Part 1

Community-Integrated Personal Assistance Services and Supports Grantees

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.