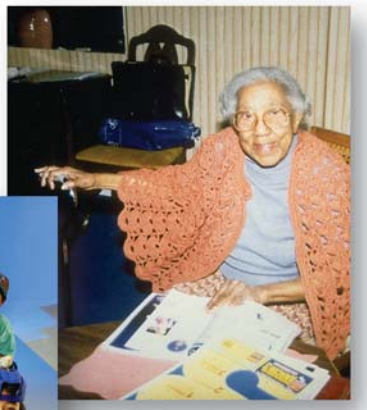
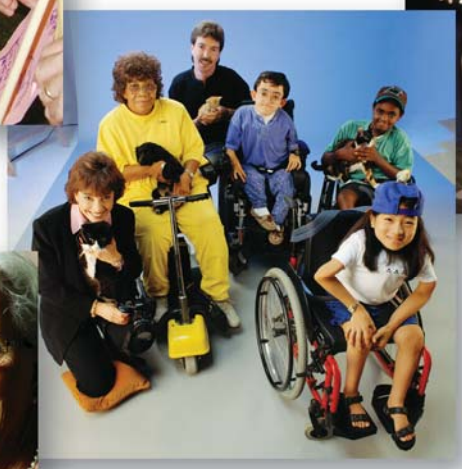
Real Choice Systems Change Grant Program

Enduring Changes of the FY 2001 and FY 2002 Nursing Facility Transition Grantees





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Enduring Changes of the FY 2001 and FY 2002 Nursing Facility Transition Grantees

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Note About This Publication

This publication combines information that was previously published in other Real Choice Systems Change Grant Program reports: *FY 2001 Nursing Facility Transition Grantees: Final Report* (August 2006) and *FY 2002 Nursing Facility Transition Grantees: Final Report* (July 2007).

CMS requested that the information for both grant years be combined to provide a summary overview of the accomplishments and enduring changes brought about by all of the Systems Change Nursing Facility Transition Grantees.

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Overview of Systems Change Grants

Starting in FY 2001, Congress began funding the Real Choice Systems Change Grants for Community Living grant program (hereafter Systems Change Grants) to assist states in making enduring changes to the long-term care (LTC) system infrastructure in order to (1) improve access to and the availability of home and community services and supports, (2) increase consumer choice and control over their services, (3) improve quality management systems, and (4) enhance access to affordable and accessible housing.

Since 2001, the Centers for Medicare & Medicaid Services (CMS) has awarded approximately $270 million in Systems Change Grants to 50 states, the District of Columbia, Guam, the Northern Mariana Islands, and 10 Independent Living Centers (ILCs). In all, 310 grants—not including technical assistance grants—have been awarded during six funding cycles, FY 2001 through FY 2007.

Bringing about enduring change in any state's LTC system is a difficult and complex undertaking that requires the involvement of many public and private entities. Recognizing this, Congress intended the Systems Change Grants to be catalysts for incremental change.

The purpose of this issue brief is to provide an overview of the enduring systems improvements accomplished through the initiatives of the FY 2001 and FY 2002 Nursing Facility Transition (NFT) Grantees.

Nursing Facility Transition Grants

A major goal of the Systems Change Grants is to build state capacity to support the transition of nursing home residents to a community-integrated living arrangement consistent with their needs and preferences. Nursing facility transition programs take as their premise that there are people living in nursing facilities who want to return to the community and could do so at a reasonable cost. These programs also reflect an increasingly accepted view that people with severe disabilities can live successfully in the community.

In FY 2001 and 2002, CMS funded two types of NFT grants: State Programs (SP) and Independent Living Partnerships (ILP). State Program grants were designed to create systems improvements that enable people of any age who reside in nursing facilities to transition to integrated community residences and participate in the social and economic activities of community life to the extent that they are able. The grants were also intended to help states develop better strategies and partnerships to increase the availability of accessible and affordable community housing. States were able to use grant funds to develop infrastructure and/or to provide direct services to achieve the outcome of community living.

Independent Living Partnership grants were designed to promote partnerships between states and ILCs to support the transition of individuals from nursing facilities to their communities. The purpose of these grants was to capitalize on ILC expertise in order to develop outreach materials, identify and support eligible nursing facility residents who desire community living, provide technical assistance, and supplement state infrastructures to make transition initiatives successful. As shown in Exhibit 1, CMS funded a total of 23 NFT-SP grants, which were awarded to state agencies, and 10 NFT-ILP grants, which were awarded to ILCs.

Exhibit 1. List of FY 2001 and FY 2002 NFT Grants

NFT-State Program		NFT-Independent Living Partnership
Alabama	Nebraska	Alabama
Alaska	New Hampshire	California
Arkansas	New Jersey	Delaware
Colorado	North Carolina	Georgia
Connecticut	Ohio	Maryland
Delaware	Rhode Island	Minnesota
Georgia	South Carolina	New Jersey
Indiana	Washington	Texas
Louisiana	West Virginia	Utah
Maryland	Wisconsin	Wisconsin
Massachusetts	Wyoming	
Michigan		

Enduring Systems Improvements

Grantees engaged in numerous activities to develop, implement, and improve transition policies, processes, and programs.[1] A major goal for most Grantees was the transition of individuals from nursing homes, although integrating a transition process into the long-term care system was equally important. Grantees' approaches to nursing facility transition varied according to the characteristics of their state's long-term care system. The availability and administration of publicly funded home and community services—Medicaid in particular—determined in large part the functioning and success of transition programs.

Although the majority of NFT-SP and NFT-ILP grants focused on transition efforts, a few focused on diverting persons with disabilities from nursing facility admission after discharge from hospitals or rehabilitation facilities. Exhibit 2 presents the total number of nursing facility residents who were transitioned and the number of individuals who were diverted from nursing homes during the grant period.[2]

Exhibit 2. Number of Individuals Transitioned or Diverted, by State

State (Grant Type)	Number Transitioned	Number Diverted	Total
Alabama (SP)	29	n/a	29
Alabama (ILP)	45	n/a	45
Alaska (SP)	99	n/a	99
Arkansas (SP)	n/a	74	74
California (ILP)	35	14	49
Colorado (SP)	124	n/a	124
Connecticut (SP)	101	n/a	101
Delaware (ILP)	18	n/a	18
Delaware (SP)	17	n/a	17
Georgia (ILP)	221	56	277
Georgia (SP)	20	n/a	20
Indiana (SP)	110	19	129
Louisiana (SP)	32	n/a	32
Maryland (ILP)	23	n/a	23
Maryland (SP)	193	n/a	193
Massachusetts (SP)	34	9	43
Michigan (SP)	258	118	376
Minnesota (ILP)	190	1,049	1,239
Nebraska (SP)	281	n/a	281
New Hampshire (SP)	15	n/a	15
New Jersey (ILP)	55	83	138
New Jersey (SP)	704	67	771
North Carolina (SP)	125	n/a	125
Ohio (SP)	127	n/a	127
Rhode Island (SP)	533	n/a	533
South Carolina (SP)	90	64	154
Texas (ILP)	n/a	n/a	n/a
Utah (ILP)	160	49	209
West Virginia (SP)	74	64	138
Washington (SP)	1,399	n/a	1,399
Wisconsin (ILP)	184	n/a	184
Wisconsin (SP)	471	n/a	471
Wyoming (SP)	140	n/a	140
Totals	**5,907**	**1,666**	**7,573**

Grantees' other accomplishments were instrumental in achieving the NFT grants' primary goal: to develop a sustainable transition infrastructure and to promote partnerships between states and ILCs to support transitions. Exhibit 3 lists the major types of enduring systems improvements and the total number of states that implemented each improvement either directly or indirectly through grant activities. The discussion that follows provides examples of the enduring systems improvements made by states.

Exhibit 3. Major Types of Enduring Systems Improvements

Systems Improvement	Total States
New funding for transition expenses	23
Increased state transition capacity	15
Increased ILC transition capacity and collaboration	14
New Money Follows the Person (MFP) policy	6
Increased waiver slots for people transitioning	6
New policies and procedures to facilitate transition and/or diversion	26
Increased availability of home and community services	8
Increased access to affordable and accessible housing	5
Continued use of grant-funded materials	19

New Funding for Transition Expenses

Unless individuals are transitioning to a residential care setting or someone else's home, they will have to set up a household in the community. Doing so requires rent, phone and utility deposits, as well as essential furnishings, basic household goods, moving expenses, and sometimes appliances. The personal needs allowance that nursing home residents are allowed to retain is insufficient to allow individuals to save enough money to cover transition expenses,[3] and this lack of resources presents a major transition barrier.

Grantees in 23 states worked successfully to amend waiver programs to include coverage for transition expenses. In most cases, the success of the grant project was instrumental in convincing the states to cover these expenses. For example, Louisiana now covers up to $1,500 in transition expenses under the Elderly and Disabled Adults waiver; Minnesota covers up to $3,000 in its Disabled waiver, serving individuals under the age of 65 with physical disabilities; and Ohio covers up to $1,500 in transition expenses for nursing facility residents who are relocating to an assisted living facility under the State's new Assisted Living waiver program.

Most states included coverage for rent and utility security deposits, basic household goods, and moving expenses, whereas others added a broader range of supports. For example, in

Washington, reimbursable transition expenses under the Aged, Blind and Disabled waiver include environmental modifications, independent living consultation services, adaptive and assistive technology, and consumable supplies such as incontinence pads.

A few states are covering transition expenses solely with state dollars. Based on the grant's demonstrated cost savings, Alaska authorized state general funds to continue the transition program beyond the grant period; New Hampshire is funding the transition of individuals with mental illness using state general funds; and Connecticut used its grant to establish a Common Sense Fund to pay for transition expenses not covered through any other source, or when payment for these expenses is delayed because of complicated applications or lengthy waiting periods. The State's new transition program also includes a Common Sense Fund, now funded by state general revenues.

Increased State Transition Capacity

The primary service needed to ensure a successful transition is case management, also called service coordination, transition coordination, or relocation assistance. In general, individuals with severe disabilities and medical needs who have no informal care will require more intensive case management than those with lesser needs. Individuals without their own or family housing in the community will also require assistance in finding affordable and accessible housing.

These services are usually provided by nursing home discharge planners and community-based case managers, who may lack the specific knowledge needed to transition individuals to the community or who may not have sufficient time and resources to provide the intensive case management that some nursing facility residents need. Hospital discharge planners similarly may lack knowledge of home and community services that can enable an individual to avoid a post-acute nursing facility placement. Lack of funding for case management services and lack of a cadre of adequately trained case managers can pose significant transition barriers.

Grantees in 15 states succeeded in increasing transition services capacity, either through new funding to increase the number of case managers or by increasing the capacity—through education and training—of current case managers and other providers to furnish transition services. For example, Connecticut extended the use of targeted case management (TCM) for persons transitioning from nursing homes from 30 days pretransition to 180 days. The TCM option is available only for people with mental illness, but the State is considering covering additional eligibility groups.

Connecticut is also funding six full-time transition coordinators to provide outreach and transition services, and a toll-free line for nursing facility residents that gives them direct access to a transition coordinator. Similarly, Wyoming's grant project used transition

specialists to help transition nursing home residents to the community, and the State decided to cover transition specialist services in the Medicaid state plan under the TCM option as of July 2006. In addition, one of the State's ILCs—Wyoming Independent Living Rehabilitation—was approved as a Medicaid provider of TCM services.

Many of the Grantees educated hospital and nursing home discharge planners, nursing facility staff, and community case managers about home and community services, generally, and nursing facility transition and diversion specifically. For example, Alabama trained 193 hospital discharge planners about waiver services; Rhode Island trained 539 discharge planners, nursing facility staff, and waiver case managers to promote transitions and diversions; and New Jersey provided training in all of the State's nursing homes and hospitals about its nursing facility transition program. North Carolina offered a five-credit Continuing Education Unit course entitled *Going Home: Helping Residents Transition from Your Facility to the Community,* which was attended by 278 hospital discharge planners and long-term care professionals. The education and training provided under the NFT grants has resulted in increased knowledge and expertise among those trained that will facilitate future transitions.

Increased ILC Transition Capacity and Collaboration

A major purpose of the NFT grants was to increase the capacity of ILCs to provide transition services and to foster an effective means by which ILCs and state agencies could learn from one another, share effective practices, actively assist one another during transitions, and disseminate the lessons learned. All of the ILP Grantees and four SP Grantees reported enduring accomplishments in these areas.

In Alabama, ILCs gained considerable transition knowledge and experience during the grant, and now recognize nursing facility transitions as a priority. After the grant ended, ILCs continued to offer transition services using their own funds. These services include case management and assistance identifying accessible housing, obtaining home modifications, and helping consumers access public transportation. Utah grant staff developed a statewide network of trained ILC transition coordinators and peer mentors who are able to provide information to any nursing home resident who contacts an ILC for transition services.

In Texas, state agency staff, ILC staff, and other stakeholders have increased their knowledge about best transition practices and how to develop community services infrastructure. When the State issued a request for proposals to provide relocation services statewide, all four contracts were awarded to ILCs based in large part on the knowledge and expertise they had gained under the grant.

In Wisconsin, even though the State has not allocated funding to cover its transition services, ILCs continue to provide a greater amount of such services than they did before

the NFT-ILP grant. Grant staff established a consistent outreach process, and all the State's ILCs now have staff trained in nursing facility outreach and transitioning strategies. They are also part of the State's transition teams. Nursing facilities and county staff view ILC staff as a resource for transition activities and are more willing to work with them. ILCs are now receiving increased referrals for transitions from a variety of sources. In addition, involving ILCs in transitioning is providing consumers with peer support, skill training, and advocacy services that they would not receive otherwise.

Several Grantees reported that collaborative working relationships developed under the grant have continued since it ended. For example, in Alabama, the State Unit on Aging, the local area agencies on aging (AAAs), and the ILCs in the pilot areas developed ongoing relationships with other state agency staff and advocates. Similarly, the California ILP Grantee is now collaborating with consumers, physicians, social workers, discharge planners, and nursing home staff to transition nursing home residents to the community.

Grantees were successful in promoting positive views of transition among some nursing facility staff who initially were resistant. In Delaware, successful collaboration between the ILP grant staff and the staff of participating nursing homes resulted in a positive change of attitude toward the transition process. In Maryland, nursing facility administrators and social workers and directors of nursing who previously were opposed to allowing advocates to work with nursing facility residents now rely on ILC staff to provide assistance with transition planning. In Georgia, the SP grant staff established a referral system between the two nursing home chains' facilities and the areas' ILCs and AAAs, which has been sustained since the grant ended.

Successful transitions from nursing homes and positive community-living experiences during the grant period provided strong evidence for ILC consumers to use when advocating for state funding of transition services by ILCs. For example, after the grant ended, Utah's legislature approved funding for one full-time nursing home transition and diversion position in each of the six ILCs, enabling them to continue providing transition services. ILC staff are now invited to be on transition teams with the State's managed care program, where they work together to discuss the needs of individuals interested in transitioning and how to meet those needs.

New Money Follows the Person Policy

A Money Follows the Person (MFP) policy allows Medicaid funds budgeted for institutional services to be spent on home and community services when individuals in nursing homes move to the community. Six states developed or continued flexible funding mechanisms to facilitate transitions. For example, Texas authorized the continuation of its MFP policy,[4] and Utah's Medicaid director initiated a pilot MFP policy for individuals in nursing homes who were eligible for the self-directed Physical Disability waiver. Previously, individuals

interested in transitioning were placed at the bottom of the waiting list. The State plans to make this policy a permanent feature of the Physical Disability waiver.

Maryland enacted the Money Follows the Individual Act, which requires admission to a Home and Community-Based Services (HCBS) waiver program if (1) an individual is living in a nursing home at the time of the application for waiver services, (2) the nursing home services for the individual were paid by the Medicaid for at least 30 consecutive days immediately prior to the application, (3) the individual meets all of the eligibility criteria for participation in the waiver program, and (4) the home and community services provided to the individual would qualify for federal matching funds.

To address its long waiting lists for waiver services, Wisconsin enacted an MFP policy for individuals in nursing homes and intermediate care facilities for persons with mental retardation and other developmental disabilities. Prior to the implementation of this policy, the state budget allocated a certain number of slots to the Department, and additional slots could be generated only if a person left a nursing home that was closing or downsizing and the bed was closed.

Increased Waiver Slots for Individuals Transitioning

If a state does not have an MFP policy, waiting lists for waiver services present a major transition barrier for institutional residents wanting to move to the community. To address this barrier, six states increased the number of waiver slots solely for people who are transitioning to the community. For example, because Wyoming's Aged/Disabled waiver programs had waiting lists, the State authorized an additional 150 slots for the waiver and 25 slots for the Assisted Living waiver to support the grant transition program.

Michigan has authorized new waiver slots for persons who are transitioning if they have been in a nursing facility for more than 6 months. Exceptions to the 6-month rule may be granted in a limited number of circumstances; for example, if individuals are at risk of losing their housing. Additionally, for each successful move to the community, the State will provide transition costs and waiver services for one additional Medicaid nursing facility resident without regard to the length of stay.

When Georgia's grant ended, the State appropriated $7.25 million for non-Medicaid covered transition expenses and the first year of home and community services for transitioning individuals for whom there were no waiver slots. The legislature specified a maximum of $50,000 per person for up to 145 individuals. Only when individuals have been supported with these funds for a year does the State create a new waiver slot to continue services.

When Connecticut's Personal Care Assistant waiver program reached its cap on the number of beneficiaries in July 2003, the grant's impact analysis was used to support a request for

additional waiver slots. Consequently, the Governor's budget recommendation included $2.2 million for 200 additional slots, which the legislature approved in June 2004.

New Policies and Procedures to Facilitate Transition/Diversion

In the course of implementing their initiatives, Grantees gained experience in developing and operating NFT programs, as well as in working to develop policies to ensure their effectiveness and sustainability. Virtually all of the NFT Grantees implemented new policies and procedures to address a wide range of challenges and barriers to transition.

Identifying Individuals Who Want to Transition

A major challenge that states face when developing transition programs is designing and implementing feasible and effective processes for identifying nursing home residents who want to transition to the community. To address this challenge, Minnesota enacted legislation in 2005 requiring the Department of Human Services to develop a methodology for sharing Minimum Data Set (MDS) data with ILCs to assist them in identifying individuals who want to live in the community. Similarly, North Carolina added a transitions protocol to the Medicaid Uniform Screening and Assessment Tool and obtained a Data Use Agreement Amendment that allows the State to use MDS data to identify such nursing home residents.

Several Grantees reported meeting resistance to transition activities among nursing home staff, but in Maryland, the resistance was so great that it necessitated the enactment of two statutes to address it. In response to the refusal of several nursing homes to allow ILC staff to meet with its residents, the State enacted a law (generally referred to as the Nursing Home Access Act) requiring nursing facilities to allow advocates and case managers to discuss transition options with nursing facility residents. The legislation also requires nursing facilities to provide newly admitted residents with information about home and community services options.

Addressing Delays, Waiting Lists, and the High Cost of Nursing Services

Another factor that can impede transition and diversion is a lengthy waiting period for waiver eligibility determination, a particular problem when services have to be coordinated with new housing arrangements. To address this problem, Alaska developed an administrative infrastructure to fast-track the waiver assessment process for persons applying for transition funds, and Arkansas modified its ElderChoices waiver for individuals aged 65 and older to allow retroactive eligibility. The new policy allows Medicaid providers to begin furnishing waiver services as soon as the level-of-care determination has been made—without waiting for the financial eligibility determination—but providers do so at their own financial risk.

In response to the grant's finding that delays in eligibility determinations could lead to institutionalization, Nebraska established a policy called *Waiver While Waiting* to enable

individuals at risk for nursing home placement to receive services while waiting for the waiver eligibility determination, which can take several months. The program screens individuals and, if presumed eligible, they can begin receiving waiver services. If later found ineligible, their services are paid for with Social Services Block Grant funds.

One approach to facilitating transition when a state has a waiting list but no MFP policy is to give priority for waiver slots to individuals who are transitioning. Indiana took this approach, amending its waiver to prioritize the waiting list so that persons waiting to transition are moved to the top of the list. Both Ohio and North Carolina changed their waiver waiting list policies to prioritize nursing home residents wanting to transition.

To address service delays, California's Sonoma County Human Services Department developed prescreening/early intervention procedures to facilitate transition, including a procedure to ensure that Medicaid waiver services are in place upon discharge. Based on grant staffs' advocacy efforts, the State Department of Social Services sent out a directive letter to county Medicaid agencies codifying this practice.

Delaware and Maryland amended their Nurse Practice Act to allow consumers to delegate duties to nonprofessionals under the supervision of a licensed professional nurse to enable those who need delegated services to be served in the community at a more affordable cost. For example, Maryland now permits cognitively intact adults who are not physically able to self-administer medications to direct personal care and other staff or family members or friends to administer them. By decreasing the cost of in-home services, this modification made community placements less expensive for some individuals.

Preventing Unnecessary Admissions and Overly Long Stays

Several states have recognized the need to prevent both unnecessary nursing facility admissions and unnecessarily long stays that result in a loss of housing. For example, Rhode Island developed a protocol for the State's long-term care nurses—who conduct level-of-care determinations—to flag individuals who appear to require only a short stay when admitted to a facility. A computer-generated letter to this effect is sent to the resident and the nursing facility, and a computer-generated reminder is sent to the nurses 45 days after admission, instructing them to evaluate the most recent MDS assessment to determine whether a continued stay is required. Based on the success of this grant protocol, in 2005 the State enacted a statute requiring that the nurses reevaluate all new nursing facility admissions 45 days after admission.

Similarly, Nebraska trained assessment staff to use the Blaylock Risk Assessment Scoring System (BRASS) screening tool, an instrument that identifies patients at risk for prolonged hospital stays at admission and in need of discharge planning services. As a result of the experience with the tool during the grant, the State changed its preadmission screening

procedures. Every AAA now employs the BRASS tool for preadmission screening to identify individuals who should be reassessed in 3 to 6 months. For these individuals, Medicaid provides only a short-term authorization to enter a nursing home so that they will have to be reassessed to remain there. This change has led to active discharge planning to return new admissions to the community and has resulted in shorter nursing home stays.

Facilitating and Ensuring Successful Transitions

Several Grantees developed protocols and procedures to facilitate transition or to help ensure successful transitions. For example, grant staff in California developed a model transition protocol for ILCs to ensure that individuals' needs will be met during and after transition. They also developed a program to train volunteer peer mentors to work with nursing facility residents on transitioning and to provide companionship and support post-transition. Staff recruited several individuals who had transitioned to serve as peer mentors, and the peer support training program has continued since the grant ended.

The SP and ILP Grantees in New Jersey worked together to develop a "Round Table Process"—a consumer-driven interdisciplinary meeting to assist nursing home residents in planning and implementing the transition process. The meetings include the consumer, nursing home staff, the community case manager, ILC staff, and a Community Choice counselor. Trained peer mentors are also involved in these discussions, as are the consumer's family and anyone else in their support network. The Department of Health and Senior Services has implemented the process statewide.

Louisiana established a statewide toll-free help line to provide information about transitioning and community supports and services, and to provide a way for consumers to address concerns and file complaints after transitioning. The Office of Aging and Adult Services has continued funding for this line, which now functions as an intake and complaint line for HCBS waiver programs. Because service problems after transition could lead to readmission to a nursing home, such help lines can prevent unnecessary readmissions as well as admissions.

Increased Availability of Home and Community Services

Insufficient home and community services can be a major transition barrier. Even if a state has a waiver program, it may not provide all of the services needed for individuals with extensive needs to live safely in the community. This was the case in West Virginia where, prior to the grant, the state plan offered more hours of assistance with activities of daily living (ADL) than did the waiver program, and waiver participants who needed more assistance were not allowed to get additional hours through the state plan benefit. The grant staff's recommendations for addressing transition barriers led the State to change the regulations so that Aged and Disabled waiver participants can now obtain personal care services through the state plan if they need more hours than the waiver will cover.

In Rhode Island, during implementation of a previous NFT grant, state staff found that lack of day services was a transition barrier for persons with traumatic brain injury (TBI). Under a contract with an adult day services provider, grant staff established an adult day services program for adults with severe cognitive disabilities, many with TBI. The new program is funded as a Medicaid state plan service under the rehabilitative services option.

Because the waiting period for a waiver slot in Louisiana can be as long as 2 to 4 years, in 2005 the State implemented a new state plan Personal Care Services program, which increased access to personal care assistance services for individuals who meet the financial and programmatic eligibility criteria.

Grant activities in New Hampshire have increased access to services by improving communication among multiple service systems, including the Bureau of Behavioral Health and the Bureau of Elderly and Adult Services. In California, the ILP grant staff developed a one-stop approach to meet the ongoing, diverse needs of transitioned individuals for public benefits, housing, environmental modifications, assistive technology, and legal assistance.

Increased Access to Affordable and Accessible Housing

Another purpose of the NFT grants was to improve collaboration among transition stakeholders, including human services agencies, state and federal housing finance agencies, and Public Housing Authorities (PHAs) to make the most effective use of housing options, including the use of HUD Section 8 rental vouchers for individuals who transition. Most Grantees cited the lack of affordable and accessible housing as a major transition barrier. However, because improving access to housing was not a primary goal for most of the NFT Grantees, only five grantees reported enduring changes related to housing.

In Arkansas, grant staff worked with several partners to develop and implement the Bridge Rental Assistance Program, which bridges the gap between income and the cost of affordable apartments for up to 2 years for persons transitioning or being diverted from nursing homes. The program is being sustained through funding from the Arkansas Development Finance Authority. Grant staff also forged working relations with several PHAs to encourage closer ties between these agencies and Medicaid waiver administrators. As a result, several of the State's larger PHAs have routinely begun to notify the Medicaid waiver administrators of the application timelines for their Section 8 vouchers.

Housing authorities in some Maryland counties changed their priority criteria on housing voucher set-asides to allow persons in a nursing facility who are on the housing voucher list to move to the top of the list when they become eligible for waiver services. Similarly, the Spokane Housing Authority in Washington has designated individuals leaving nursing facilities as "homeless," enabling them to bypass a 2-year waiting list for rental assistance vouchers. An ILC in Spokane now has an ongoing process for assisting nursing facility

residents with housing voucher applications. Waiver transition funds or state general funds pay for this service.

The Ohio Department of Job and Family Services hired a housing coordinator as a permanent full-time staff member to work with grant staff to identify housing resources and to develop a web-based registry of subsidized, accessible housing. The Department of Aging, the Ohio Housing Finance Agency, and the Developmental Disability Council are providing additional resources to develop the registry. The housing coordinator also co-chairs the Inter-Agency Coalition on Homelessness and Housing, which has helped move the State toward developing a multidepartmental approach to housing policy for all of Ohio's residents, including those with disabilities.

Maryland provided incentives for developers to set aside a greater percentage of new housing units for people with disabilities than under federal requirements. As a result, 98 new units will be set aside for people with disabilities. The State also instituted a new requirement for developers to have a marketing strategy and to work with disability organizations to help ensure that persons with disabilities use these units. In addition, units set aside for individuals with disabilities must be held for 30 days when they become vacant to allow time to apply for and coordinate the services, rental assistance, and other activities that need to be completed before an individual with a disability can move into the unit.

Continuing Use of Outreach, Educational, and Technical Materials

Many Grantees reported that resources developed under the grant continue to be used. For example, training materials developed by Alabama will be used to train discharge planners and case managers, and a transition manual developed by California will be disseminated to all ILCs in the State. Similarly, Utah grant staff produced a transition manual, *My Own Place: A Personal Guide for Leaving a Nursing Home*, which provides training materials and information about statewide and local resources. The manual has been distributed to ILCs to disseminate to nursing home residents and is being updated annually. Ohio developed educational materials and related training guidelines and an assessment tool and an individual relocation plan for participating consumers. Both the forms and the educational materials will continue to be used.

Arkansas designed and implemented a marketing campaign, "Choices in Living," that promoted five HCBS waiver programs as alternatives to institutional living for persons of all ages with disabilities. The marketing campaign targeted community resource staff in hospitals, residential care facilities, senior centers, area agency on aging offices, physicians' offices, clinics, and county offices. The campaign is being sustained with funding from the Arkansas Department of Human Services, Division of Aging and Adult Services, and will be an integral component of the marketing plan for the One Stop initiative being developed under the State's Systems Transformation grant. The Choices in Living brochure and DVD

are also being used to train newly hired staff for the Division of County Operations, which determines financial eligibility for the Medicaid program.

Transition training materials developed under the Texas NFT-ILP grant were also used by the State's MFP grant (FY 03) to develop a structured, consistent process for regional coordination of transition activities. Texas also noted that other states were using the transition assessment and service planning materials developed under the grant, which are posted on the HCBS.org website.

Grant Activities as a Catalyst for Additional Systems Change

In many states, grant activities have been the catalyst for additional systems improvements not originally included in the grant's goals. In some states, advisory committees, task forces, and other coalitions formed to implement the grant are continuing work on transition policy. In Alabama, for example, the project implementation team is now functioning as a coalition working to enact policy changes to increase the availability of home and community services. The team worked with members of the state legislature to introduce a budgetary amendment to establish an MFP policy modeled on Texas's Rider 37 and is also advocating for additional funding from the Department of Rehabilitation Services to continue project activities, including independent living skills training, peer support, and transition coordination.

Due in part to the increased awareness that many nursing home residents can be served in the community and the demonstrated cost savings through the transition program, Indiana has undertaken a number of initiatives to rebalance its LTC system. The Indiana Director of Aging and the Secretary of the Family and Social Services Administration have made a commitment to both reduce the number of nursing home beds and to reduce nursing home occupancy by 25 percent by state FY 2009. The State has also established a goal to transition 1,500 Medicaid-eligible nursing home residents to the community in the same time period.

Grant staff in Utah instituted quality assurance mechanisms to obtain ongoing feedback from consumers on their satisfaction and quality of life after transitioning. The *Transitions Follow-Up Assessment* measures the extent and quality of the services consumers receive, and the *Quality of Life* survey focuses on their feelings and attitudes about their new independent living arrangement.

Continuing Transition Barriers

Despite these systems improvements, Grantees identified many transition barriers that remain. A primary barrier is the scarcity of affordable and accessible housing. Many institutional residents have no home to go to, forcing some beneficiaries to rely on residential care facilities or families. Affordable housing is particularly scarce for persons

receiving Supplemental Security Income (SSI). Compounding the difficulty is that less expensive housing tends to be in more outlying areas where essential public transportation is less available. People with disabilities rely heavily on public transportation to participate in community activities, and transition staff often try to locate housing near public transportation or near an individual's social support circle. However, in many areas, public transportation is simply not available; in other areas, it is infrequent and not disability friendly.

The second most frequently cited transition barrier was a lack of home and community services, exacerbated by waiver waiting lists. Medicaid HCBS waivers vary greatly in the comprehensiveness of services they provide, and in many states, the home and community services system does not provide the amount, duration, and scope of services needed by people with severe disabilities. For example, 15 states did not cover personal care services as a state plan benefit in FY 2005.[5] In addition, financial and functional eligibility criteria for Medicaid home and community services is restrictive, leaving some people unable to qualify for services in the community. Depending on the specific eligibility criteria, some people may qualify for expensive institutional care but not for potentially less expensive community services. Furthermore, in some states the level of protected income and assets for community spouses is far higher for Medicaid beneficiaries in nursing homes than it is when both spouses are in the community, which creates a strong financial disincentive for some married institutional residents to return to the community.

The third most frequently cited transition barrier was lack of funding for case management and for transition expenses. Transitioning individuals from nursing homes to the community is difficult, time consuming, and costly, requiring expenditures to establish a community residence. In many states, funding for case management and transition services is limited and, in some cases, inadequate to the needs of people trying to move to the community. Also, administrative and bureaucratic barriers to transitions can be daunting. Moving persons from nursing homes and other institutions to the community requires approvals of eligibility and care plans and, in many cases, the use of government funds in creative ways that do not fit standard payment categories. Gaining approvals so that individuals can receive the necessary services as soon as the person leaves the institution can be difficult and can delay the transition for months.

Several Grantees considered resistance to transition—whether from families or nursing home staff—to be a major barrier. Some nursing home staff do not believe that individuals with extensive functional limitations or medical and nursing needs can be safely served in the community. In addition, nursing homes may actively resist transition efforts, believing that such efforts will decrease their occupancy rates and profitability. Even if families do not oppose their relative's transition, their ability to support it and/or provide informal care depends on a wide range of factors, including work commitments, available time and

money, distance from their home, and the age of any dependent children. In some instances, family members may not want to provide informal care, particularly if the relative's admission to a nursing facility followed many years of informal care at home.

Another barrier is the long-term care workforce shortage. As demand increases for home and community services, states and providers are finding it difficult to recruit direct service workers to provide services for people with disabilities. Low wages, lack of health insurance and other fringe benefits, lack of a career ladder, and the difficult physical and sometimes psychological demands of the work are barriers to recruiting staff into long-term care. Other workforce issues include lack of reliable workers, primarily due to the lack of transportation, and difficulty finding workers for weekend work.

Grantees' Recommendations

To address remaining challenges, Grantees made both general and specific recommendations for increasing home and community services, addressing workforce issues and housing shortages, improving or maintaining NFT programs, and for changes in state and federal policies to facilitate and support transition and the provision of home and community services. Grantees noted a general need for

- educating state legislators about the lack of affordable housing and the number of younger persons with disabilities living in nursing facilities;
- building strong, local coalitions and networks to develop and sustain the nursing facility transition infrastructure; and
- making changes in state policy to better support transitions—some state specific but many applicable to most if not all states. Needed changes include
  - increasing funding of nursing facility diversion as well as transition services;
  - improving nursing home discharge-planning procedures;
  - increasing the scope of community services; and
  - implementing an early-intervention transition program to ensure that people who can be served in the community are discharged before they lose their housing.

Recommendations specific to Medicaid policy include

- decreasing institutional bias by implementing a Money Follows the Person policy or funding additional waiver slots for individuals transitioning;
- implementing global budgeting that combines budgets for nursing home and home and community services so that people with long-term care needs can be served in the least restrictive setting;
- amending all waiver programs to cover transition expenses;

- establishing a dedicated transition program that funds case managers specifically to work on transitions; and
- developing a waiver program to serve adults of all ages with all types of disabilities in order to serve persons not eligible for existing waivers who are falling through the cracks.

To address the lack of affordable and accessible housing, recommendations included the following:

- increasing the supply of affordable and accessible housing;
- enforcing existing building codes regarding accessibility;
- setting up systems for landlords to list current and upcoming vacancies in publicly subsidized, accessible rental units so that individuals with disabilities can obtain timely information about available units; and
- developing more single-room occupancy units to provide an affordable housing option.

Grantees also recommended that the Department of Housing and Urban Development (HUD) increase the time that individuals can keep their housing subsidy if they are temporarily institutionalized—from 4 months to 6 months.

Conclusions

The long-term care system is heavily tilted toward institutional care even though most people with disabilities prefer to live in the community. States, with the help of the federal government, are pursuing a number of strategies, including nursing facility transition programs, to create a more balanced long-term care system. This issue brief described the enduring changes brought about by the FY 2001 and FY 2002 Nursing Facility Transition Grantees who used their grants to either establish or improve nursing facility transition programs or to help establish the infrastructure necessary for such programs. Once fully implemented, nursing facility transition programs identify people in nursing homes who want to return to community living and help them to do so.

Despite bringing about many enduring systems improvements, Grantees reported that many transition barriers remain. Grantees made recommendations to help states address continuing barriers to nursing facility transition and diversion so that no one need live in a nursing home simply because sufficient community services and supports are unavailable. It is particularly important to ensure that states have nursing home diversion and transition infrastructure as the population ages and the need for long-term care increases. Diverting individuals from nursing homes and transitioning nursing home residents to the community can reduce the need for new nursing home construction in the future while creating a more balanced long-term care system for people of all ages with disabilities.

Endnotes

[1] For details of each Grantee's accomplishments, see *FY 2001 Nursing Facility Transition Grantees: Final Report* and *FY 2002 Nursing Facility Transition Grantees: Final Report* available at http://www.hcbs.org/moreInfo.php/doc/1678 and http://www.hcbs.org/moreInfo.php/doc/2060, respectively. Also, the 2005 topic paper *Nursing Facility Transition Initiatives of the Fiscal Year 2001 and 2002 Grantees: Progress and Challenges* at http://www.hcbs.org/moreInfo.php/doc/1308.

[2] The grant period for most Grantees was 4 years, which included a 1-year no-cost extension.

[3] Federal law requires that Medicaid nursing home residents be allowed to retain at least $30 of their income each month as a "personal needs allowance" (PNA) to cover the costs of clothing, personal care items, telephone service, postage and similar expenses. States may allow a higher PNA and a majority have, recognizing that $30 is no longer adequate to afford nursing home residents a minimum level of comfort and dignity. However, in 2006, the highest PNA was $90.45, and 37 states had PNAs of $50 a month or less. Source: National Long-Term Care Ombudsman Resource Center, National Citizens' Coalition for Nursing Home Reform, update of data from Hughes, S., G. MacInnes, and T. Geraghty (2004), *Personal Needs Allowances For Long-term Care Residents*, available at http://www.ltcombudsman.org/ombpublic/49_352_1015.cfm under documents.

[4] Anderson, W. L., Wiener, J. M., and O'Keeffe, J. (June 2006). *Money Follows the Person Initiatives of the Systems Change Grantees: Final Report*. Research Triangle Park, NC: RTI International. Prepared for the Centers for Medicare & Medicaid Services. Available at http://www.hcbs.org/moreInfo.php/doc/1667. The MFP initiative in Texas was first authorized by the Texas Legislature through a "rider" to the State's budget appropriation bills for FY 2002–2003 (Rider 37). A rider is a direction by a legislature on how already appropriated money is to be used, but it does not have the force of law. Although the MFP policy was estimated to be cost neutral, many lawmakers anticipated it would save money since the policy approved community-based services used by transitioning nursing facility residents only up to the amount of their nursing facility expenditures. Individuals with developmental disabilities residing in intermediate care facilities for persons with mental retardation are not covered by the MFP initiative. The State is currently exploring ways to do so.

[5] *Medicaid at a Glance 2005*, Department of Health and Human Services, Centers for Medicare & Medicaid Services, Center for Medicaid and State Operations. CMS publication No. CMS-11024-05, available online at http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf.