Part 2

Money Follows the Person Grantees

Section One. Overview

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

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

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

Exhibit 2-1. FY 2003 MFP Grantees

California	Pennsylvania
Idaho	Texas
Maine	Washington
Michigan	Wisconsin
Nevada	

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

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

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

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

Enduring Systems Improvements

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

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

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

Section Two provides more detailed information about each state's grant initiatives—both their accomplishments and their enduring changes. Grantees' accomplishments were preliminary steps in the process of bringing about enduring systems improvements. For example, developing a waiver rate setting methodology and new service definitions is an accomplishment, whereas amending a waiver and revising administrative rules in order to change service definitions and payment rates are an enduring systems improvement.

New Assessment and Budgeting Process for Individualized Portable Budgets

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

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

individual budgets to follow the person from provider to provider. The new service definitions and associated rates also ensure that participants have sufficient funds to support their service choices.

New MFP Funding Mechanism

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

New Infrastructure/Funding to Support Transition Services and MFP Policy

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

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

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

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

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

Training to Support Transitions and MFP Policy

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

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

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

Increased Access to and Funding for HCBS

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

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

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

Increased Access to and Funding for Supported Housing

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

New Process to Involve Consumers in Policy Development

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

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

provider groups, advocates, and nursing facility industry representatives. The Commission serves as a source of public input on long-term services and supports planning.

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

Continuing Challenges to Transition and Balancing

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

Lack of Funding for HCBS

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

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

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

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

Lack of Affordable and Accessible Housing

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

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

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

Medicaid and State Policies and Practices

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

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

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

Lessons Learned and Recommendations

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

Lessons Learned

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

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

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

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

Recommendations

Program Implementation

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

Involving Stakeholders

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

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

State Policy

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

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

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

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

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

State Medicaid Policy

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

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

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

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

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

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

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

Federal Policy

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

program, which pays for home modifications. The state knows how to develop and finance affordable, accessible housing, but there are insufficient resources to meet the many competing demands for housing.

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

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

CMS

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

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

Section Two. Individual MFP Grant Summaries

California

Primary Purpose and Major Goals

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

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

Role of Key Partners

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

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

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

Major Accomplishments and Outcomes

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

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

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

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

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

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

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

Enduring Systems Change

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

Key Challenges

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

  In addition to waiting lists, services were often unavailable for a variety of reasons, including the following: (1) residential care facilities participating in the ALWPP were not always available in preferred locations; (2) setting up an IHSS assessment could take as long as 60 to 90 days, and there was confusion about whether assessments could be

conducted in a nursing facility; and (3) each waiver program has restrictive targeting criteria (age, diagnoses, and functional limitations) that some nursing facility residents did not meet, as well as limitations in service coverage. Finding a waiver that fit the resident—in terms of both eligibility criteria and covered services—was a major challenge.

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

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

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

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

Continuing Challenges

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

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

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

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

Lessons Learned and Recommendations

- Transition staff need training to learn how to converse objectively and tactfully with individuals and proxy decision makers. Social networks and family communications are complex, and decisions about transitioning back to community living affect many aspects of a person's life. Conversations and follow-up actions must be highly coordinated and

clearly communicated. Also, it is important to clearly define roles and responsibilities to avoid confusion about who is handling the discharge and transition planning.

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

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

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

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

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

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

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

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

Key Products

Educational Materials

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

Technical Materials

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

Reports

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

Idaho

Primary Purpose and Major Goals

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

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

Role of Key Participating Partners

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

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

Major Accomplishments and Outcomes

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

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

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

continuing to work together to develop an accessible playground for children with disabilities.

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

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

Key Challenges

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

Continuing Challenges

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

Lessons Learned and Recommendations

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

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

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

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

Key Products

Outreach Materials

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

Reports

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

Maine

Primary Purpose and Major Goals

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

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

Role of Key Partners

- The Office of MaineCare Services (the state Medicaid agency), the Office of Information Technology, and other DHHS agencies helped coordinate grant activities, wrote rules to establish new service definitions and rates, and communicated with stakeholders.

- The Maine Association of Community Service Providers worked with grant staff on a wide range of grant activities to develop a standardized assessment and budgeting process for mental retardation waiver services.

- Two consumer groups played significant roles. The Disability Rights Center provided input on proposed rules for rate setting, reviewed existing DHHS service rules and practices, and reviewed individual service authorizations on behalf of individual service users. Speaking Up For Us helped establish and review service definitions for home supports, work supports, and community supports.

Major Accomplishments and Outcomes

- DHHS developed eligibility, service assessment, and budget assessment tools to assist in creating new service definitions, as well as a method for determining new waiver service rates to allow portability of individual budgets, fairness and equity in service determination, and community integration of persons needing services.

- To determine the new rate structure, DHHS obtained and evaluated historical cost data for waiver services from regional offices to identify strategies for adjusting rates.

- A contractor conducted a provider cost survey and follow-up interviews to clarify and confirm survey findings.

- DHHS developed a waiver rate setting methodology for home, community, and work supports and tested the new rates and service definitions with 18 providers to assess their financial impact.

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

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

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

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

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

Enduring Systems Change

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

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

Key Challenges

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

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

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

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

Continuing Challenges

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

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

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

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

Lessons Learned and Recommendations

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

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

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

Key Products

Educational Materials

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

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

Technical Materials

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

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

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

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

Reports

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

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

Michigan

Primary Purpose and Major Goals

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

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

Role of Key Partners

- A Project Work Group—comprising service users, advocates, service providers, and state agency staff—oversaw all grant activities and product development with guidance from participants and advocates experienced in IP design features. Additional work groups were formed to develop specific IP components.

- The Michigan Association of Community Mental Health Boards partnered with grant staff in organizing training, hosting planning meetings, and arranging communications.

- The Michigan Partners for Freedom (MPF), a grassroots advocacy group organization, was subcontracted by the Grantee to conduct statewide awareness and leadership training for service users, and also training for peer mentors to assist individuals beginning the transition to self-determination.

- The Arc of Michigan was a member of the Project Work Group and also provided technical consultation for writing technical reports about participant direction.

- The Michigan Disability Rights Coalition was a member of the Project Work Group, and also provided staffing services for the grant project coordinator, some consultants and support staff, as well as web hosting and support for service users' participation in grant activities. It also hosted the grant project's website.

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

- The Michigan Developmental Disabilities Council was a member of the Project Work Group and also funded the Michigan Partners for Freedom organization.

- The Paraprofessional Healthcare Institute (PHI) conducted training workshops to support participants who wish to hire their own staff.

Major Accomplishments and Outcomes

- Grant staff developed a standardized model for participant-controlled services in Michigan's mental health and developmental disabilities service system, which includes fiscal intermediary services and methods for determining individual budgets. Staff also refined and implemented models for participant-controlled long-term services and supports in the MI Choice waiver. In both service systems, these models include independent facilitators for person-centered planning (PCP) and the option to use independent support brokers.

- To support all the target populations, grant staff drafted new technical assistance materials on the following topics: working with fiscal intermediaries, introduction to self-determination for service users and allies, hiring staff, and guidelines on PCP policy and practice. The guidelines' purpose was to define how person-centered planning should be used in home and community-based long-term services and supports—specifically the MI Choice waiver—and to establish the State's expectations for provider agencies' policies and practices. The materials also provide guidance for self-directed services in the State's Section (§) 1915(b)(c) Managed Care Specialty Supports waiver, and §1915(c) Children's waiver.

- Grant staff partnered with Michigan Partners for Freedom—a coalition of people with disabilities, family members, advocates, organizations, and other allies working together to build statewide demand for self-determination. During the grant period, MPF conducted 14 community training events and 3 local leader training events in 16 communities throughout Michigan, to empower people with disabilities and to develop their advocacy skills and awareness of state and local issues. In addition, MPF presented at six statewide and three county conferences.

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

  In part through IP grant funding, MPF developed effective training and advocacy materials and a website (http://www.mifreedom.org/) that includes many resources. The organization has secured funding beyond the grant time frame and will continue to provide advocacy, training, and support for people with disabilities, their families, and their allies.

- Grant staff worked with the Paraprofessional Healthcare Institute to create and conduct a train-the-trainer program for participants in self-determination arrangements who wish to learn how to hire and manage their own staff. This initiative developed seven teams of participant and staff trainers, and adapted the PHI curriculum (Employing, Supporting and Retaining Your Personal Assistant: A Workshop Series for People with Disabilities) to the needs of Michigan participants with developmental disabilities.

- Grant funds were used to develop a participant quality of life assessment, and the University of Michigan Gerontology Institute has been working on validation studies for the draft survey tool: Participant Outcomes and Status Measures (POSM). The tool currently has 59 items in nine categories, and pilot studies indicate that the number of items could be reduced without compromising the measure.

- Grant staff developed a bimonthly Self-Determination Implementation Leadership Seminar as a forum for sharing information and strategies as well as for clarifying technical requirements. Communities that had already implemented self-determination arrangements shared policy documents with communities that had been slower to implement. As part of these forums, participants who had made the transition to self-determination explained to developmental disabilities and mental health agency staff—in person and through video interviews—the specific outcomes of person-centered planning, individual plans of services, individual budgets, how to code services for reimbursement, working with fiscal intermediaries, developing quality of life measurement and evaluation systems, and supported employment options.

- The grant funded the participation of service users in annual self-determination conferences that were held each year of the grant project, with a typical attendance of more than 500 people, half of whom were people with disabilities and family members. These conferences have served to showcase progress and as learning laboratories for others interested in self-determination.

- The grant's activities led to other developments that have built on the IP initiative. For example, two of the goals for Michigan's Systems Transformation grant (dealing with person-centered planning and self-determination for long-term services and supports) grew out of the success and acceptance of these policy initiatives within mental health services; and the PCP and other self-determination materials and approaches will be used to implement a single point of entry approach through an Aging and Disability Resource Center grant.

Enduring Systems Change

A self-determination option became available statewide on October 1, 2007, for participants in the MI Choice waiver. Grant funds were used to provide training for the Area Agency on Aging waiver staff as they prepared to initiate self-determination in long-term services and supports. Regional training events and statewide meetings provided awareness, information, and skill-building activities to program managers, social workers, and nursing staff in the areas of person-centered planning, quality assurance, developing a plan of

service, and individual budgets. As of November 2008, 550 individuals had elected to use the new option.

Key Challenges

- One of the grant goals was to plan and develop the infrastructure for a research and demonstration waiver to offer individuals with disabilities the option to receive and direct a cash allotment in lieu of receiving services and supports through traditional methods. The goal was dropped because of a lack of state resources to do the technical work required for the waiver.

- There have been no state General Fund increases for local mental health services in Michigan in more than 12 years. Implementing new services in this type of budget environment has posed challenges.

- Implementing self-determination policy and practice in the mental health services delivery system has been a major challenge. Resistance and misunderstanding among local service delivery agencies have delayed the development of a series of documents to define and describe recommended practices for self-determination implementation. Local agencies' adoption of these practices has varied from one part of the State to another, depending partly on local leadership; some areas have not adopted them at all.

- The State has found that the nature of services and supports for persons with mental illness has posed a challenge to the development of individual budgets. Many supportive services for persons with mental illness are combined and billed at a combined rate (e.g., Assertive Community Treatment), making it difficult to determine the amount that would be available for one individual budget. This issue arises most often when states offer rehabilitative services in their Medicaid State Plans or in an HCBS waiver program, because they have used reimbursement methodologies that combine payment for multiple rehabilitative services performed by multiple practitioners within a single combined rate. The challenge is to develop a method to cost-out the amount of funds available to an individual who wishes to self-direct his or her mental health services in an individual budget.

- Another challenge is that the "unbundled" individual cost for certain services, such as group therapy, can be very low. A potential approach to addressing this problem is the development of consumer cooperatives that pool individual funds for several service users who are working together to directly manage their services. Michigan developed such a cooperative model with an FY 2001 Real Choice Systems Change grant, and one cooperative is currently operating.

Continuing Challenges

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

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

Lessons Learned and Recommendations

- Participant involvement in planning, staff training, and policy development through advisory groups is a way to ensure that participant issues are identified and that participant support for actions is likely. Without such involvement, a valuable reality check to policy initiatives is overlooked.

- Presenting success stories from participants in initial implementation efforts was an effective means for teaching others how to implement self-direction.

- Michigan needs to allocate additional funding for increased waiver slots to reduce the number on the waiting list for the MI Choice waiver.

- New program approaches—such as self-determination—are more likely to be successfully implemented when they are mandated.

Key Products

Outreach Materials

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

Educational Materials

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

Technical Materials

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

Reports

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

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

Nevada

Primary Purpose and Major Goals

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

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

Role of Key Partners

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

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

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

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

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

Major Accomplishments and Outcomes

- Consultants helped grant staff develop recommendations for state legislative committees to address barriers to community living, such as the lack of an MFP policy and of coverage for the medically needy, restrictive financial eligibility criteria, and limited exemptions from Medicaid cost-sharing obligations. For example, individuals admitted to a nursing facility are given only a 1-month exemption from cost-sharing liability. If their

nursing facility stay exceeds 1 month, they have no income other than $30 per month (the personal needs allowance) to maintain their community housing.

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

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

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

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

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

Enduring Systems Change

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

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

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

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

Key Challenges

- The lack of affordable, accessible housing was a major transition barrier. The State has fewer Section 8 vouchers than in prior years, and Nevada's housing authorities have not

been willing to give priority for vouchers to transitioning nursing facility residents. The grant's Housing Registry has helped to identify available housing for these individuals.

- Lack of informal care presented a transition barrier for some individuals, particularly those with extensive and complex needs.

- The pilot diversion program was not implemented because of a lack of interest among hospital discharge planners.

Continuing Challenges

- Finding affordable, accessible housing is a continuing challenge. An individual who is receiving a housing subsidy and is subsequently institutionalized is required to reapply for the subsidy. Nevada has at least a 12-month waiting list for Section 8 vouchers, during which individuals can become dependent on institutional services, making it difficult for them to return to or remain in the community.

- A complex funding structure for Medicaid coverage of nursing facility stays has greatly complicated the development of an MFP policy. Counties do not contribute to the cost of waiver services but pay the nonfederal share of institutional care for individuals with income between 156 percent and 300 percent of SSI. Because many counties do not track these payments, it has been difficult to determine the fiscal impact of an MFP policy for the State.

- Recommendations to liberalize Medicaid financial eligibility criteria have not yet been successful, given concerns about their budgetary impact.

Lessons Learned and Recommendations

- It is important that nursing facility transition program staff not focus their efforts on individuals who are easy to transition while putting those who face challenges at the bottom of the transition list. With additional time and effort, even individuals who face many transition challenges can move into the community.

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

- The State should extend the cost-sharing exemption for nursing facility residents from 1 to 6 months.

- CMS and HUD should coordinate housing and services policy to enable individuals with disabilities to live in the community.

- HUD should increase funding for rental assistance and the development of affordable, accessible housing.

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

Key Products

Outreach Materials

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

Educational Materials

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

Technical Materials

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

Reports

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

Pennsylvania

Primary Purpose and Major Goals

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

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

Role of Key Partners

- The Departments of Aging and Public Welfare created an NFT program.
- Two Area Agencies on Aging (AAAs) and one Independent Living Center conducted NFT projects in their areas to demonstrate the use of state transition funding and the transfer of state-appropriated Medicaid institutional funding for use in community settings.
- The Pennsylvania Housing Finance Agency worked with local housing agencies to help identify affordable, accessible housing for nursing facility residents transitioning into the community.

Major Accomplishments and Outcomes

- Grant staff and staff from the Departments of Aging and Public Welfare developed an NFT technical assistance guide identifying NFT policies and procedures. They also worked with the Pennsylvania Housing Finance Agency to help increase the number of housing authorities supplying affordable, accessible housing for the NFT program by providing incentives through the Low Income Housing Tax Credit Program. Points were awarded for developing additional affordable, accessible units through the Qualified Allocation Plan, and a system was set up that provides biweekly e-mails listing available units throughout the State.
- Grant staff and staff from the Departments of Aging and Public Welfare conducted monthly technical assistance calls to address issues identified by AAAs and waiver service providers; these issues concerned the use of information systems such as OMNIA, Social Assistance Management System (SAMS), and the Front Door Information System, and identifying housing options and barriers to community transitions.
- Since 2003, the State has funded the transition of more than 2,500 service users from institutions to community living.

Enduring Systems Change

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

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

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

Key Challenges

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

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

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

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

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

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

Continuing Challenges

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

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

Lessons Learned and Recommendations

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

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

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

Key Products

Outreach Materials

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

Educational Materials

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

Technical Materials

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

Texas

Primary Purpose and Major Goals

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

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

Role of Key Participating Partners

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

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

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

Major Accomplishments and Outcomes

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

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

Enduring Systems Change

- The State established regional transition teams to coordinate services for nursing facility residents to increase their access to community living. These teams include DADS program, clinical, and social services staff; relocation specialists; advocacy

representatives; HMO representatives; a Medicaid specialist from the Texas Health and Human Services Commission; AAAs; and provider organizations.

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

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

Key Challenges

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

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

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

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

Continuing Challenges

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

Lessons Learned and Recommendations

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

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

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

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

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

Key Products

Outreach Materials

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

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

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

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

Educational Materials

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

- COIL developed an *MFP Transition Team Overview Guide*. The curriculum includes an overview of the *Olmstead* decision and its implications for people with disabilities; the

mission, roles, and responsibilities of the team members; and recommended policies and procedures for conducting transitions.

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

Washington

Primary Purpose and Major Goals

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

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

Role of Key Partners

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

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

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

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

Major Accomplishments and Outcomes

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

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

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

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

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

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

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

Enduring Systems Change

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

Key Challenges

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

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

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

Continuing Challenges

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

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

Lessons Learned and Recommendations

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

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

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

Key Products

Outreach Materials

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

Educational Materials

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

Technical Materials

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

Wisconsin

Primary Purpose and Major Goals

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

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

Role of Key Partners

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

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

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

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

Major Accomplishments and Outcomes

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

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

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

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

Enduring Systems Change

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

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

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

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

Key Challenges

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

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

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

Continuing Challenges

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

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

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

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

Lessons Learned and Recommendations

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

- States should not underestimate the time and resources needed to educate county staff, judges, guardians, and guardians ad litem about transitions. Talent and commitment are

also critical components; without them, transitions will be compliance driven and could have a negative impact on the quality of supports, health, safety, and personal growth of the individuals with disabilities. Guardians and guardians ad litem need to be informed and involved, and mediation occasionally is needed when a lack of trust at any point in the process or among any of the parties jeopardizes transitions that are critical to an individual's best interest.

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

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

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

Key Products

Outreach Materials

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

Educational Materials

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

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

Technical Materials

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

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

Reports

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