (PRTFs). If feasible, the State would develop an implementation and evaluation plan for the demonstration.

The grant was awarded to the Maryland Department of Health and Mental Hygiene, Mental Hygiene Administration. The grant was subcontracted to the University of Maryland School of Medicine, Center for Mental Health Services Research, to implement the grant.

Results

Grant staff conducted a study, which determined that the HCBS wraparound model was feasible and provided information on how to develop and implement such a model, which would include outpatient mental health therapies, respite care, and in-home support services for youth and their families. The information was given to the State Departments of Education, Juvenile Services, Human Resources, Health and Mental Hygiene, and the Governor's Office for Children.

The study's findings guided the State's application for a CMS-funded psychiatric residential treatment facility demonstration grant and in December 2006 the state was awarded the grant to extend HCBS wraparound services to youth who meet the criteria for admission to a PRTF and are Medicaid eligible.

Recommendation

Congress should amend Section (§) 1915(c) of the Social Security Act to allow psychiatric residential treatment facilities for children with serious emotional disturbance to be considered institutions so that these children can receive home and community-based services through §1915(c) waivers.

Products

None.

Massachusetts

Primary Purpose

The grant's primary purpose was to evaluate the feasibility of using a Section (§) 1915(c) waiver to provide community-based treatment alternatives for children with serious emotional disturbance (SED). The study included a review of other states' §1915(c) waiver programs for this target population.

The grant was awarded to the State's Executive Office of Health and Human Services. The University of Massachusetts Medical School, Center for Health Policy & Research, was a subcontractor on the grant. (Subcontractor staff are referred to as grant staff.)

Results

Grant staff conducted an analysis of current service and reimbursement options and relevant Medicaid laws governing services for children with SED, in particular, those receiving care through the State's Coordinated Family Focused Care (CFFC) program, to determine which services could be eligible for federal financial participation through a §1915(c) waiver program. (When the State applied for the Community-based Treatment Alternatives for Children [CTAC] grant, there was a discussion at the federal level about a possible statutory change that would allow psychiatric residential treatment facilities [PRTFs] to be considered an institutional level of care for purposes of determining eligibility for services under a §1915(c) waiver for certain targeted groups. However, the statutory change was never made.)

Grant staff also interviewed staff in states with §1915(c) waivers for children with SED and states that use the Rehabilitation option to serve this population.

The feasibility study determined that if PRTFs were considered to be institutions under §1915(c) of the Social Security Act, only a subset of CFFC participants might meet the level-of-care criteria for §1915(c) waiver services.

Lessons Learned and Recommendations

- The success of §1915(c) waiver programs for children with SED would depend largely on the availability of qualified mental health providers in the community.
- When considering whether to develop a §1915(c) waiver for children with SED, states should carefully balance the administrative costs of a waiver with the cost of providing waiver services for a relatively small number of waiver-eligible children with SED.

Products

The Grantee produced a report and corresponding presentation that describes grant activities, including findings and lessons learned from five states and a detailed analysis of the §1915(c) waiver as a feasible service delivery option for serving children with SED.

Mississippi

Primary Purpose

The grant's primary purpose was to conduct a study to determine the feasibility of developing a Section (§) 1915(c) waiver program to provide home and community-based services (HCBS) for children with serious emotional disturbance (SED) who have a history of placement in psychiatric residential treatment facilities (PRTFs) or who are at immediate risk of being placed in a PRTF. The grant's ultimate goal was to win a 5-year Community Alternatives to PRTF demonstration grant, authorized by the Deficit Reduction Act of 2005.

The grant was awarded to the Mississippi Division of Medicaid. Mississippi Families as Allies for Children's Mental Health and Vanderbilt University were subcontractors.

Results

The feasibility study determined that the State's existing service system would be able to handle the operation of a §1915(c) HCBS waiver for children with SED and that the cost neutrality requirement could be met. The study's findings, along with findings from focus groups conducted by the Mississippi Families as Allies for Children's Mental Health, guided the State's application for a §1915(c) waiver and an application for a Community Alternatives to PRTF demonstration grant, and a corresponding implementation plan.

The State was awarded the demonstration grant in December 2006.

Recommendation

Section 1915(c) of the Social Security Act should be amended to allow PRTFs to be considered institutions. Currently, federal policy allows HCBS to be provided only as an alternative to PRTFs under a §1115 research and demonstration waiver or under the Community Alternatives to Psychiatric Residential Treatment Facilities Demonstration Grant Program.

Products

- Mississippi Families as Allies for Children's Mental Health produced a report that presented the findings of focus groups with caregivers. The focus groups were conducted to gather information on gaps and needs in a community-based treatment system.

- Vanderbilt University conducted an extensive literature review to help grant staff examine the use of residential treatment: characteristics of those served, positive and negative outcomes, and any limitations associated with PRTFs. The University also prepared (1) a general summary of data on Medicaid-eligible children and adolescents served in PRTFs, and (2) a report describing children and adolescents served in PRTFs during the FY 2002–FY 2004 period, based on state Medicaid enrollment and claims data.

Missouri

Primary Purpose

The grant's primary purpose was to conduct a study to determine the feasibility of developing and implementing a comprehensive system of community services and supports under a Section (§) 1915(c) waiver for children with serious emotional disturbance (SED) who would otherwise require care in a psychiatric residential treatment facility.

The grant was awarded to the Missouri Department of Mental Health.

Results

The State will not be able to implement the comprehensive system described above because it has determined that it cannot meet the cost-neutrality requirements of a §1915(c) waiver.

Lessons Learned and Recommendations

- HIPAA requirements regarding the sharing of personal health care information made it difficult to create a children's data warehouse. The State has elected to pursue a system that will focus on aggregate data supplied by state agencies to inform policy and budget development.

- CMS should amend the recent guidance regarding cost-neutrality for §1915(c) waivers, which severely restricts the costs that may be used (i.e., only inpatient hospital services) to offset the cost of home and community-based services. This requirement makes it difficult for states to achieve the cost-neutrality needed to provide psychiatric waiver services in the community to youth under age 21.

- CMS should strengthen the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) screening requirements related to children's mental health needs by increasing the indicators of mental health and substance abuse issues or by mandating that physicians assess these issues.

- Congress should amend Medicaid law to allow coverage for services in Institutions for Mental Diseases.

Products

Grant staff produced a report: *Children in State Custody Solely for Mental Health Needs and More Comprehensive Strategies for System of Care Development*. It includes an analysis of state expenditures for children's services, including expenditures per child before and after entering state custody. The report also outlines the pros and cons of expanding the State Plan rehabilitation option, pursuing a §1915(c) or a §1115 waiver, and implementing the Voluntary Placement Option under Title IVE within the State. This document provides a blueprint for the development of additional children's community-based mental health services and makes recommendations to the State to expand home and community-based services for children with SED.

Texas

Primary Purpose

The grant's primary purpose was to explore the feasibility of providing community-based treatment for children with severe emotional disturbance (SED) who are at risk of entering psychiatric hospitals for treatment.

The grant was awarded to the Texas Health and Human Services Commission. CommunityTIES of America, Inc., was a subcontractor on the grant.

Results

Results of the feasibility study showed that the State could consider implementing a Section (§) 1915(c) waiver to provide a flexible array of services and supports for children with SED as an alternative to inpatient psychiatric care. The State subsequently applied for a psychiatric residential treatment facility (PRTF) waiver demonstration grant program but did not receive one.

The Commission, in collaboration with the Department of State Health Services (DSHS), developed and submitted a §1915(c) waiver application in June 2008 to the Centers for Medicare & Medicaid Services. If approved, Youth Empowerment Services, the new waiver program, will provide home and community-based services (HCBS) for children with SED as an alternative to a hospital level of care. The waiver program was developed by DSHS with the assistance of a contractor to determine its cost neutrality.

Lessons Learned and Recommendations

Section 1915(c) waivers are potentially valuable strategies for providing home and community-based services to children with severe emotional disturbance, particularly in states where children have long stays in Medicaid-funded psychiatric inpatient facilities and/or high recidivism rates due to a lack of community services and supports.

However, the §1915(c) waiver authority was not designed to serve individuals with mental health needs. Developing a §1915(c) waiver program requires much time, effort, and stakeholder involvement to ensure that it will meet the needs of children with severe emotional disturbance. States considering whether to use a §1915(c) waiver program for this population need to develop the infrastructure to provides services and supports through the waiver. If the waiver will be implemented in the mental health system, its staff will need to develop the appropriate expertise to design and administer the waiver program.

Products

The Grantee and its subcontractor, CommunityTIES, Inc., produced three reports: (1) *A Feasibility Study of Options for Children with Serious Emotional Disturbances*; (2) an *Implementation Report* for the §1915(c) HCBS waiver option; and (3) a *Final Report* that summarizes the first two reports. These reports analyze how a waiver would operate and provide an overview of data on the current costs of institutional services. Together the reports provide stakeholders and policy makers with good basic information and a common point of reference for discussions regarding future program development.

Appendix

Real Choice Systems Change Grants for Community Living Reports on the FY 2003 Grantees

I. Formative Research Reports

Real Choice Systems Change Grant Program: *Third Year Report*

This report describes the FY 2002 and FY 2003 Grantees' accomplishments and progress, using information provided by the Grantees during the reporting period October 1, 2003, to September 30, 2004. The report summarizes findings from the Year Two annual reports of the 49 FY 2002 Systems Change Grantees and the Year One annual reports of the 48 FY 2003 Grantees. Data from the 9 FY 2003 Family to Family Health Care Information Center Grantees' Year One annual reports and the 16 FY 2003 Feasibility Grantees' Year One annual reports were also analyzed and included. The report presents examples of Grantees' activities in four areas of systems change: (1) access to long-term services and supports; (2) services, supports, and housing; (3) administrative and monitoring infrastructure; and (4) long-term services and supports workforce. For each of the focus areas the report describes Grantees' accomplishments, illustrates the challenges, and discusses consumers' roles in the implementation and evaluation of activities. *Available at:* http://www.hcbs.org/moreInfo.php/doc/1363.

Real Choice Systems Change Grant Program: *Fourth Year Report*

This report describes the FY 2003 and FY 2004 Grantees' accomplishments and progress, using information provided by the Grantees during the reporting period October 1, 2004, to September 30, 2005. The report summarizes findings from the Year Two annual reports of the 48 FY 2003 Grantees, the Year One annual reports of the 42 FY 2004 Grantees, and the Year Two and Year One annual reports of the 9 FY 2003 and 10 FY 2004 Family to Family Health Care Information Center Grantees, respectively. Data from the 16 FY 2003 Feasibility Grantees' Year Two annual reports were also analyzed and included. The report describes grant activities in three major long-term services and supports systems areas: (1) access to long-term services and supports; (2) services, supports, and housing; and (3) administrative and monitoring infrastructure. For each of the focus areas the report describes Grantees' accomplishments, illustrates the challenges, and discusses consumers' roles in the implementation and evaluation of activities. *Available at:* http://www.hcbs.org/moreInfo.php/doc/1668.

II. Topic Papers

Real Choice Systems Change Grant Program: *Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees*

This report describes the activities of the 19 Grantees funded in fiscal years 2003 and 2004 by CMS and 6 Grantees funded in fiscal year 2002 by the Maternal and Child Health Bureau. Family to Family Health Information Centers assist families of children with special health care needs. This paper describes grant implementation challenges and accomplishments, and provides information that states and stakeholders will find useful when planning or implementing similar initiatives. *Available at:* http://www.hcbs.org/moreInfo.php/doc/1570.

Real Choice Systems Change Grant Program: *Money Follows the Person Initiatives of the Systems Change Grantees*

This report highlights the work of 9 CMS Money Follows the Person (MFP) Grantees, with a focus on Texas and Wisconsin. The report describes the initiatives, and discusses policy and design factors states should consider when developing MFP programs, including developing legislation and budget mechanisms for making transfers of funds, ensuring availability of services and housing, identifying potential consumers for transition, developing nursing facility transition infrastructure, and monitoring and quality assurance. *Available at:* http://www.hcbs.org/moreInfo.php/doc/1667.

Real Choice Systems Change Grant Program: *Increasing Options for Self-Directed Services: Initiatives of the FY 2003 Independence Plus Grantees*

This report describes the activities of 12 Grantees that received Independence Plus grants in FY 2003 and used them to increase self-directed services options for persons of all ages with disabilities or chronic illnesses. Grantees encountered a range of issues while implementing the grant projects. This report provides information for states and stakeholders planning, implementing, or expanding self-direction programs, whether through solely state-funded programs or the Medicaid program. *Available at:* http://ww.hcbs.org/moreInfo.php/doc/2134.

Real Choice Systems Change Grant Program: *Improving Quality Assurance/Quality Improvement Systems for Home and Community-Based Services: Experience of the FY 2003 and FY 2004 Grantees*

The purpose of this report is to inform the efforts of states that are trying to develop and improve QA/QI systems by describing and analyzing how selected Systems Change Grantees went through this process. Nine out of the 28 states with QA/QI grants were selected for detailed analyses for this report. These states used their grants to improve

QA/QI systems for individuals of all ages with various disabilities. The initiatives examined fall into six categories: administrative technology and information technology, standards for services, discovery, remediation, workforce, and public information. *Available at:* http://www.hcbs.org/moreInfo.php/doc/2397.

III. Summaries

Summaries of the Systems Change Grants for Community Living—FY 2003 Grantees

This document provides a 6- to 8-page summary of the grant applications for each FY 2003 Research and Development Grantee. The 48 grants are grouped in the following categories: Community-Integrated Personal Assistance Services and Supports Grants, Independence Plus Initiative, Money Follows the Person Rebalancing Initiative, and Quality Assurance and Quality Improvement in Home and Community Based Services. *Available at:* http://www.hcbs.org/files/35/1725/2003_FINAL_Summaries.doc.

Filename: 2k3SCG_Final_Report.doc
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Creation Date: 2/25/2009 12:16:00 PM
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Last Saved On: 5/1/2009 2:12:00 PM
Last Saved By: Pam Prevatt
Total Editing Time: 414 Minutes
Last Printed On: 5/13/2009 1:01:00 PM
As of Last Complete Printing
    Number of Pages: 425
    Number of Words: 130,643 (approx.)
    Number of Characters: 744,668 (approx.)