Real Choice Systems Change Grant Program

FY 2001 Nursing Facility Transition Grantees: Final Report

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Background

Starting in FY 2001, Congress began funding the Systems Change for Community Living Grants program (hereafter Systems Change grants) to help states increase home and community services and to improve their quality. The first round of three-year grants were awarded in September 30, 2001 and included two types of Nursing Facility Transition (NFT) grants: State Programs and Independent Living Partnerships (ILP). A total of 12 NFT State Program grants were awarded to state agencies, and five ILP grants were awarded to Independent Living Centers.

This report on the FY 2001 Nursing Facility Transition Grantees is the first in a series of final reports that RTI will prepare to document the outcomes of the Systems Change Grants.

Data Sources and Methods

The principal sources of data for this report are Grantees semi-annual, annual, and final reports, a topic paper on the NFT Grantees prepared by RTI in 2005, and Grantee-prepared final reports and evaluation results as well as publications and materials developed under the grant. RTI used these reports and materials to prepare final report summaries for each Grant, which were reviewed by key grant staff. In-depth interviews to obtain additional information and to clarify information were conducted by the RTI Project Director with each Grantee. The final summary was sent to grant staff for their final review and approval.

The long-term care (LTC) system is heavily tilted towards 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 system. This paper reports on the activities and experiences of the FY 2001 Nursing Facility Transition Grants of the Real Choice Systems Change program. Once fully implemented, nursing facility transition programs identify people in nursing homes or intermediate care facilities for the mentally retarded (ICF-MRs) who want to return to community living and help them to do so. These grants either directly established and operated nursing facility transition programs or helped to establish the infrastructure necessary for such programs.

Enduring System Improvements and Continuing Transition Barriers

Grantees reported a wide range of enduring system improvements that directly and indirectly helped to create a more balanced delivery system. These activities included:

- Establishing new funding for transition services and expenses.

- Increasing the number of waiver slots for individuals transitioning to the community.
- Enacting new statutes and developing new policies and procedures to facilitate transitions.
- Increasing Independent Living Center transition capacity and collaboration with the state on transitions.
- Increasing the supply of affordable and accessible housing.
- Increasing outreach and the use of educational and technical materials.
- Acting as a catalyst for additional systems change activities.

Despite these accomplishments, Grantees found that many barriers remain to transitioning individuals from institutions to the community.

- Many residents of institutions have no home to go to and affordable and accessible housing is scarce, forcing some beneficiaries to rely on residential care facilities or families. Affordable housing is particularly scarce for persons receiving Supplemental Security Income, who have very low incomes. Compounding the difficulty is that less expensive housing tends to be in more outlying areas where essential public transportation is less available.

- In many states, the home and community service system does not provide the amount, duration and scope of services needed by people with severe disabilities. Medicaid home and community-based services waivers vary greatly in the range of services they provide and 14 states did not cover personal care services as a state plan benefit in FY 2005.

- Transitioning individuals from nursing homes and ICF-MRs to the community is difficult, time consuming and requires a variety of expenses, such as apartment security deposits, that are beyond the scope of traditional Medicaid programs or even many waiver programs. In many states, funding for case management and transition services is limited and, in some cases, is not adequate to the needs of people trying to move to the community.

- Financial and functional eligibility criteria for Medicaid home and community services is restrictive, and states vary considerably in the comprehensiveness of their coverage of these services, leaving some people unable to qualify for services in the community. Depending on the specific eligibility criteria, some people can qualify for expensive institutional care, but not for potentially less expensive services in the community. In addition, 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, creating a strong financial disincentive for married institutional residents to return to the community.

- 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.

- Many providers, government officials and family members are skeptical of the concept of nursing facility transition programs and do not believe that nursing home and other institutional residents can successfully return individuals to the community. In addition, the nursing home and ICF-MR industries may have concerns that transition programs will adversely affect their occupancy rates and profitability.

- 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 physical demands and sometimes difficult psychological character of the work, are barriers to recruiting staff into long-term care.

- Finally, people with disabilities rely heavily on public transportation to participate in community activities. In many areas, public transportation is simply not available; in other areas, it is infrequently provided and not disability-friendly.

Conclusion

The information in this report is designed to help states address these barriers so that no one has to live in a nursing home or an ICF-MR simply due to the lack of adequate supports in the community. It is particularly important to assure this infrastructure is in place as the American population ages and the need for long-term care increases. Transitioning nursing home and other institutional residents to the community can reduce the need for new nursing home construction in the future and help create a system more responsive to the desires of people of all ages with disabilities.

Part I.

FY 2001 Nursing Facility Transition Grants: Overview of Enduring Changes, Remaining Challenges, and Lessons Learned and Recommendations

1. Introduction

Historically, the amount of public funding for home and community services has been less than that for institutional services. Still, over the past 20 years, many states have created long-term care (LTC) systems that enable people with disabilities or long-term illnesses to live in their own homes or in other residential settings and to have more control over the services they receive. The 1999 Supreme Court decision *Olmstead v. L.C.* has reinforced states' efforts and given legal weight to this policy direction. However, despite the movement to rebalance LTC systems in virtually all states, spending for community-based LTC services (Home and Community-Based Services [HCBS] waivers, personal care, and home health services) accounted for only 37 percent of all Medicaid LTC expenditures in fiscal year (FY) 2005.[1]

Overview of Systems Change Grants

Starting in FY 2001, Congress began funding the Systems Change for Community Living Grants program (hereafter Systems Change grants) to help states increase home and community services and to improve their quality. Since 2001, the Centers for Medicare & Medicaid Services (CMS), has awarded approximately $245 million in Systems Change grants to 50 states, the District of Columbia, Guam, the Northern Mariana Islands, and 10 Independent Living Centers. In all, 287 grants—not including technical assistance grants—have been awarded during five funding cycles, FY 2001 through FY 2005.

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, the Systems Change grants are intended to be catalysts for incremental change. The grants' overriding purpose is to enable states to make enduring changes to the underlying framework upon which the LTC system operates 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.

FY 2001 Grantees

The first round of grants were awarded for a 3-year period on September 30, 2001. For most Grantees, implementation was delayed due to difficulties in hiring staff. Thus, while the original completion date for these Grantees was September 30, 2004, most received 12-month no-cost extensions and did not conclude their activities until September 30, 2005. These Grantees were required to file their final reports by December 31, 2005.

Nursing Facility Transitions Grants

A major goal of the Systems Change Grant Program 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.

Transitioning individuals from ICFs-MR to the community has been a central component of LTC policy for people with mental retardation and other developmental disabilities for over three decades. On the other hand, the recent emphasis on identifying people in nursing homes who want to live in the community and actively working to transition them out of the institution is a radical change in approach for older people and younger persons with physical disabilities. For the past 25 years, the overwhelming focus has been on preventing admissions to nursing homes, not discharging residents from them.

Nursing facility transition programs take as their premise that there are people living in nursing facilities who want to return to the community and can do so at a reasonable cost, and that some people admitted to nursing facilities improve rather than decline in functional status and also may desire to return to the community. These programs also reflect an increasing view that people with severe disabilities can successfully live in the community.

In FY 2001, CMS funded two types of Nursing Facility Transition (NFT) grants: State Programs and Independent Living Partnerships (ILP). A total of 12 NFT State Program grants were awarded to state agencies, and five ILP grants were awarded to Independent Living Centers.[2] Exhibit 1 lists all of these grants.

Exhibit 1. List of FY 2001 NFT Grants

NFT-State Program		NFT-Independent Living Partnership
Alaska	Massachusetts	Alabama
Colorado	Michigan	Georgia
Connecticut	New Hampshire	Maryland
Georgia	Washington	Texas
Indiana	West Virginia	Wisconsin
Maryland	Wisconsin	

Grant Reporting

The Systems Change Grants have been awarded in late September of each year since FY 2001. CMS contracted with RTI International to compile a number of reports about the FY 2001, 2002, 2003, and 2004 Grantees, including (1) annual reports to detail the progress of the grants at a specific point in time and (2) papers on a single system change focus area.[3]

This report on the FY 2001 Nursing Facility Transition Grantees is the first in a series of final reports that RTI will prepare to document the outcomes of the Systems Change Grants. The second final report will cover the FY 2001 Community-integrated Personal Assistance Services and Supports Grantees and the Real Choice Grantees.[4]

Organization of this Report

Chapter 2 presents the methodology used to prepare this report. Chapter 3 provides an overview of enduring systems improvements brought about directly or indirectly through grant activities. Chapter 4 provides an overview of continuing challenges to nursing facility transitions that the Grantees identified. Chapter 5 provides an overview of lessons Grantees learned in implementing their initiatives, and their recommendations for operating NFT programs and changing state and federal policy to facilitate transition. Chapter 6 presents our conclusions.

Part II of this report presents final report summaries for each of the FY 2001 NFT Grantees.

2. Methods

Data Sources

The principal sources of data for this report are: (1) the final year reports of the 17 FY 2001 Nursing Facility Transition Grantees, (2) their semi-annual and annual reports submitted during the grant period, (3) a topic paper on the NFT Grantees prepared by RTI in 2005,[5] and (4) Grantee-prepared final reports and evaluation results as well as publications and materials developed under the grant, which were sent to CMS at the grant's completion.

Methods

Grantees submitted their final reports on December 31, 2005, and RTI staff reviewed these reports and the other materials cited above. RTI prepared a draft summary of each Grantee's final report, compiling the information into eight categories: primary purpose and major goals, role of key partners, major accomplishments and outcomes, enduring systems changes, key challenges, continuing transition barriers, lessons learned and recommendations, and key products.

The summaries were sent to the grant project directors for their review.[6] The RTI project director then conducted an in-depth interview with the grant project director and other grant staff to obtain additional information and to clarify information obtained.

The RTI project director revised the summaries based on the interviews and sent them again to the grant project directors for their final review and approval. Once approved, these summaries became the primary data for this report. All of the final summaries for each Grantee are in Part II of this report.

Limitations of Approach

The information in this report is subject to the limitations of the data and the methods used. Specifically, the content of this report depends on both the quality and thoroughness of each Grantee's final report and other materials.

3. Overview of Enduring System Improvements

Grantees engaged in numerous activities to develop, implement, and improve transition policies, processes, and programs and reported major accomplishments in these areas. These accomplishments are reported in the individual final report summaries for each grant in Part II of this report. A key accomplishment for the Grantees has been the transition of nursing home residents to community-integrated living arrangements. The primary goal for the Grantees was the building of a sustainable infrastructure for nursing home transition programs.

Exhibit 2 presents the total number of nursing facility residents transitioned and diverted from nursing homes during the grant period.[7]

Exhibit 2. Number of Nursing Home Residents Transitioned

State (Grant Type)	Number Transitioned	Number Diverted from Nursing Homes
Alabama (ILP)	45	n/a
Alaska (SP)	99	n/a
Colorado (SP)	124	n/a
Connecticut (SP)	101	n/a
Georgia (ILP)	221	56
Georgia (SP)	20	n/a
Indiana (SP)	110	19
Maryland (ILP)	23	n/a
Maryland (SP)	193	n/a
Massachusetts (SP)	34	9
Michigan (SP)	258	118
New Hampshire (SP)	15	n/a
Texas (ILP)	n/a	n/a
West Virginia (SP)	74	64
Washington (SP)	1,399	n/a
Wisconsin (ILP)	184	n/a
Wisconsin (SP)	471	n/a
Totals	**3,371**	**266**

n/a = not applicable.

Other accomplishments were instrumental in achieving the grants' primary goal: to assure that transition activities would be sustained after the grant ended through enduring system improvements and increased Independent Living Centers (ILC) and state transition capacity.

Grantees were successful in making enduring changes in several key areas. Exhibit 3 lists the enduring changes brought about directly or indirectly through Grantees' activities.

New Funding for Transition Services and Expenses

Successful transitions require case management services and expenditures to move and set up a new household in the community. The cost of these services and expenses will vary depending on the needs of the person transitioning. 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.[8] 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 2001, the highest PNA was $77 and 27 states had PNAs that were $40 a month or less, amounts that are not sufficient to cover transition expenses.

Grantees in 10 states worked successfully to amend waiver programs to include coverage for transition expenses. Most reported adding coverage for rent and utility security deposits, basic household goods, and moving expenses. 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. The Grantee noted that waiver funding is now used to leverage state general revenue funds earmarked for nursing facility transition to expand the types of supports that are available and to increase access to services.

In addition to covering transition services under its Aged and Disabled (A/D) waiver, Texas' Vocational Rehabilitation agency created a new policy to allow payment for relocation assistance as part of an individual's employment plan.

A few states are covering transition expenses solely with state dollars. New Hampshire is funding the transition of individuals with mental illness using state general funds. Georgia appropriated funds for transition expenses not covered by Medicaid. 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 due to complicated applications or lengthy waiting periods. Common Sense funds, which were limited to $1,000 per person, paid for expenses such as security deposits, furniture, utility deposits, and clothing. The State's new transition program also includes a Common Sense Fund, now funded by state general revenues. The Connecticut Association of Centers for Independent Living also has a Common Sense Fund for individuals not eligible for the state program, which is funded through voluntary contributions.

Exhibit 3. Major Types of Enduring System Improvements Achieved by Grantees

	AL-ILP	AK-SP	CO-SP	CT-SP	GA-ILP	GA-SP	IN-SP	MD-ILP	MD-SP	MA-SP	MI-SP	NH-SP	TX-ILP	WA-SP	WV-SP	WI-ILP	WI-SP	Total States
New Funding for Transition Services and Expenses	•	•	•	•		•	•	•	•	•	•	•	•	•		•	•	**15**
a. Transition Services Added to Waiver	•		•					•	•	•	•		•	•		•	•	**10**
b. New Funding for Transition Services and Expenses (Medicaid and/or non-Medicaid)		•		•		•	•					•	•					**6**
c. New non-Medicaid Funding for HCBS When no Waiver Slot is Available						•	•											**2**
Increase in Waiver Slots for People Transitioning				•		•	•				•				•			**5**
Flexible Funding Policies to Enable Money to Follow the Person						•		•	•				•				•	**5**
New Statutes, Policies, and Procedures to Facilitate Transition		•	•	•		•	•	•	•	•		•	•	•	•	•		**13**
Increased ILC Transition Capacity and Collaboration with State on Transitions								•	•	•		•	•	•		•		**7**
New Policy to Increase Access to Affordable and Accessible Housing									•					•				**2**
Continuing Use of Grant-Funded Outreach, Educational, and Technical Materials			•			•		•	•				•	•	•	•		**8**

Massachusetts added transitional support as a service under the Elderly and Mental Retardation/Developmental Disabilities (MR/DD) waivers. These supports include those needed to locate accessible, affordable housing and to develop community skills that will facilitate transition. Examples include moving-related expenses (e.g., security deposits, furnishings, deposits for utility or services access, pest eradication, allergen control, or one-time cleaning prior to occupancy), and costs for recruitment, screening, and training of staff who will support the individual in the community.

Michigan amended its Choice waiver program to allow waiver service providers to furnish up to $3,000 of transition services. Plans projected to total more than $3,000, which includes both transition and support/coordination costs, must be pre-approved. Allowable transition costs include (1) one-time deposits to secure housing or to obtain a lease; (2) utility hook-ups and deposits; (3) furniture, appliances, and moving expenses; and (4) one-time cleaning expenses, including pest eradication and allergen control. The State has also developed a permanent fund to reimburse transition costs not covered by other sources, funded with civil monetary penalties levied on nursing facilities for quality of care violations.

Wisconsin's Governor has instituted a *Community Relocation Initiative* with a goal of transitioning 1,400 individuals. The initiative allows individuals who have been in a nursing home longer than 90 days to obtain transition funds and is providing a means to continue the activities instituted under the NFT State Program Grant.

Finally, some states have chosen to continue the transition program implemented by the grant by using state general revenue funds. Connecticut is now funding five full-time transition coordinators to provide outreach and transition services and one full-time statewide coordinator. The program also funds a toll-free line for nursing facility residents, giving them direct access to a transition coordinator. The program will collect data and conduct analyses to monitor and evaluate the effectiveness of transition procedures.

Increase in Waiver Slots for Individuals Transitioning

Money Follows the Person (MFP) policies allow Medicaid funds budgeted for institutional services to be spent on home and community services when individuals in nursing homes and intermediate care facilities for persons with mental retardation (ICF-MRs) move to the community. Without an MFP policy, waiting lists for waiver services are a major transition barrier for institutional residents wanting to move to the community. To address this barrier, five states increased the number of waiver slots solely for people who are transitioning to the community. 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. In January 2004, the Governor's budget recommendation included $2.2 million for 200 additional slots, which the legislature approved in June 2004.

Michigan has authorized new waiver slots for persons who are transitioning if they have been in a nursing facility 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.

Indiana enacted legislation in 2002 to increase the income limit for waiver services from 100 percent of Supplemental Security Income (SSI) to 300 percent of SSI and increased the number of waiver slots, but required a study to determine the fiscal implications of these changes. Grant funds were used to commission a report. The State initially said the changes would be too expensive, but decided in April 2006 to implement them in July 2006.

Flexible Funding Policies to Enable Money to Follow the Person

Four states developed or continued flexible funding mechanisms to facilitate transitions. Texas authorized the continuation of its MFP policy.[9] As discussed just above, Georgia has allocated state funds to cover one year of home and community services for 145 transitioning individuals for whom there are no waiver slots and creates a slot if they are still in the community after a year.

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 only be generated if a person left a nursing home that was closing or downsizing and the bed was closed.

To assure that Medicaid-eligible nursing facility residents have access to waiver services when no slots are available, Maryland enacted the *Money Follows the Individual Act,* which makes it requires admission to an 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.

New Statutes, Policies, and Procedures to Facilitate Transition

Most Grantees reported the implementation of new policies and procedures to address a wide range of transition challenges and barriers. For example, the Colorado ILCs discussed eligibility and application barriers with the state, which eliminated them by revising the eligibility and application process.

A major challenge states face when developing successful transition programs is designing and implementing feasible and effective processes for identifying nursing home residents who wish to transition to community living. In Georgia, the State has hired a contractor to use the minimum data set (MDS) to help identify individuals in a nursing facility who may want to transition to a community setting. The names of these individuals are given to a case management agency that provides transition services. The State is also using a person-centered care plan developed under the grant to facilitate transitions.

Several Grantees reported 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 Center for Independent Living (CIL) 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 law states that CIL staff and employees or representatives of protection and advocacy agencies shall have reasonable and unaccompanied access to residents of public or private nursing facilities that receive Medicaid reimbursement, to provide information, training, and referral to home and community services programs that can meet their needs. The legislation also requires nursing facilities to provide newly admitted residents with information about home and community service options.

To further assure that nursing home residents have information about community living options, Maryland also enacted the *Money Follows the Individual Accountability Act*, which requires a nursing facility (1) to refer a resident to the Department of Health and Mental Hygiene or its designee for assistance in obtaining home and community services; (2) to review quarterly assessments to identify individuals indicating a preference to live in the community; and (3) to provide specified residents with information and assistance, including transition assistance.

Maryland also modified its *Nurse Practice Act* to permit 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.

Another barrier that can impede transition is lengthy waiting periods 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. Based on the grant's demonstrated cost savings, Alaska also authorized state general funds to continue the transition program beyond the grant period.

One approach to facilitate 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.

The lack of funding for intensive case management services prior to transition can be a major barrier. To address this, Connecticut expanded the use of targeted case management for persons transitioning from nursing homes from 30 days pretransition to 180 days. The targeted case management option is only available for people with mental illness, but the State is considering covering additional eligibility groups.

As a result of high nursing home expenditure and the increased focus on nursing facility transition, several states recognized the need to prevent both unnecessary admissions and unnecessarily long stays that resulted in a loss of housing. Massachusetts instituted in-person screening for Medicaid eligible and potentially eligible nursing facility residents to insure that facilities begin discharge planning at the time of admission. Similarly, New Hampshire now requires an in-person consultation for every Medicaid-eligible individual seeking nursing home placement or home and community services to ensure that community options have been explored.

A potential transition barrier for individuals with extensive physical impairments is that HCBS programs may not provide the services needed 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.

Increased Independent Living Center Transition Capacity and Collaboration with State on Transitions

A primary 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 each other, share effective practices, actively assist one another during transitions, and disseminate the lessons learned. All of the ILP Grantees and two states 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 continue to offer transition services using their own funds. These services include case management and assistance identifying accessible housing, obtaining home modifications, and identifying and helping consumers access public transportation.

In Texas, state agency staff, CIL 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 CILs based in large part on the knowledge and expertise they gained under the grant.

In Washington, the independent living network has traditionally been involved in providing independent living services to individuals living in the community but were rarely involved in transitions. The grant has built the capacity of this network to facilitate and support nursing facility transitions, particularly for long-term nursing home residents. Independent living consultant services are now a resource for local case managers in transition planning.

In Wisconsin, ILP grant staff established a consistent outreach process. 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. Although the State has not allocated funding to cover their services, ILCs continue to provide a greater amount of transition services than they did before the NFT-ILP grant. 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. Involving ILCs in transitioning also is providing consumers with peer support, skill training, and advocacy services that they would otherwise not receive.

Grantees also reported increased transition capacity among state staff. In Washington, state-employed case managers have broadened their scope of work to include the transition of long-stay as well as short-stay nursing facility residents, and are focusing their efforts on persons of all ages rather than primarily on those age 65 and older. In Maryland, the State created a housing specialist position in the waiver's case management agency.

Several Grantees reported that collaborative working relationships with nursing facilities have continued after the grants ended, with nursing facility staff working on transitions with Medicaid and independent case mangers who conduct transition assessments. In Maryland, nursing facility administrators and social workers and directors of nursing who were

previously opposed to allowing advocates to work with nursing facility residents now rely on CIL staff to provide assistance with transition planning. In Georgia, the state program grant staff established a referral system between the two nursing home chains' facilities and the areas' CILs and Area Agencies on Aging, which has been sustained after the grant ended.

Housing

Another purpose of the NFT grants was to improve collaboration among transition stakeholders, including human service agencies, state and federal housing finance agencies, and Public Housing Authorities to make the most effective use of housing options, including the use of HUD Section 8 rental vouchers for individuals who make the transition.

Every Grantee 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 two Grantees reported enduring changes related to housing.

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 assure that persons with disabilities use these units. The State also now requires that units set aside for individuals with disabilities 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.

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. 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.

Connecticut grant staff collaborated with the state housing authority to change its voucher administration plan to prioritize 50 Section 8 vouchers annually for transitioning individuals. Housing and Urban Development (HUD) approved the change in July 2003 and evaluation data showed that the availability of the vouchers decreased transition time by an average of 79 days. However, due to administrative issues with the housing authority, the vouchers have been discontinued and the State's Rental Assistance Program is now working with the NFT program to provide housing subsidies to individuals enrolled in the program.

Continuing Use of Outreach, Educational, and Technical Materials

Eight Grantees reported that transition materials developed under the grant continue to be used after their grants ended. Texas noted that other states as well were using their transition assessment and service planning materials, which are posted on the HCBS.org Web site. Transition training materials developed under the Texas-ILP grant were also used by the State's Real Choice Systems Change MFP grant (FY03) to develop a structured, consistent process for regional coordination of transition activities. Regional coordination groups include contracted relocation services providers, state agency regional supervisors, and the MFP grantee, and they address specific transition problems or issues at an individual and systems level.

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' 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 increased awareness that many nursing home residents can be served in the community and 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 over the next 18 months.

Grant activities in New Hampshire have improved access to services by improving communication among multiple service systems, including the Bureau of Behavioral Health and the Bureau of Elderly and Adult Services. Prior to the grant, persons with multiple disabilities might have had difficulty obtaining the services they need because they are offered through different programs and administered by different state agencies. This was particularly true for individuals with mental illness applying for waiver services. With improved education for field staff, persons with mental illness who meet nursing home level-of-care criteria now face fewer barriers to obtaining waiver services.

In Washington, a multidisciplinary housing team established during the grant period is continuing its work after the grant has ended. The team includes housing authority staff, home and community services social workers, representatives from developmental disabilities service agencies and veterans affairs, and mental health advocates. The team meets monthly to work on a range of issues, including streamlining the housing voucher application process, arranging for intensive housing searches for nursing facility residents when needed, and coordinating with the relevant community service system to ensure appropriate services and supports are in place at the time of transition and thereafter.

4. Overview of Remaining Transition Barriers

Grantees successfully addressed many transition challenges but reported numerous remaining barriers. The major barriers are listed in Exhibit 4 and discussed below.

Lack of Affordable and Accessible Housing

Virtually all Grantees cited the lack of affordable housing and residential care options to address the varied needs of persons with disabilities as they age as a continuing transition barrier in both rural and urban areas. The lack of housing is particularly a problem for individuals eligible for the SSI program, who may not be able to afford housing even with rental assistance. Due to the housing shortage, many individuals who transitioned had to live with family members or in community residential settings because private housing was difficult to find.

Grantees cited a number of factors that contribute to the lack of accessible and affordable housing including: (1) 2- to 3-year waiting lists for subsidized housing and Section 8 vouchers, (2) a low vacancy rate and high demand for apartments, and (3) no requirements or incentives for property owners to list vacancies in housing registries. The HUD requirement for a clear credit history and no criminal background also excluded some nursing facility residents from rental assistance programs.

Some Grantees noted the lack of a full continuum of supportive housing, including group homes, assisted living, supported living, and other residential options, particularly for older adults with mental illness. One Grantee noted that residential care settings that might be suitable have specific admission requirements that some individuals cannot meet, such as the need to be continent and to be able to self-manage medications and self-administer insulin injections.

Although some Grantees were successful in having housing authorities set aside vouchers for transitioning residents, challenges remained in finding accessible, affordable apartments in a very competitive rental market and landlords who are willing to accept vouchers and have environmental modifications made. Wisconsin noted that some housing providers and private landlords are reluctant to rent to people with disabilities, particularly those with mental illness, because they view them as a problem group.

Successful housing searches in a competitive market require a swift, rigorous, and thorough approach and several Grantees said that staff resources were insufficient to carry out such searches. Limited accessible transportation adds to the challenge.

Exhibit 4. Key Continuing Transition Barriers

	AL-SP	AK-SP	CO-SP	CT-SP	GA-ILP	GA-SP	IN-SP	MD-ILP	MD-SP	MA-SP	MI-SP	NH-SP	TX-ILP	WA-SP	WV-SP	WI-ILP	WI-SP	TOTAL
Lack of Affordable and Accessible Housing	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•	•	16
Lack of Home and Community Services	•	•	•	•	•				•	•	•	•	•	•	•	•		13
Lack of Funding for Case Management/Relocation Assistance	•				•		•	•		•	•	•	•	•				9
Restrictive Eligibility Criteria for HCBS	•		•	•						•		•			•			6
Administrative and Bureaucratic Barriers	•	•	•	•			•		•	•	•	•			•	•		11
Resistance to Transition and Independent Living	•	•		•				•	•	•		•			•			8
Shortage of LTC Workers		•										•			•	•	•	5
Lack of Transportation	•	•		•					•	•		•					•	7

Lack of Home and Community Services

Another frequently cited transition challenge was a lack of home and community services, exacerbated by waiver waiting lists and freezes on waiver slots. Some Grantees noted that undertaking transitions was especially challenging in remote rural areas with few community resources. One Grantee stated that allowing states to offer waiver services on a less than statewide basis creates inequities in access to home and community services for nursing home residents seeking transition. West Virginia noted that a prior court decision prohibiting the prioritization of individuals on a waiting list for the MR/DD waiver prevented discussions about prioritizing the State's A/D waiver waiting list for nursing home residents wishing to transition.

In Massachusetts, because there is no HCBS waiver program for persons under age 60 who have only medical needs or physical disabilities, it was difficult to put together a comprehensive service package that would meet the needs of this population. In addition, once in the community, the consumer alone has total responsibility for monitoring and maintaining services.

In addition to a lack of waiver slots, some Grantees cited inadequate budgets for home and community services, particularly for long-term nursing home residents with complex medical needs or who need assistance or supervision to be available 24 hours a day. One Grantee noted that some individuals with multiple diagnoses require services from more than one waiver, which can be very complex to arrange and coordinate.

Others cited a lack of specific services, such as resources for financial management, surrogate decision-makers, guardians, and representative payees for individuals with cognitive impairment. Wisconsin cited lack of timely access to home modifications, durable medical equipment, and assistive devices as significant transition barriers. In some cases, funding for these items was denied.

While 10 states added transition services to their waiver programs, others did not. ILP grant staff in Georgia said that lack of waiver coverage for transition expenses and insufficient waiver slots are continuing transition barriers.

Finally, one Grantee noted that the lack of parity for mental health benefits, particularly in Medicare, and the lack of a wellness and recovery treatment approach for older adults with mental illness in the community prevented transition because individuals with mental illness often cannot obtain the treatment and other services they need to successfully transition to and remain in the community.

Lack of Funding for Case Management/Relocation Assistance

Nine Grantees cited lack of funding for case management and relocation assistance as a continuing transition barrier. Several Grantees noted that transitions in sparsely populated and geographically isolated areas with limited community services required more intensive case management, as did transitions for individuals with complex medical needs. Washington noted that the ability of the State's six CILs to support nursing facility transitions statewide is constrained by a large geographic area to cover as well as a lack of community services.

In Maryland, the ILP grant provided funding and a process for CILs to successfully partner with the State on transition activities. But because the funding and the process were not sustained when the grant ended, the State now has no formal mechanism or reimbursement to assure participation by, or collaboration with, the CILs in the transition process. The State has a contract with another agency to provide case management services for waiver clients, including transition services. CILs can be reimbursed for the provision of some training in consumer direction for people who are transitioning, but this service is infrequently provided. CILs are attempting to continue transition activities with existing staff but are limited by tight budgets.

Massachusetts noted that relocation assistance through targeted case management is available to only a few Medicaid-eligible consumers, and that even for those covered under existing HCBS waivers (MR/DD, Elderly, Traumatic Brain Injury), relocation supports are limited. While case management is available to all elderly persons, not just those eligible for waiver services, it is not at the level needed to plan and implement a move.

Targeted case management is available under the state plan only to young persons with DD under the age of 18 and to persons with MR of all ages whether or not they are under the waiver. However, the targeted case management benefit is also not at the level needed to plan and implement a move. Consequently, both elderly persons and younger adults with DD receiving case management also need "relocation assistance," which is a much more intensive level of assistance to assure that all supports and resources (not just those funded by Medicaid) are in place to enable the person to return to and/or remain in the community.

Some Grantees noted that community agencies and nursing facilities do not have the resources to continue providing the type of relocation assistance provided through the grant. One noted that community providers are not reimbursed to participate in planning meetings prior to discharge and often cannot complete an assessment until a firm discharge date is given. Michigan noted that in most areas of the State, agencies are eligible for only $3,000 per person for transition services and transition program growth is slow. Grant staff believe that paying a higher rate to cover start-up and training costs would provide an incentive to agencies to start transition programs.

Texas reported that it has four contracts with CILs to provide relocation services statewide. Relocation services are more like intensive case management and include assessment of community needs, identification of housing, coordination of medical and personal care needs, transportation, financial supports, and completing the move to a community residence. In Texas, about 10 percent of individuals who transition need these services, according to the Grantee, because they have extensive or complex needs that cannot be adequately addressed by the waiver or other state case management services. However, relocation services are funded by state general revenue funds and are capped. To assure the availability of these services for all who need them and minimize state expenditures, the Grantee believes that the State should cover relocation services either as a Medicaid administrative expense through the waiver program or through the targeted case management option.

Washington noted that because case managers are required to prioritize newly admitted Medicaid-eligible residents for discharge and transition and have limited time to spend on transition activities, they generally work on short-stay resident discharges. Short-stay residents typically have current housing and strong connections to their family and other community supports—key factors assuring a successful transition. Because long-stay residents lack housing, often have weakened community connections, and can be dependent on the institutional environment, their needs can exceed case managers' ability and time to address them. During the grant, the collaboration between case managers and independent living providers who were able to provide intensive supports for these residents was critical to their successful transition.

Restrictive Eligibility Criteria for Home and Community Services

A few Grantees noted that although their states had several waiver programs, people who need services can "fall through the cracks" due to restrictive diagnostic eligibility criteria, restrictive financial eligibility criteria, and a lack of comprehensive services. For example, in Alabama, one waiver covers only individuals over age 18 with specific medical diagnoses, such as spinal cord injury and traumatic brain injury, and the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) waiver is limited to individuals over age 21 with HIV or AIDS. The Elderly and Disabled waiver has no diagnostic requirements but has more stringent financial eligibility criteria than the other waiver programs: 100 percent of SSI compared to 300 percent of SSI. Other Grantees noted that waivers cover different services and that consumers sometimes have to choose between two waivers based on which one will meet most but not all of their needs.

Connecticut noted that the State has several waiver programs for individuals with different needs but some individuals do not meet the specific eligibility criteria for any of these programs and still need services. For example, the Personal Care Assistant waiver requires

participants to self direct or have a conservator. Another problem is that a person with multiple minor needs may not meet a waiver program's functional criteria if it requires a person to have moderate to severe needs. Alternatively, individuals may be eligible for a waiver program that does not provide all of the services they need. For example, the Personal Care Assistant waiver provides only personal care services, but a person may also need home modifications and a personal emergency response system.

In Massachusetts, a large number of nursing home residents who wanted to transition had chronic diseases characterized by episodic flare-ups and remissions (e.g., mental illness, diabetes, multiple sclerosis). Their fluctuating needs for LTC services made it very difficult for them to consistently meet service eligibility criteria and maintain supports. Additionally, the Grantee noted that the eligibility criteria for personal assistance services under the state plan are stringent. To qualify, a person must need physical assistance with at least two ADLs. Although meal preparation and medication oversight and reminders were the most common support needs for many consumers, these needs are no longer counted when determining eligibility.

New Hampshire said that the State's nursing home and waiver level-of-care eligibility criteria require applicants to have a medical need, which excludes many individuals with LTC needs, including those with mental illness. West Virginia noted that some nursing home residents do not meet either the waiver target group criteria, financial eligibility criteria, or the level-of-care criteria. Some who meet all the criteria need services not provided under the waiver, such as ventilator care.

Several states noted that some nursing home residents did not meet waiver level-of-care criteria when seeking transition. Georgia ILP grant staff said that a little less than half of the people transitioned under the grant required no services once living in the community. A few persons needed only home modifications, such as a ramp. They noted that because setting up and coordinating home and community services takes a lot of time and effort, hospital discharge planners often send people to a nursing home after a hospitalization. Once there, they lose their housing, their savings, and their community support network, and need help to transition. In some cases, individuals needed only money for utility security deposits.

Administrative and Bureaucratic Barriers

Eleven Grantees cited a wide range of administrative and bureaucratic transition barriers. In Alabama, inaccurate agency records were not corrected in a timely manner and delayed transitions (e.g., a nursing home resident was listed as deceased by the Social Security Administration and a consumer living in the community could not get waiver services for more than 9 months because the State's records indicated he was still in a nursing home).

Alaska noted that delays in waiver eligibility determinations and service plan development presented barriers for some individuals.

Colorado found that establishing billing procedures and obtaining federal financial participation for the new waiver transition services were very complicated and time consuming, particularly given the small amount of money involved. The maximum reimbursement for transition services under the waiver is $2,000, which includes $800 for transition navigator services and $1,200 for one-time expenses such as security and utility deposits. Although only $100 of this amount is allowed for the initial purchase of basic food items such as milk, the State had to spend a lot of time working with CMS regional and central offices to provide assurances that this amount would not be misused to purchase nonessential food items.

In Massachusetts, consumers and service planners found it difficult and time-consuming to navigate multiple programs and initiatives that provide services to discrete target populations, each with its own eligibility rules, service names, and definitions. The difficulty was increased for individuals with multiple disabilities or co-occurring health conditions because duplicative applications and documentation requirements often led to service delays. Additionally, many programs have a "payer of last resort" policy that requires consumers to expend considerable time and energy documenting their inability to obtain services from other programs.

Massachusetts also noted that consumers cannot obtain equipment they will need in the community until after they transition. As a result, the opportunity is lost to gain familiarity with the equipment with the assistance of nursing facility staff, including occupational and physical therapists. Similarly, individuals are not eligible for community services until after their move. While eligibility is being determined and services authorized, there is a delay in the receipt of essential services such as medications and personal care. The resulting delays can result in medical emergencies and a return to the nursing home.

In New Hampshire, the eligibility determination process for waiver services sometimes took several months and other service arrangements needed to be made before waiver services were authorized. Arranging all of the necessary services and supports in a timely and coordinated manner has been extremely challenging; for example, establishing eligibility for services, arranging for guardians, establishing a representative payee, and obtaining information release forms required by the Health Insurance Portability and Affordability Act. In some cases, it has been difficult to obtain a consultation for individuals with multiple co-occurring conditions, including developmental disabilities, substance abuse disorders, acquired brain injury, and complex medical conditions. In other cases, "turf" issues or lack of staff expertise regarding individuals' specific needs caused delays.

Resistance to Transition and Independent Living

Eight Grantees noted resistance to transition as a major barrier. Resistance is found among family members who do not believe their relative can live in the community or who do not want to have to provide informal care. It is also found among nursing staff who do not believe the individuals can be safely served in the community, particularly those with extensive functional limitations or medical and nursing needs. One Grantee noted the lack of support for the independent living philosophy among physicians and other health care professionals. While such resistance may be overcome with education, it can require a considerable amount of a case manager's time to address and can slow the transition process. However, one Grantee said that opposition or lack of support from families totally impeded transition in some cases, regardless of the person's potential or desire for transition.

Shortage of LTC Workers

Five Grantees cited the LTC workforce shortage as a transition barrier, some noting that low reimbursement rates have a negative impact on the availability of workers and community services. Other Grantees noted that some transitioning residents did not receive community support services in a timely fashion due to a shortage of direct service workers. One Grantee said that addressing workforce issues is difficult because the State does not employ direct care workers and efforts to solve workforce shortages were dependent on multiple local and private agencies over which the State has only minimal control.

Lack of Transportation

Several Grantees noted that the lack of transportation has a negative impact on both individuals with disabilities who want to live in the community and on the personal care workers they need. Because most workers have very low incomes and no cars, they depend on public transportation. Individuals who transition to areas with no public transportation may feel more socially isolated than they did in the nursing home. One Grantee reported that some transitioned individuals returned to the nursing home after a few months in the community because they missed friends and nursing home activities.

Other Barriers

A few Grantees noted that some residents' medical needs, mental health needs, and logistical and personal care needs presented significant transition challenges. Some participants were unable to follow a treatment plan or had a lack of insight into their illness. Others' needs exceeded available community resources, including housing, staff support, and waiver services. Sometimes participants' desires did not match their needs or proved unrealistic. Many were not familiar with the different types of housing, or feared or resisted unfamiliar situations, such as group homes or adult medical day care. Some candidates did not want a "roommate" yet needed live-in assistance. Individuals who needed substance

abuse treatment had difficulty obtaining it in the community. And some individuals with medical problems that needed ongoing nursing oversight could not be served either due to a lack of nursing services or because the cost of such services in the community was too high.

One Grantee noted that the high turnover of nursing facility social workers/discharge planners hindered transitions because of the need for new training. Another obstacle was nursing home reluctance to purchase equipment, such as motorized wheelchairs, which some residents may need to look for community housing. Additional obstacles include conflicts between the individual transitioning and family members or legal representatives and delays in Social Security payments.

ILP grant staff in Wisconsin reported the lack of a systematic method to identify individuals who want to transition and their inability to use MDS data due to help identify residents with transition potential. The ILCs continue to pursue collaboration with state staff to use MDS data, but to date have not been successful.

Grantees also mentioned larger systemic and societal transition barriers. One Grantee said a major transition barrier is poverty because many individuals with disabilities simply cannot afford to live in the community. Several Grantees said that a federal barrier to transition is that the Medicaid program considers home and community services to be optional while nursing home services are mandatory. Others noted that while grant activities have brought about significant changes in state policies that assist people who want to transition from nursing facilities, state Medicaid funding retains an institutional bias. One Grantee said in order for the State's *Olmstead* plan to be fully realized, institutions need to be the last resort for the provision of LTC services.

One Grantee felt that the lack of global budgeting for all of the State's LTC services is a barrier to serving consumers in the community setting of their choice, and a few Grantees said that until all states enact Money Follows the Person funding, people with disabilities will not be assured a choice between home and community services and institutional care.

Finally, a number of Grantees went beyond transition policy and noted the need for nursing home diversion programs. A Grantee in Indiana said that the State's pre-admission screening law has numerous exceptions, many people are admitted to nursing homes without being screened, and the process does not discuss the range of home and community service options. Wisconsin said that the lack of an effective statewide nursing home diversion program and a long waiting list for waiver services results in many people being unnecessarily institutionalized and losing their homes. Once in a nursing home, SSI-eligible residents receive only a personal needs allowance of only $30 a month, making it impossible to save enough to transition back to the community without government assistance.

5. Overview of Lessons Learned and Recommendations

In the course of implementing their initiatives, Grantees obtained experience in developing and operating NFT programs, as well as working to develop and implement policies to assure their sustainability. Grantees reported numerous lessons learned, which they believe can assist other states and ILCs to develop sustainable NFT programs. They also cited many continuing transition barriers and made recommendations to address them.

Ensuring the Involvement of All Stakeholders

Most Grantees agreed that prior to implementing an NFT initiative or program, it is essential to obtain buy-in from all stakeholders and assure that they are "on board" from the outset. Stakeholders include consumers, families, nursing facility administrators and discharge planners, HCBS providers, ILCs, consumer advocates, housing developers, housing authorities, and Medicaid agency staff. One Grantee stressed the importance of including cross-disability and consumer-controlled organizations in the development of NFT policy. The basic lesson learned was that any planning to introduce or change policies or practices should involve individuals who will be affected by the changes.

They specifically stressed the importance of developing strong collegial relationships with nursing facility staff to assure their involvement as full partners both in individual transition efforts and in any rethinking and redesign of the current LTC system. They also highlighted the importance of helping advocates and providers find common ground regarding goals and parameters for working together.

One Grantee reported that some ILCs and nursing facilities found it extremely difficult to work together. Involving the Medicaid agency in the early stages of transition initiatives could have helped to facilitate more cooperative and effective working relationships by, for example, having agency staff meet with state nursing home associations and ILCs to discuss and establish in advance how stakeholders will communicate and work together on transition activities. While efforts to involve stakeholders may be time consuming, the good will and improved communication they can generate will ultimately contribute to successful transitions.

Another Grantee felt that two approaches were needed for a successful transition program: (1) a "top-down" approach eliciting the involvement and support of the leadership of key agencies to reduce barriers and urge cooperation, and (2) a "bottom-up" approach of fostering cooperative staff relationships in the field to ease referrals and address case specifics.

For example, some nursing home staff were reluctant to refer individuals for transition for a variety of reasons, including financial disincentives and fear that residents would not have

their needs met in the community. When grant staff developed relationships with nursing home staff and addressed their concerns, they were more likely to make referrals. To increase referrals of potential transition candidates by nursing facilities, it can also be helpful if agency directors communicate with them about the State's transition goals.

Finally, a Grantee emphasized the importance of developing the internal infrastructure needed to assure successful transitions, including (1) developing strong relationships among the community organizations that provide services and supports; (2) identifying a range of community resources for individuals, including overall support as well as social and recreational opportunities; and (3) ensuring that the entities responsible for case management, such as AAAs, prioritize the transition process and designate specific staff to focus on transition.

Design and Operation of NFT Programs

When designing and implementing an NFT program, Grantees noted the importance of utilizing technical assistance to learn about best practices, seeking information from other states to identify solutions to common challenges, and utilizing a quality assurance framework for both transition activities and home and community services. Additional lessons learned regarding various program components are presented next.

Outreach and Education

Outreach and education are the first steps of the transition process. Because nursing facility residents may need time to process information and make decisions, outreach and education efforts may need to be provided several times using various approaches to be effective. Due to staff turnover, educating nursing home staff and discharge planners as well as state agencies and state legislature staff about transition issues is not a one-time effort. Transition programs need to be prepared to provide education on an ongoing basis.

Undertaking education activities early in the transition process also helps to decrease resistance to transition based on negative preconceptions, and encourages broad involvement in transition planning processes at an early stage. Education of paid and volunteer transition staff as well as families, judges, and guardians about the rights of individuals in nursing facilities and the availability of home and community services also helps to assure the success of outreach activities.

In some instances, transitioned individuals returned to a nursing home. While some returned for medical reasons, others returned because they did not receive authorized services due to workforce shortages, and others because community living was not what they thought it would be. Some did not feel secure without the 24-hour availability of staff; some missed friends and being around other people; and others missed nursing home activities.

To assure that individuals will remain in the community once transitioned, they must have realistic expectations for community living. In particular, they must understand that they will not have the same level of supports and services available in a nursing home. Additionally, while case managers can help to connect individuals with church, social, and recreational groups, individuals will need to take active roles in establishing their own networks for social interactions and activities.

Case Management

Adequately funded dedicated case management is essential for successful transitions. The number of hours needed for a successful transition varies considerably depending on the extent of an individual's needs and the availability of housing and informal supports. Transition programs must be available to offer guidance and support for at least 6 months after the transition to assure that the individual does not permanently return to the nursing home. For example, if recently transitioned individuals are admitted to a hospital and then discharged to a nursing home, intensive case management may be needed for a short period of time to assure that the stay is as brief as possible and that community housing is not lost.

Successfully addressing housing issues requires a great deal of time and effort just to understand how the housing system works. Using housing specialists in the transition process may be the most effective approach to locating affordable accessible housing. One Grantee noted that it may be easier for independent living providers to form collaborative relationships with local case management providers than to attempt to institute these relationships at the state level through the Medicaid agency. This is particularly true when working on issues that can vary statewide, such as housing and transportation.

Flexible Funding

It is essential to have a source of flexible funds to cover any transition expenses not reimbursable through other sources. Flexible funds are also essential to provide "bridge" funding when coverage of essential services and supports is delayed.

Peer Supports

While it may be difficult initially for CILs to find people who have transitioned who are willing to help others to transition, activities to promote self-advocacy can be effective. A well-matched, trained peer outreach advocate can be an important resource to help individuals transition to the community. Consumers' reactions to peers are markedly different than their reaction to professionals because peers are able to share their personal experiences about how they have overcome barriers to independence in ways that professionals cannot.

Having a role model—someone who has already transitioned and is active and doing well in the community—can bring hope to nursing home residents who may be skeptical that they can make the transition. Peers can show them how independence is possible. However, matching those transitioning with a peer of a similar age and lifestyle is not always possible given existing resources, and some individuals prefer to receive advice from professionals or from persons they know.

Data Collection

Comprehensive data are needed to document a transition program's cost effectiveness to convince the State to fund transition expenses and waiver slots. If technical assistance to develop methods for data collection and analysis are needed, it should be obtained before the program is implemented. While having data to document the success of relocations is critical, policy makers also respond to personal stories. Programs need to ensure that their data reports have a "face."

State Policy

Recommendations for State Policy

Grantees made many recommendations for changes in state policy to better support transitions, some requiring regulatory or administrative rule changes and others new legislation. Some of the recommendations were state-specific, but many applied generally to all states.

Medicaid

Most of the Grantees' recommendations addressed Medicaid policy, including:

- Require nursing homes to provide information about home and community services to newly admitted residents.
- Establish a "fast track" process for eligibility determinations and service approvals for nursing facility residents who are transitioning.
- Provide the same financial protections for the spouses of waiver participants as is provided for the spouses of nursing home residents. Doing so will eliminate financial disincentives to transition for those nursing home residents who have community-dwelling spouses.
- Cover counseling services specifically designed for people transitioning to explain the process and educate them on issues involved in a successful transition.
- Have dedicated Medicaid case management staff to move transitions at a faster pace.

- Allow higher personal needs allowance for persons on SSI or SSDI who are actively planning transitions to enable them to save money to cover transition expenses.

- Combine waiver programs to simplify service delivery for individuals with multiple diagnoses who require services from more than one waiver.

- Provide relocation assistance for all Medicaid-eligible persons who are transitioning, whether or not they are eligible for a waiver program.

- Cover transition services as either a Medicaid administrative expense through the waiver program or through the targeted case management option to assure their availability for all who need them and to maximize use of state dollars.

Flexible Funding

- Provide seamless funding of LTC services and supports so that individuals have options from which to choose without the limitations imposed by funding sources. Seamless funding approaches that can address lack of services due to waiver program waiting lists include global budgeting for all LTC services and supports and MFP policies.

- Offer a "cash and counseling" service model to help to assure that all individuals can receive all of the services they need in the community setting of their choice.

- Provide flexible transition funds during transitions, not just to cover rental and utility security deposits and essential household items, but to address the service gaps during the critical period immediately after discharge when all home and community services are not yet in place.

Administration

- Develop specific guidelines and protocols for both planning and implementing NFT programs. In particular the roles and responsibilities of the transition planning team must be clear, including not only hospital and nursing home discharge planners, but also community support providers who will implement the program.

- Develop a state-level integrated information system to help people identify transition resources, support collaborative service planning and coordination, and provide cost data. Such a system is needed to link transportation providers, housing providers, and LTC service and supports providers with consumers to develop and initiate successful transition plans.

Other recommendations

- Medicaid staff and case managers need to develop a solid understanding of Project ACCESS rental assistance vouchers to facilitate nursing facility transition.

- Transition activities cannot be operated in isolation of ongoing programs. Transition programs should either be an integral component of state waiver program(s) or, at the least, coordinated with waiver programs. Doing so eliminates the administrative costs of a separate, stand-alone transition program and utilizes the extensive experience of waiver case managers. It also allows faster start-up because much of the infrastructure is already in place, from computers to Medicaid billing systems.

Nursing Home Diversion

Require a formal process to assure that everyone applying for nursing facility admission is assessed for community living options.

Single Entry Points

- Design and mandate the use of a single application form for all LTC services and supports and housing.
- Provide benefits counseling specific to persons who are interested in transitioning from nursing facilities.
- Establish an adequately staffed statewide single point of entry that will divert people from nursing homes, prevent long nursing home stays, and transition people back to the community.

Housing

- Increase funding for rental assistance and home modifications such as widening doors and installing ramps and grab bars.
- Redirect funding from developing age- and disability-segregated housing to tenant-based rental assistance programs that allow individuals more choice in selecting community-integrated housing.
- Target housing assistance to people at the lowest income levels.
- Expand HUD's capacity to monitor and enforce accessibility standards.

Federal Policy

- The federal government should increase the federal match for waiver expenses to 100 percent for a period of 12 months following a transition from an institution to the community to provide a major incentive for states to initiate policies to transition more people.
- Federal policy and regulations should emphasize and promote community living as the "gold standard" of LTC and require waivers for institutional/nursing facility services.

- Home and community services should be required on a statewide basis. Allowing states to offer waiver services on a less than statewide basis creates inequities in access to home and community services for nursing home residents seeking transition.

- HUD should provide additional Section 8 vouchers, with a proportion of them set aside for individuals transitioning from nursing facilities.

- Revise the MDS Resident Assessment Instrument (RAI) to provide information to assist transition efforts: (1) Add a question asking residents if they will authorize the release of their medical information to a third party—either a caregiver, a transition program, case manger, or another designee. Without this authorization, once the MDS data are in the CMS repository, it is necessary to get data use agreements to be able to use the data to identify people who want to transition. (2) Move question Q1a to the beginning of the MDS RAI so that the first question individuals are asked when being assessed is whether they want to return to the community. (3) Add a question about the individual's housing so that transition programs can easily identify individuals at risk of losing their housing.

6. Conclusions

The LTC system is heavily tilted towards 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 system. This paper reports on the activities and experiences of the FY 2001 Nursing Facility Transition Grants of the Real Choice Systems Change program. Once fully implemented, nursing facility transition programs identify people in nursing homes or intermediate care facilities for the mentally retarded (ICF-MRs) who want to return to community living and help them to do so. These grants either directly established and operated nursing facility transition programs or helped to establish the infrastructure necessary for such programs.

Grantees reported a wide range of enduring system improvements that directly and indirectly helped to create a more balanced delivery system. These activities included:

- Establishing new funding for transition services and expenses.
- Increasing the number of waiver slots for individuals transitioning to the community.
- Enacting new statutes and developing new policies and procedures to facilitate transitions.
- Increasing Independent Living Center transition capacity and collaboration with the state on transitions.
- Increasing the supply of affordable and accessible housing.
- Increasing outreach and the use of educational and technical materials.
- Acting as a catalyst for additional systems change activities.

Despite these accomplishments, Grantees found that many barriers remain to transitioning individuals from institutions to the community.

- Many residents of institutions have no home to go to and affordable and accessible housing is scarce, forcing some beneficiaries to rely on residential care facilities or families. Affordable housing is particularly scarce for persons receiving SSI, who have very low incomes. Compounding the difficulty is that less expensive housing tends to be in more outlying areas where essential public transportation is less available.
- In many states, the home and community service system does not provide the amount, duration and scope of services needed by people with severe disabilities. Medicaid home and community-based services waivers vary greatly in the range of services they

provide and 14 states did not cover personal care services as a state plan benefit in FY 2005.

- Transitioning individuals from nursing homes and ICF-MRs to the community is difficult, time consuming and requires a variety of expenses, such as apartment security deposits, that are beyond the scope of traditional Medicaid programs or even many waiver programs. In many states, funding for case management and transition services is limited and, in some cases, is not adequate to the needs of people trying to move to the community.

- Financial and functional eligibility criteria for Medicaid home and community services is restrictive, and states vary considerably in the comprehensiveness of their coverage of these services, leaving some people unable to qualify for services in the community. Depending on the specific eligibility criteria, some people can qualify for expensive institutional care, but not for potentially less expensive services in the community. In addition, 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, creating a strong financial disincentive for married institutional residents to return to the community.

- 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.

- Many providers, government officials and family members are skeptical of the concept of nursing facility transition programs and do not believe that nursing home and other institutional residents can successfully return individuals to the community. In addition, the nursing home and ICF-MR industries may have concerns that transition programs will adversely affect their occupancy rates and profitability.

- 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 physical demands and sometimes difficult psychological character of the work, are barriers to recruiting staff into long-term care.

- Finally, people with disabilities rely heavily on public transportation to participate in community activities. In many areas, public transportation is simply not available; in other areas, it is infrequently provided and not disability-friendly.

The information in this report is designed to help states address these barriers so that no one has to live in a nursing home or an ICF-MR simply due to the lack of adequate supports in the community. It is particularly important to assure this infrastructure is in place as the American population ages and the need for long-term care increases. Transitioning nursing home and other institutional residents to the community can reduce the need for new nursing home construction in the future and help create a system more responsive to the desires of people of all ages with disabilities.

Notes

[1] In FY 2005, reported Medicaid spending for nursing home expenditures was $47.2 billion and for intermediate care facilities for people with mental retardation (ICFs/MR) was $12.1 billion. Expenditures for community-based LTC services were $35.2 billion and HCBS waivers accounted for two-thirds of this spending.

[2] The Systems Change Grant Program also funded Real Choice grants in FY 2001 and several states with these grants used them to pilot and/or implement transition and diversion initiatives.

[3] Grants awarded in FY 2005 are called Systems Transformation Grants. Reports about their activities and accomplishments wil be prepared by a different CMS contractor.

[4] Most of the FY 2002 Grantees received no-cost grant extensions and will be completing their activities September 30, 2006. Their final reports are due to CMS on December 31, 2006 and RTI will prepare two final reports for these Grantees in the following months.

RTI will prepare final reports for the FY 2003 Grantees in early 2008 and final reports for the FY 2004 Grantees in early 2009.

[5] Report is available at http://www.hcbs.org/files/74/3656/NFT_final_web.pdf

[6] In some cases, grant staff—including the project director—no longer worked for the state agency that was awarded the grant. In this instance, RTI staff asked to speak to the person most knowledgeable about the grant.

[7] The grant period for most Grantees was 4 years (October 1, 2001 through September 30, 2005).

[8] The minimum $30 PNA amount was set by federal law in 1988 and has not increased since then. Persons eligible for SSI receive only $30 a month from the Social Security Administration. Bruen, B., Wiener, J. M., and Thomas, S. (November 2003). Medicaid Eligibility Policy for Aged, Blind, and Disabled Beneficiaries. Washington, DC: AARP Public Policy Institute.

[9] 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.

Part II.

Final Report Summaries

ALABAMA

Nursing Facility Transitions—Independent Living Partnership Grant

Primary Purpose and Major Goals

The grant's primary purpose was to assist nursing home residents in five counties who want to live in the community to obtain transition services and ongoing long-term services and supports. The grant had three major goals: (1) to increase awareness about transition and home and community services among nursing home residents and their families; (2) to assist nursing home residents who want to transition to the community to do so; and (3) to recruit, hire, and train qualified personnel who are committed to the philosophy of independent living and person-centered planning to assist nursing home residents in transitioning to the community.

The grant was implemented by the Mid-Alabama Chapter of the Alabama Coalition of Citizens with Disabilities, also known as the Birmingham Independent Living Center.

Role of Key Partners

- The Mobile Independent Living Center (ILC) and the Montgomery Center for Independent Living (CIL) provided nursing home transition services, with technical support from the Birmingham Independent Living Center (BILC).
- The Alabama Department of Senior Services' Ombudsman program identified people in nursing homes wishing to return to the community.
- The project Implementation Team, comprising representatives of state, local, and nonprofit agencies, developed partnerships to solve problems, promote consumer transitions, and prevent the re-institutionalization of individuals once transitioned. Members included the State of Alabama Independent Living Program, the Jefferson County Housing Authority (JCHA), the Jefferson County Office of Senior Citizens, the state Ombudsman Program, and the Office of Senior Citizens Services.
- The staff of JCHA provided extensive information and advice about obtaining housing vouchers and advocated for vouchers for individuals transitioning. In one case, a housing authority required a nursing home resident to stand in line to get a voucher and JCHA advised BILC how the requirement could be waived as a reasonable accommodation.
- The Alabama Handicapped Association, a consumer organization of people with disabilities, provided peer outreach advocacy services and ongoing peer support before, during, and after transition.
- Faith-based groups assisted consumers transitioning from nursing homes to the community, providing meals and transportation.

Major Accomplishments and Outcomes

- Grant staff and partners increased awareness of the availability of transition and home and community services among nursing home residents and their families through various methods including the distribution of a transition guide to 1,200 nursing home residents and staff.
- Grant staff developed a consumer-directed, person-centered independent living transition planning model and a policy and procedure manual for implementing it.
- Grant staff and Peer Outreach Advocates relocated 45 nursing facility residents to the community. All but a few moved into their own house or apartment and only three returned to nursing homes within 3 months of having transitioned.
- Grant staff trained 10 Peer Outreach Advocates to provide outreach to nursing home residents.

Enduring Systems Change

- ILCs now recognize nursing facility transitions (NFT) as a priority. The BILC and the Mobile ILC will continue offering transition services after the grant ends using their own funds. These services include case management and assistance identifying accessible housing or obtaining home modifications, and identifying and accessing public transportation.
- ILCs gained considerable transition knowledge and experience during the grant, and they are now viewed as NFT leaders.
- The grant helped the ILCs to develop ongoing relationships with key agency staff and advocates, which will continue when the grant ends. For example, the project Implementation Team is continuing its activities after the grant ends. It is functioning as a Long Term Care Coalition working to enact policy changes needed to increase the availability of home and community services for persons of all ages with disabilities.

  The Team worked with members of the state legislature to introduce a budgetary amendment to establish a Money Follows the Person (MFP) policy modeled on Texas' Rider 37. The Team 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.
- Since grant funding ended, some Peer Outreach Advocates continue to work with the ILCs on a volunteer basis.
- The ILCs and grant partners advocated for the provision of transition services in the waiver program and after the grant ended, the Medicaid Commissioner committed to covering transition services under several waiver programs in October 2006.

Key Challenges

- During the grant period, the State did not pay for transition services under its waiver programs. As a result, nursing home residents could not receive an eligibility assessment or case management services until the day they left the nursing home, which resulted in long delays in receiving services. Some waiver programs would not allow nursing home residents to get on the waiver waiting list until they moved out. In some situations, ILCs had to arrange services from other sources and informal care from families until waiver services were authorized. This situation has led to some residents with significant needs staying in the nursing home because they do not want to risk being in the community without services.
- Inaccurate agency records were not corrected in a timely manner and delayed transitions (e.g., a nursing home resident was listed as deceased by the Social Security Administration and a consumer living in the community could not get waiver services for over 9 months because the State's records indicated he was still in a nursing home).
- Insufficient waiver slots and limited services and supports needed to live in home and community settings, such as adaptive equipment and personal emergency response systems, presented a major challenge.
- State personnel who supported the grant initially left before implementation and the state Medicaid agency did not consider grant implementation to be a priority. Consequently, state staff did not return calls in a timely manner and lack of follow-up was common.
- A constellation of challenges impeded transitions: (1) lack of affordable, accessible, and community-integrated housing; (2) a complex and lengthy process to establish eligibility for housing subsidies; (3) lack of accessible transportation throughout most of the State; (4) failure of some doctors and social workers to understand and accept the independent living philosophy; (5) information about home and community service options is not always readily available; (6) service providers often do not communicate effectively; and (7) persons who need substance abuse treatment have difficulty obtaining it in the community.

Continuing Transition Barriers

All of the key challenges cited above remain with the following continuing barriers.

General

- Lack of information about home and community services and CILs contributes to unnecessary institutionalization.
- Lack of state leadership and commitment to finalize and implement an Olmstead plan that would make nursing facility transition a priority is a continuing barrier.

State

- The State has a continuing funding bias toward nursing home care with insufficient waiver slots and an extensive waiting list, which varies by waiver and geographical area.
- Although there are several waiver programs, people who need services "fall through the cracks" due to restrictive diagnostic eligibility criteria, restrictive financial eligibility criteria, and a lack of comprehensive services. The State of Alabama Independent Living (SAIL) waiver covers only individuals over age 18 with specific medical diagnosis, such as spinal cord injury and traumatic brain injury, and the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) waiver is limited to individuals over age 21 with HIV or AIDS.

  The Elderly and Disabled (E&D) waiver has no diagnostic requirements but its financial eligibility criteria are more stringent than the other waiver programs: it only serves people at 100 percent of Supplemental Security Income (SSI), whereas the SAIL waiver serves people who are at 300 percent of SSI. The SAIL waiver covers assistive technology and personal emergency response systems but the E&D waiver does not. The E&D waiver program covers home delivered meals but the SAIL waiver does not.
- The State does not have an MFP policy. The MFP provision that was considered by the state legislature failed to be enacted in April 2006, due in part to the public opposition of the nursing home lobby, which raised safety concerns and disputed the cost savings of home care.
- None of the waiver programs cover transition services or fund transition expenses such as rent and utility security deposits. However, the Medicaid Commissioner has committed to covering case management services prior to discharge, pending CMS approval of proposed waiver amendments.

Federal

- Federal Medicaid policy remains institutionally biased because nursing home services are a mandatory benefit and home and community services are optional benefits.

Lessons Learned and Recommendations

- The Medicaid program should require nursing homes to provide information about home and community services to newly admitted residents.
- A well-matched, trained peer outreach advocate is an important resource to help individuals transition to the community. Consumers' reactions to peers are markedly different than their reaction to professionals because peers are able to share their personal experiences about how they have personally overcome barriers to independence in ways that professionals cannot. Having a role model—someone who has already transitioned and is active and doing well in the community—can bring hope to nursing home residents who may be skeptical that they can make the transition. Peers can show them how independence is possible.

Key Products

Outreach Materials

Grant staff produced a transition guide for nursing home residents and staff.

Educational and Training Materials

Grant staff developed a manual, *Partnerships to Independence: An Advocate's Guide to Nursing Home Transition*, which is available on CD-ROM and in hard copy. The project's ILCs are distributing the guide to advocates, service providers, state agency personnel and elected officials, and to additional ILCs in both Alabama and other states.

ALASKA

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to address deficiencies in housing, direct service providers, transportation, and resource information in order to enable successful transitions from nursing facilities to the community. The grant had two major goals: (1) to provide services to transition people from nursing facilities to the community, and (2) to develop an enduring system to transition and divert people from nursing facilities to the community to the extent they desire.

The grant was awarded to the Division of Senior Services and was managed by the State Independent Living Council for 6 months. When the Division of Senior Services and the Division of Developmental Disabilities merged, grant management reverted to the new Division of Senior and Disabilities Services.

Role of Key Participating Partners

- The Alaska Housing Finance Corporation provided rental assistance vouchers for individuals who were transitioning.
- The grant subcontracted with the Alzheimer's Resource Agency (ARA) to administer transition funds for nursing home residents age 60 and older. ARA also provided some care coordination.
- The grant subcontracted with the Kenai Peninsula Independent Living Center (ILC) to provide transition services, including counseling and assessment of clients for readiness to transition, and obtaining essential household items such as kitchen utensils and furniture. The ILC also administered transition funds for nursing home residents under age 60.
- A Consumer Task Force (CTF) comprising Medicaid recipients and consumer advocates was formed to provide oversight of the Nursing Facility Transitions (NFT) Grant and two other federal CMS grants received at the same time, the Real Choice Systems Change Grant and the Community-Integrated Personal Assistance Services and Supports Grant. The CTF met quarterly to review progress and offer policy recommendations to the Division of Senior and Disabilities Services. In addition, CTF subcommittees worked with each of the grant projects on a more regular basis as needed and CTF members attended grant staff meetings in person and via conference call.
- The Division of Medical Assistance, the single state Medicaid agency, worked with grant staff to expedite eligibility determinations and to provide services in a timely manner.
- The University of Alaska Anchorage, Center for Human Development collected data and conducted an evaluation of grant activities.

Major Accomplishments and Outcomes

- The Transition Program established itself as the means for nursing home residents to realize a measure of self-determination through a more independent living situation. It has gained the attention of nursing facility administrators and discharge planners in the majority of the State's 14 nursing facilities, as well as administrators within the Alaska Department of Health and Human Service's Division of Senior and Disabilities Services.
- Grant staff developed a systematic approach to identify and recruit potential transition candidates, developed an administrative infrastructure to expend transition funds and facilitate transitions, and designed and developed an information processing system to track the transition process for individuals while simultaneously providing aggregate summaries of transition efforts. The information processing system tracks data across all aspects of the transition experience, including: nursing facility stay information, family member contacts, discharge planner and care coordinator contacts, transition costs, and length of transition process.
- The Division and its key partners assisted 99 individuals to transition to their own homes or other community settings. The Division was responsible for education, information dissemination, outreach, and coordination of the transition process, which included working with nursing facility staff to identify transition candidates, assess transition and community needs, provide care counseling, and arrange for peer counseling when desired by the transitioning individual. The majority of those transitioned remained in the community, as determined by surveys conducted in 2004 and 2005, and 91 percent reported that their health and the quality of their lives improved or remained the same since leaving a nursing facility.
- Transitioning suitable candidates to the community has opened up limited beds for others who require nursing facility placement, thereby reducing the need for new nursing home construction. It has also opened up nursing home beds so that people in wait-day beds of acute care facilities have a placement opportunity, thereby saving a significant amount of funds that would have otherwise been spent keeping the person in an acute care setting.

Enduring Systems Changes

- The Division of Senior and Disabilities Services developed an administrative infrastructure to fast-track the waiver assessment process for persons applying for transition funds. In addition, the Division's long-term care staff instituted a new process for identifying potential candidates by notifying the grant project director of requests for authorization of nursing facility admissions.
- The grant project demonstrated detailed cost savings to both state and Medicaid programs, resulting in legislative budget approval to continue the transition program beyond the grant period supported by state general funds.

Key Challenges

- An early challenge was the resistance by nursing facilities to the idea of transitioning "their" residents. Grant staff were able to overcome the majority of resistance by assisting nursing facility staff with discharge planning, particularly with clients who might otherwise not have the resources to transition to the community.
- Family members, care coordinators, and discharge planners identified a number of areas as obstacles to overcome in the transition process: (1) locating sufficiently accessible and affordable housing, including extended wait times for environmental modifications to be completed; (2) resistance from family members; (3) inadequate public transportation services; (4) lack of home and community services and supports—particularly in small, geographically isolated towns; and (5) the presence of medical problems that needed ongoing nursing oversight.
- Delays in waiver eligibility determinations, service plan development, and locating appropriate personal care assistant services prior to transition presented barriers for some individuals.

Continuing Transition Barriers

The major continuing challenge is the lack of affordable and accessible housing, particularly in the villages and, to a large extent, in the regional and urban centers. The original New Freedom Initiative directed HUD to provide housing vouchers, but Alaska has not had an increase in vouchers in four years.

Lessons Learned and Recommendations

Before implementing a transition program, it is very important to involve and obtain buy-in from all stakeholders. In particular, you need to develop strong relationships with nursing facility staff and state agency staff and management.

Key Products

Outreach and Educational Materials

Grant staff designed a brochure called *Going Home* that explained the NFT program in detail and provided information about nursing facility residents' rights, program eligibility, the transition process, and contact information. The brochure was distributed to nursing home residents and staff, care coordinators, and ILCs.

Technical Materials

- Grant staff designed a Nursing Facility Transition Funds Application form, with information about which services and items were available under the grant as a one-time transition expense and program eligibility criteria.
- Grant staff designed a contract for program participants to sign, which included authorization for the care coordinator to aid the transition from the initial planning stage

through the actual transition and follow up, and a release from responsibility for the entire transition team for any consequences to health resulting from a transition to the community care and/or a residential setting. Program participants have the option to revoke the contract at any time.

Reports

Grant staff prepared three internal reports: *Summary of Transition Trends of Medicaid Recipients in Alaskan Nursing Facilities April 2001 through March 2004*; *Summary of Best Practice Standards for Select Nursing Home-to-Community Transitions Models*; and *Final Report for Alaska's Nursing Facilities Transition Program: A Centers for Medicare and Medicaid Services Grant Funded Initiative*, prepared for the Division of Senior and Disabilities Services by The Center for Human Development, University of Alaska Anchorage. The final report includes cost data that demonstrates significant savings to the state Medicaid system and consumer satisfaction survey results.

COLORADO

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to create infrastructure at the state and local level to transition consumers from nursing facilities into the community. The grant had three major goals: (1) to build capacity across the State to conduct outreach and to support the transition of individuals residing in nursing facilities to a community-integrated living arrangement, (2) to assure that information about the transition process and community living is available in appropriate formats for individuals with varying cognitive abilities, and (3) to assure that individuals desiring transition have the supports necessary to sustain long-term residence and participation in the community.

The grant was awarded to the Department of Health Care Policy and Financing, who partnered with Colorado's 10 Independent Living Centers (ILCs) to achieve these goals. The State hired one of the ILCs—the Center for People with Disabilities—to serve as the primary contractor to administer grant funds awarded to the other nine ILCs for transition coordination services (called navigator services).

Role of Key Participating Partners

- ILCs worked very closely with the grant administrator to build closer relationships within the ILC network itself and with single-entry-point case managers across the State to better identify and serve individuals interested in transitioning.
- To build linkages within the disability community to support transitions, the grant administrator, representatives from Colorado's ILCs, consumers, a nursing facility administrator, a representative from the state Ombudsman program, and representatives from the Department of Human Services participated in a consumer task force which oversaw grant activities.

Major Accomplishments and Outcomes

- With leadership from the Center for People with Disabilities, the ILCs built their own transition capacity and increased efforts to coordinate their transition activities with Colorado's single-entry-point caseworkers. The ILCs directly informed 942 nursing facility residents of their right to live outside an institution and assisted in the transition of 124 people from nursing facilities to the community.
- The Department of Health Care Policy and Financing collected data about successful transitions under the grant and presented it to the Colorado General Assembly to support a proposal to cover transition services under the Elderly, Blind, and Disabled (EBD) waiver program. In May 2004, the legislature authorized coverage of transition services under the EBD waiver program, and the Department conducted training with case managers across the State to explain these services.

- To build long-term capacity to support transition activities by ILCs, single-entry-point case managers, and transition coordination agencies that coordinate the delivery of community transition services under the waiver program, the Center for People with Disabilities developed a *Handbook for Transition Navigators.* The Center also developed a DVD with information about the transition process and community living options for individuals with limited verbal communication. The DVD was sent to each case management agency in the State's single-entry-point system to use when relevant.

Enduring Systems Change

The grant directly resulted in the coverage of transition services under the Elderly, Blind, and Disabled waiver program. This is a major systems change that will ensure the continuation of transition activities after the grant ends.

Key Challenges

- The ILC grant navigators and the grant administrator reported that securing affordable and accessible housing posed one of the greatest challenges to transitioning people to the community. Despite the availability of HUD Project Access vouchers targeted to individuals transitioning out of nursing facilities, many transitions were delayed due to the lack of appropriate housing. Grant navigators also reported that the criminal history of several clients created difficulties in securing housing. When a criminal background posed an impediment to transition, grant navigators advocated on behalf of the affected clients.
- Grant navigators and the grant administrator reported that outreach and resource identification in rural and frontier areas proved to be difficult. Navigators were only able to complete 25 transitions in those areas. Due to the limited resources, grant navigators spent more time per transition on average on frontier and rural transitions than did navigators on urban transitions.

Continuing Transition Barriers

Establishing billing procedures and obtaining federal financial participation for the new waiver transition services was very complicated and time consuming, particularly given the small amount of money involved. The maximum reimbursement for transition services under the waiver is $2,000, which includes $800 for transition navigator services and $1,200 for one-time expenses such as security and utility deposits. Although only $100 of this amount is allowed for the initial purchase of basic food items such as milk, the State had to spend a lot of time working with CMS regional and central offices to provide assurances that this amount would not be misused to purchase nonessential food items.

Lessons Learned and Recommendations

Some ILCs and nursing facilities found it extremely difficult to work together. To facilitate more cooperative and effective working relationships, the state Medicaid agency may need

to be involved in the early stages of transition initiatives. For example, agency staff could meet with state nursing home associations and ILCs to discuss and establish in advance how stakeholders will communicate and work together on transition activities. It is very important that all stakeholders be "on board" from the outset and that advocates and providers find common ground regarding goals and parameters for working together. Such efforts may be time consuming, but the good will and improved communication such efforts can generate will ultimately contribute to successful transitions.

Key Products

Technical Materials

A *Handbook for Transition Navigators* provides step-by-step information about the transition process, from identifying and contacting nursing home residents to handling the moving day and managing the post-transition period. The handbook also provides a copy of the intake form (including language on informed consent), a transition checklist, a consumer satisfaction survey, and other resource materials to facilitate the transition process. All of the hard copies were distributed, but ILCs can update the handbook and these versions will become available in due course.

CONNECTICUT

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The project's goals were (1) to develop an effective and sustainable community-based transition system for nursing facility residents who want to live in the community and can be appropriately served in this setting, and (2) to establish a strong partnership with the State's Centers for Independent Living.

The grant was awarded to the Department of Social Services, which contracted with the Connecticut Association of Centers for Independent Living to administer and manage it.

Role of Key Participating Partners

- Consumers, consumer advocacy organizations, providers, and representatives from a wide range of state agencies that serve persons with disabilities of all ages, participated in the grant's steering committee and work groups.
- The Office of the State Ombudsman for Long Term Care (LTC) collaborated with grant staff to conduct outreach to persons in nursing homes.
- Five Independent Living Centers (ILCs) worked closely with grant staff to identify and serve individuals interested in transitioning.

Major Accomplishments and Outcomes

- Grant staff assisted 101 individuals to transition from nursing facilities to the community.
- To provide transition information to nursing home residents and housing information for professionals working on transitions, grant staff produced and disseminated a *Transition Guide* and a *Guide to Housing Resources in Connecticut*, and conducted an outreach campaign informing nursing facility residents of their right to live in the community.
- Due to the education and advocacy efforts of grant staff and partners, in December 2004, the State Bonding Commission appropriated $500,000 for home modifications beginning in spring 2005. The Commission stipulated that the State's transition program has priority for the funds.

  The Corporation for Independent Living, the largest nonprofit housing developer in Connecticut, will oversee the allocation of funds in coordination with the transition program. Although the State has the option to modify its waiver programs to cover home modifications, not all individuals who need modifications are eligible for waiver services. Additionally, modifications have to be completed before an individual transitions, but waiver coverage does not begin until an individual has been discharged from the nursing home.

Enduring Systems Changes

- In June 2004, the state legislature authorized the establishment of the transition program initiated by the Nursing Facility Transitions (NFT) Grant as a continuing state program and appropriated funds for its operation. The program is funded solely with state dollars and funds five full-time transition coordinators to provide outreach and transition services and one full-time statewide coordinator. The program also funds a toll-free line for nursing facility residents giving them direct access to a transition coordinator. The program will collect data and conduct analyses to monitor and evaluate the effectiveness of transition procedures. The data collected will also provide the State with essential information regarding gaps in home and community services that must be addressed in order to successfully rebalance the LTC system.

- The grant was used to establish a Common Sense Fund, which pays for transition expenses not covered through any other source, or when payment for these expenses is delayed due to complicated applications or lengthy waiting periods. The funds, which were limited to $1,000 per person, paid for expenses such as security deposits, furniture, utility deposits, and community-appropriate clothing. The State's new transition program includes a Common Sense Fund, funded by state general revenues. The Connecticut Association of Centers for Independent Living also has a Common Sense Fund for individuals not eligible for the state program, which is funded through voluntary contributions.

- Grant staff collaborated with the state housing authority to change its voucher administration plan to prioritize 50 Section 8 vouchers annually for transitioning individuals. HUD approved the change in July 2003 and evaluation data showed that the availability of the vouchers decreased transition time by an average of 79 days. Due to administrative issues with the housing authority, the vouchers have been discontinued and the State's Rental Assistance Program is now working with the NFT program to provide housing subsidies to individuals enrolled in the program.

- When the Personal Care Assistant waiver program reached its cap in July 2003, the grant's impact analysis was used to support a request for additional waiver slots. In January 2004, the Governor's budget recommendation included $2.2 million for 200 additional slots and the legislature approved them in June 2004. The additional slots represent a 40 percent increase in the number of people with physical disabilities who can be served in the community.

Key Challenges

- Lack of affordable accessible housing was a major barrier for individuals seeking to transition. Historically, subsidized housing and Section 8 vouchers have had waiting lists exceeding 2 years.

- Other challenges that delayed or prevented transition include ineligibility for needed services, poor credit histories, lengthy application processes, lack of family support, and absence of discharge planning at the nursing facility.

- Transitioning individuals with substance abuse disorders or mental illness was particularly challenging because some mental health service providers were reluctant to initiate the transition process due to concerns about the adequacy of home and community services to meet their needs.

Continuing Transition Barriers

- Although prioritizing housing subsidies for individuals who are transitioning has enabled many transitions, the widespread lack of affordable and accessible housing remains a major factor that delays and can in some instances prevent transition.
- The State has several waiver programs for individuals with different needs. However, some individuals do not meet the specific eligibility criteria for any of these programs but still need services. For example, the Personal Care Assistant waiver requires participants to self direct or have a conservator. Another problem is that a person with multiple minor needs may not meet a waiver program's functional criteria if it requires a person to have moderate to severe needs. Alternatively, individuals may be eligible for a waiver program that does not provide all of the services they need. For example, the Personal Care Assistant waiver provides only personal care services, but a person may also need home modifications and a personal emergency response system.
- Lack of work supports and lack of transportation are barriers. Some areas of the State have good public transportation systems, but others do not. The lack of transportation has a negative impact on both individuals with disabilities who want to live in the community and on the personal care workers they need. Most workers have very low incomes and do not have cars, so they depend on public transportation.
- A major transition barrier is poverty. Many individuals with disabilities cannot afford to live in the community.

Lessons Learned and Recommendations

- Successfully addressing housing issues requires a great deal of time and effort to understand how the housing system works.
- Because nursing facility residents may need time to process information and make decisions, outreach and education efforts may need to be provided several times using various approaches to be effective.
- Establishing an effective nursing facility transition program requires the involvement of all stakeholders, including consumers, families, nursing facility administrators and discharge planners, consumer advocates, housing developers, housing authorities, and state agency staff.
- Evaluating an initiative helps to maximize its efforts, improve efficiency, and identify in a timely manner issues that need to be addressed and activities that need to be modified. The collection of validated data acceptable to policy makers is critical to bring about systems change.

- Individuals seeking to transition need to focus as much on obtaining the supports and services necessary to live in the community as on the transition process itself. ILCs have a long history of assisting individuals not only with the transition process, but with making community connections and obtaining needed supports. Having such locally-based staff greatly facilitates the transition process.
- The State needs both a Money Follows the Person policy and a cash and counseling service model to assure that all individuals can receive all of the services they need in the community setting of their choice.

Key Products

Outreach Material

Grant staff developed several outreach materials to inform nursing home residents about transitioning to independent living. The materials included a toll-free number to call for additional information, a list of resources for people in nursing facilities, and a description of an individual who successfully transitioned.

Education and Technical Materials

Grant staff developed *The Transition Guide,* a booklet for individuals who want to leave a nursing facility and move to the community. The guide contains a self-assessment for community living, resource materials for planning a transition, and information about available transition and home and community services. Grant staff also developed the *Guide to Housing Resources in Connecticut*, a handbook on how to find and obtain affordable housing in Connecticut.

GEORGIA

Nursing Facility Transitions—Independent Living Partnership Grant

Primary Purpose and Major Goals

The grant's primary purpose was to assist people in institutions who were interested in transitioning to resettle in the community by increasing outreach and expanding available supports. The grant had three major goals: (1) to develop a transition infrastructure within the Independent Living Network to introduce people with disabilities to peer supporters and role models; expose interested persons to home and community services; offer information, training, and skill development; develop community connections or circles of support; and develop comprehensive transition plans to assist those who choose to resettle in the community; (2) to develop partnerships with nursing homes to identify residents who want to live in the community, to work with discharge planners and consumers to prevent unnecessary nursing facility placement, and to work with housing authorities to increase the availability of housing for people being transitioned or diverted; and (3) to work with the state Medicaid Agency to address consumer-identified problems with waiver programs.

The grant was awarded to disABILITY LINK, a Georgia Center for Independent Living.

Role of Key Participating Partners

- The Grantee partnered with five other Centers for Independent Living (CILs) to identify residents wanting to transition and to provide transition services throughout the State.
- Two of Georgia's largest nursing home chains—Golden Age and United Health Services—collaborated with the state Medicaid Agency and the CILs in the grant's transition activities. Nursing homes in these two chains assisted in the identification, assessment, and transitioning of individuals to the community.
- Consumers, consumer advocacy groups, providers, and representatives from a wide range of state agencies that serve persons with disabilities of all ages, participated on the grant's task force and in the effort to transition individuals from nursing facilities to community living. The task force and its committees organized waiver improvement meetings that were attended by high-level staff from the Department of Community Health—the state Medicaid agency—as well as regional CMS staff, national experts on home and community services, and managers of waiver programs considered to be cutting edge. The task force also designed and implemented an online housing database.
- The State's Real Choice Grant staff worked with the CILs on the peer support initiative.

Major Accomplishments and Outcomes

- Grant staff transitioned 221 nursing home residents, exceeding its original goal of only 37 transitions.

- Grant staff worked with the Department of Community Health, the Department of Human Resources, and the statewide Independent Living Council to divert 56 consumers from nursing home placement.
- Grant staff held a "Building Lives: Building Communities" conference to disseminate information on the transition process to consumers and consumer advocacy groups, nursing homes, and CIL and state agency staff. The conference was attended by over 100 people and included workshops on housing issues, the transition process, how to hire/supervise personal assistance staff, and state budget issues.
- Grant staff developed a *Nursing Facility Transition Manual* to train transition coordinators. The manual provides information about all the steps needed to successfully transition nursing home residents.
- Grant staff coordinated efforts with the Governor's Developmental Disabilities Council to develop a peer support certificate program that trained 98 people to support individuals during and after the transition process. Certified peer supporters are providing services as part of a 6-month pilot project implemented at three CILs. They are being paid with funds from the State's Real Choice Grant, which has not yet ended. The results of the effectiveness of peer support will be evaluated and submitted to the State's Medicaid office for review.
- Grant staff established relationships with local housing authorities and one grant partner, the Macon CIL, received a local award for their collaboration with their local housing authority to set aside Section 8 vouchers for consumers transitioning into the community and those at risk of institutionalization.

Enduring Systems Changes

CILs now view transition as one of their core services. They are using the *Nursing Facility Transition Manual* developed under the grant in their continuing transition activities.

Key Challenges

The State's lack of commitment to help nursing home residents transition was and continues to be the greatest transition barrier. There are insufficient waiver slots due to limited state funding and the waiver program does not cover transition services. Lack of accessible and affordable housing was also a major challenge.

Continuing Transition Barriers

- The biggest obstacle is the lack of a meaningful commitment by the Department of Community Health (DCH)—the state Medicaid agency—to transition people from institutions to the community. The State does not cover transition services under the waiver program and case managers do not want to work on transitions because they will not be reimbursed for their time.

- Although DCH awarded a contract to a home health agency to identify individuals through the nursing home minimum data set (MDS) data who are interested and able to live in the community and to assess them for transition potential, it is our understanding that out of 700 residents assessed, only 148 were identified as appropriate for transition. Those identified have been placed on waiting lists for waiver services. The State is spending up to $150,000/year under this contract to identify residents with the potential for transition but has not made a meaningful commitment to transition them.
- A little less than half of the people transitioned under this grant required no services once living in the community. A few persons needed only home modifications, such as a ramp. Because setting up and coordinating home and community services takes a lot of time and effort, hospital discharge planners often send people to a nursing home after a hospitalization. Once there, they lose their housing, their savings, their community support network, and need help to transition. The grant originally budgeted $5,000 for each transition, but the average transition cost was only $1,500. In some cases, people only needed money for utility security deposits.
- Because transition clearly saves money, we believe the nursing home lobby is a major factor responsible for the State's lack of commitment to transition.
- A federal barrier to transition is that the Medicaid program considers home and community services to be optional while nursing home services are mandatory.

Lessons Learned and Recommendations

It is important to establish collegial relations with nursing facilities and to assure that they have opportunities to provide input on transition initiatives.

Key Products

Educational and Technical Materials

Grant staff developed a *Nursing Facility Transition Manual,* which provides information for consumers and case managers about essential transition steps. The manual was completed in CD-ROM format and is ready for dissemination to interested parties. There is some interest from other states who are implementing transition initiatives in receiving a copy of the CD.

GEORGIA

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to build the State's capacity to provide outreach and sustained support for transitioning nursing facility residents to the community living arrangements of their choices. The grant had four major goals: (1) to establish a Georgia Consumer/Provider Task Force to facilitate policy changes addressing system improvement; (2) to facilitate up to 24 individuals' transition to appropriate community-integrated living arrangements; (3) to encourage collaborative relationships among the staff of nursing homes, Centers for Independent Living, and case management agencies to facilitate community placement for residents of nursing homes who want to transition; and (4) to increase the number of trained and reliable quality community service workers.

The Department of Community Health, Division of Medical Assistance, Aging and Community Services implemented the grant in close partnership with disABILITY LINK, a Georgia Center for Independent Living.

Role of Key Participating Partners

- Grant staff worked closely with disABILITY LINK, a Georgia Center for Independent Living (CIL), which was awarded a Nursing Facility Transitions-Independent Living Partnership (NFT-ILP) grant. Staff from this CIL were responsible for establishing working relationships with nursing home staff, providing transition services, and completing community placements.
- Staff in facilities operating under two nursing home chains worked with the CILs to transition residents who wanted to move to a community setting.
- The Governor's Council on Developmental Disabilities collaborated in the distribution of worker registries developed by grant staff.

Major Accomplishments and Outcomes

- To address existing policy barriers to the development of community support services, the grant was used to establish a Consumer/Provider Task Force, which compiled a list of bureaucratic barriers to the transition process, and forwarded it to the Medicaid Director for action. Representatives of the Task Force also met with the state Medicaid Director to discuss these barriers and prioritize activities to address them.
- Two of Georgia's largest nursing home chains—Golden Age and United Health Services—collaborated with the state Medicaid agency and the CILs in the grant's transition activities. Nursing homes in these two chains assisted in the identification, assessment, and transitioning of individuals to the community. After the grant ended, staff in these nursing homes continued to assist residents who want to transition.

- Grant staff successfully relocated 20 nursing facility residents to the community.
- Grant staff developed a new training curriculum for personal care assistants.
- To help people transitioning to find workers, grant staff developed six workforce registries listing individuals who want to work as personal assistants. The workforce coordinator collaborated with the Governor's Council on Developmental Disabilities and Area Health Education Centers to distribute the registries quarterly throughout the State.
- CILs enlisted and trained people with disabilities to provide peer support to nursing home residents who want to transition.
- Grant staff fostered collaboration between local and state organizations through their involvement on task forces and advisory committees to identify and implement strategies for obtaining accessible affordable housing for individuals leaving nursing homes.

Enduring Systems Changes

- Grant staff established a referral system between the two nursing home chains' facilities and the areas' CILs and Area Agencies on Aging, which they are continuing to use since the grant ended. Nursing facility staff continue to work on transitions with Medicaid and independent case mangers who conduct transition assessments.
- The grant's Transition Planning Team developed a person-centered care plan to facilitate transition and enroll individuals in SOURCE, a state home and community service program.
- When the grant ended, the legislature appropriated $7.25 million for non-Medicaid covered items and the first year of home and community services for transitioning individuals for whom there is no waiver slot. The legislature specified a maximum of $50,000 per person for up to 145 individuals. The State creates a new waiver slot to continue services for individuals who have been supported with these funds for a year. The Grantee anticipates new funding when the current appropriation is completely used.
- The State implemented a consumer-directed care option in the Physical Disabilities waiver program in October 2005. The option will be available in the Mental Retardation waiver program in January 2006, and in the Aged and Disabled waiver program in spring 2006. Grant staff in the Medicaid agency and the CILs promoted this option to meet the needs of transitioning individuals who wanted to directly hire their own workers.
- The State has hired a contractor to use MDS data to help identify individuals in nursing facilities who may want to transition to a community setting. The data are given to a case management agency that provides transition services. This agency was selected on a competitive basis using a Request for Proposal process.
- The Governor's Council on Developmental Disabilities has assumed responsibility for updating and distributing the workforce registries after the grant ends.

Key Challenges

- The biggest challenge was the lack of affordable and accessible housing in the State, which is an ongoing problem. The State continues to work with the local housing authorities and Department of Community Affairs to identify affordable accessible housing.
- Another primary challenge was a lack of waiver slots for people transitioning. The Olmstead appropriation to cover services when there is a waiting list for the waiver program was not enacted until after the grant ended.

Continuing Transition Barriers

The lack of affordable and accessible housing is an ongoing barrier to timely transitions.

Lessons Learned and Recommendations

- Assuring successful transitions requires the involvement of all stakeholders—the Medicaid agency, Independent Living Centers, nursing home staff, residents, and informal caregivers when appropriate—in the development of a person-centered transition plan.
- Transition programs must be available to offer guidance and support for at least 6 months after the transition.
- About 70 percent of those transitioned under the grant were still in the community 24 months later. The primary reason some returned to a nursing home was that community living was not what they thought it would be. Some did not feel secure without the 24-hour availability of staff, some missed friends and being around other people, and others missed nursing home activities.

  To assure that individuals will remain in the community once transitioned, they must have realistic expectations for community living. In particular, they must understand that they will not have the same level of supports and services available in a nursing home, and that they will need to establish their own networks for social interactions, activities, and support.

Key Products

Outreach, Educational, and Technical Materials

Grant staff developed a *Nursing Facility Transition Manual* in CD-ROM format, which has been distributed to interested parties. The target audience was consumers, nursing home staff, and case managers. The manual provides information for consumers and case managers about what needs to be done in order to transition.

INDIANA

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to create system and policy changes that will enable individuals who need long-term care services to reside in the housing environment of their choice. The grant had three major goals: (1) to establish at least three local coalitions to develop models for transitioning and diverting eligible persons from institutions to community settings, (2) to transition at least 100 individuals from nursing homes, and (3) to divert at least 60 individuals from nursing homes.

The grant was awarded to the Family and Social Services Administration, Division of Disability, Aging and Rehabilitative Services.

Role of Key Participating Partners

- Several entities participated in the coalition that created the transition/diversion process. They include representatives of Area Agencies on Aging (AAAs), Independent Living Centers (ILCs), and the Office of Medicaid Policy and Planning.
- The Office of Medicaid Policy and Planning helped to clarify existing policies and to identify policy barriers to transitions.
- The Grantee contracted with four AAAs to provide technical assistance, identify overall policy issues, and develop models for the transition/diversion of eligible persons to the community. Other contracted activities included: relationship and coalition building within the community; developing promotional, education, and outreach efforts and materials; outreach to nursing home residents, individuals at risk for nursing facility placement, their families, and caretakers; developing a housing directory for case managers; developing pilot transition care plans and follow-up documentation tools; implementing a transition evaluation tool and best practice guidelines; and basic demographic data collection and outcome reporting.

Major Accomplishments and Outcomes

- Grant staff and the four contracted AAAs transitioned 110 residents from nursing homes to community settings at an average cost of $5,000 per transition. Transition costs varied considerably based on individual needs. Many individuals transitioned at a cost of $1,000 or less.
- Grant staff and the AAAs developed a best practices manual that provides technical assistance, useful techniques implemented by AAAs, and examples of materials AAAs used to develop and market the transition program.

- The successful community coalition building and outreach efforts by grant staff and partners resulted in an increase in overall awareness throughout the State about the importance and value of transition services.

Enduring Systems Changes

- Grant activities promoted interagency partnerships and a closer working relationship among the various departments that administer the waiver programs, which have continued after the grant ended.
- Because the waiver waiting list was a major transition barrier, the State amended its waiver to prioritize the waiting list so that persons awaiting transition could move to the top of the list.
- The State enacted legislation in 2002 to increase the income limit for waiver services from 100 percent of SSI to 300 percent of SSI and to increase the number of waiver slots, pending adequate funding. Before implementing the changes, the State required a study to determine the fiscal implications and grant funds were used to commission a report. While the State initially said the changes would be too expensive, in April 2006 it decided to implement them in July 2006.
- The grant began a process that provided a foundation for other initiatives to build on. Due in part to increased awareness that many nursing home residents could be served in the community and demonstrated cost savings through the transition program, the State has undertaken a number of initiatives to rebalance its long-term care system.
    - The Director of Aging and the Secretary of Family and Social Services Administration (FSSA) have made a commitment to both reduce the number of nursing home beds and reduce nursing home occupancy by 25 percent by state fiscal year 2009.
    - In 2004, the State implemented the *Hoosiers at Home Program* to increase options for home or community care for Medicaid-eligible nursing home residents.
    - The Division on Aging is developing a comprehensive statewide directory of affordable and accessible housing.
    - The study commissioned by the State also found that that FSSA, local waiver administration offices, and local AAAs lacked the administrative infrastructure to support the changes in the proposed waiver program. The State has established a work group to address these and other issues. The work group is using the grant's manual—*Back to the Community: A Best Practice Guide for Nursing Facility Transition*—as a guide in establishing a statewide transition process. The work group is also developing transition teams—that include a social worker and a nurse—to conduct assessments and provide case management until individuals receive waiver case management services. These teams will be reimbursed through the State's targeted case management option. The State's goal is to transition 1,500 Medicaid-eligible nursing home residents over the next 18 months.

Key Challenges

- In some areas of the State, a lack of affordable and accessible housing is a major transition barrier.
- The state contracting process was cumbersome and delayed project implementation in several instances. Turnover in state staff delayed implementation to such an extent that the Grantee needed to revise the project's goals and objectives late in the grant period.
- The AAAs lacked the capacity to conduct transitions. Their case mangers have caseloads of 50 to 80 individuals and did not have the time to provide the intensive case management needed for transitioning. For this reason, the State contracted with four AAAs and paid them to hire staff to work on transitions only.

  In the final phase of the project, the AAAs were reluctant to sign a performance-based contract with the State, which specified that the AAAs would receive payment for their services only after each transition was completed ($1,000 per transition). They were reluctant because all previous contracts had not been performance-based. Their reluctance to sign the contracts resulted in a several-month delay of transition services after the grant received a no-cost extension.

Continuing Transition and Diversion Barriers

- Lack of affordable and accessible housing in some areas of the State.
- The State's pre-admission screening law has numerous exceptions, many people are admitted to nursing homes without being screened, and the process does not discuss the range of home and community service options. The term "pre-admission screening" implies that the goal of the screen is to determine eligibility for nursing home admission.

Lessons Learned and Recommendations

- The State's pre-admission screening law should be changed to eliminate exceptions and the screen should be called "long-term care options counseling," to clarify that nursing homes are the option of last resort. These changes would help individuals to avoid unwanted and unnecessary nursing home placement.
- To develop the internal infrastructure needed for successfully transitioning individuals from nursing facilities to the community, it is critical to develop strong relationships among the community organizations that provide services and supports; identify a range of community resources for individuals, including overall support as well as social and recreational opportunities; and ensure that the AAA leadership prioritizes the transition process and designates specific staff to focus on transition. Transition services must become integrated into all functions of the AAA.
- The number of case management hours needed for transitioning was less than anticipated; the average was 14 hours.

- People who have resided in a facility for an extended period of time can be transitioned successfully. For the 110 individuals transitioned under the grant, the average length of stay in a nursing home was 10 months.
- States should use performance-based contracts for any entities doing transition work.

Key Products

Outreach Materials

Grant staff and the four AAAs designed, implemented, and evaluated outreach, promotional, educational, and communication materials. The materials were provided to residents, institutional facilities, social service professionals, and the community-at-large. They were also shared with local AAAs and ILCs.

Educational and Technical Materials

The manual—*Back to the Community: A Best Practice Guide for Nursing Facility Transition*—was developed to assist AAA care managers and administrators in developing programs to transition consumers from nursing facilities. The manual includes a review of the 110 clients transitioned under the grant.

Reports

The State commissioned a report funded by the grant titled *"Impact of SEA 493 Provisions on Indiana's Aged and Disabled Waiver"*, which examined the impact of specific provisions in the 2002 legislation on the Aged and Disabled waiver, such as increasing the financial eligibility income standard from 100 to 300 percent of SSI. The report also examined whether transitioning a specific number of individuals out of nursing homes would offset the additional costs of raising the income standard for waiver eligibility. The report included policy recommendations for addressing bureaucratic transition barriers.

MARYLAND

Nursing Facility Transitions—Independent Living Partnership Grant

Primary Purpose and Major Goals

The grant's primary purpose was to establish a model program in Maryland, using the statewide network of Centers for Independent Living as peer mentors to facilitate the successful transition of individuals from nursing homes to the community. The grant had four major goals: (1) to identify nursing home residents who wanted to better understand their service options and possibly relocate to the community; (2) to educate and assist those individuals and their families to understand, identify, and obtain community resources; (3) to compile and distribute resource materials from the local community; and (4) to empower individuals with disabilities to advocate for themselves.

The grant was awarded to Making Choices for Independent Living, Inc., Maryland's oldest and largest Center for Independent Living (CIL), who worked in partnership with the State's network of CILs to accomplish these goals.

Role of Key Participating Partners

- The Department of Human Resources was awarded a Nursing Facility Transitions-State Program (NFT-SP) Grant, and worked collaboratively with the NFT- Independent Living Partnership (ILP) Grant's peer mentors to identify people interested in transitioning and to provide transition services. In many cases, the same staff person who served as the NFT-ILP Grant peer mentor also acted as the housing transition specialist under the State's NFT-SP Grant.
- Peer Mentors also worked with the transition coordinators hired under the NFT-SP Grant to identify resources for people transitioning and coordinated their activities with the State Medicaid waiver case management agencies.
- Grant staff solicited input and advice about grant activities from its Consumer Advisory Board.

Major Accomplishments and Outcomes

- The grant raised awareness statewide about the importance of transition services. Peer Mentors hired by the CILs conducted extensive outreach to over 2,800 Medicaid beneficiaries residing in 231 nursing facilities across the State. They visited every nursing facility that accepts Medicaid in the State at least once and discussed community living options with over 1,000 nursing facility residents. They also educated nursing home staff, state agencies, and other stakeholders about these options and state responsibilities under the Olmstead decision.
- As a result of the outreach initiative, nursing facility administrators, discharge planners, and social workers have become aware of community living options and have become

transition allies, voluntarily contacting CILs on behalf of residents who want to explore these options.

- The grant increased knowledge of home and community service options statewide. Grant staff developed the *Moving Home Manual*, which includes information on community resources and serves as a statewide reference for people interested in transitioning. Over 2,600 copies of the manual have been distributed and it is available on the Grantee's Web site.
- For 23 nursing home residents, the NFT-ILP Grant peer mentors provided the only assistance they had to transition to the community.

Enduring Systems Changes

- The State enacted a law that requires nursing facilities to allow advocates and case managers to discuss transition options with nursing facility residents. It also enacted the *Money Follows the Individual Act* in 2003. This law makes it illegal for the Department of Health and Mental Hygiene to refuse an individual access to a home and community-based services (HCBS) waiver program if (1) the 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 Maryland Medical Assistance program 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.
- The following year, the State enacted the *Money Follows the Individual Accountability Act*, which requires a nursing facility to (1) refer a resident to the Department of Health and Mental Hygiene or its designee for assistance in obtaining home and community services, (2) review quarterly assessments to identify individuals indicating a preference to live in the community, and (3) provide specified residents with information and assistance, including transition assistance.
- Nursing home administrators and social workers and directors of nursing who were previously opposed to allowing advocates to work with nursing facility residents now value and rely on CIL staff to provide assistance with transition planning.
- While many CILs could not employ peer mentors when grant funding ended, each CIL is attempting to continue activities performed under this grant with existing staff.
- The State modified the *Nurse Practice Act* to permit 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 can make community placements more affordable for some individuals.

Key Challenges

- At the beginning of the grant, some nursing facilities refused to permit CIL/ILP staff to speak with residents. To address this problem, grant staff engaged in outreach and education, and a successful effort to enact legislation in 2002 to assure access to nursing home residents. Although the legislation made it easier to meet with residents in some nursing facilities, other facilities continued to make it difficult for grant staff to meet with residents. The state Medicaid agency was helpful in enforcing the directive in such instances, but it was not always a simple process.
- When working with residents who wanted to transition, a major challenge was reconciling their hopes to transition quickly with the realities of the process, such as long waiting lists for subsidized housing.
- Grant staff addressed these challenges and others that occurred throughout the grant through teamwork, cooperation, and resource sharing. Staff generally addressed issues and challenges by identifying someone who had already experienced the problem and getting their input to help solve it.

Continuing Transition Barriers

- While grant activities have brought about significant changes in state policies that assist people who want to transition from nursing facilities, Medicaid funding retains an institutional bias. In order for Maryland's Olmstead plan to be fully realized, institutions need to be the last resort for the provision of long-term care services.
- The grant provided funding and a process for CILs to successfully partner with the State on transition activities. Because the funding and the process were not sustained when the grant ended, there is now no formal mechanism or reimbursement to assure participation by, or collaboration with, the CILs in the transition process. The State has a contract with another agency to provide case management services for waiver clients, including transition services. CILs can be reimbursed for the provision of some training in consumer direction for people who are transitioning, but this service is infrequently provided as it is just one of many reimbursable transition services. CILs are attempting to continue transition activities with existing staff but are limited by tight budgets.

Lessons Learned and Recommendations

- Coordinating with state agencies and other programs and initiatives provides valuable information and can be a source of referrals.
- CILs should know that while it may be difficult initially to find people who have transitioned who are willing to help others to transition, activities to promote self-advocacy can be effective. At the end of the grant, each CIL had found many self-advocates who were willing to share their experiences with others.
- The State should assure the participation of cross-disability, consumer-controlled organizations in any new transition initiative and the development of transition policies.

Key Products

Outreach Materials

Grant staff produced one major product, the *Moving Home Manual*, which serves as a statewide transition reference book, and is available in alternative formats and languages and on the Grantee's Web site: http://www.mcil-md.org/Moving_Home_Manual.htm.

The manual provides information about centers for independent living and a list of all the CILs in Maryland with contact details. It also contains many success stories with advice from people who have achieved independent living in the community, and over 100 pages of information about resources and other relevant topics.

Following the original print run of 600 booklets, grant personnel incorporated feedback from individuals who had successfully transitioned and revised the manual before printing 2,500 copies of the second edition. Each CIL is treating the manual as a living document, which can be modified and adapted as needed so that accurate and current information can be disseminated, and each has compiled its own success stories that they use in their ongoing activities.

MARYLAND

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to establish a sustainable and replicable model program to transition people from nursing facilities to home and community settings. The grant was designed to address two major problems: (1) the lack of accessible, affordable, and safe housing for persons desiring to move from nursing facilities to the community; and (2) the need for assistance with transition-related activities and costs, including security deposits, utility hookups, furnishings, environmental modifications, and procuring community-based support services. The grant had four main goals: (1) to transition a minimum of 150 individuals, allowing for choice and self-direction; (2) to better coordinate community housing with support services; (3) to improve the quality of transition services; and (4) to expand community housing.

The grant was awarded to the Department of Human Resources, who worked with the Department of Disabilities (formerly the Governor's Office for Individuals with Disabilities), the Department of Housing and Community Development, the Department of Health and Mental Hygiene, public housing authorities, and the State's six Centers for Independent Living (CILs).

Role of Key Participating Partners

- Making Choices for Independent Living, Inc., Maryland's oldest and largest CIL, was awarded a Nursing Facility Transitions-Independent Living Partnership (NFT-ILP) Grant, and collaborated with the NFT-State Program Grant by providing critical outreach to identify individuals wanting to transition.
- Consumers, advocacy groups, and state departments provided feedback about and input for various grant activities.
- The Maryland Disability Law Center, ADAPT, the Cross Disability Rights Coalition, CILs, Maryland Disability Forum, and others supported legislation to assure access to nursing home residents and the enactment of the *Money Follows the Individual Accountability Act.*
- State departments and local governments worked together to address challenges with housing, nursing facility access, waiver enrollment, and service delivery.

Major Accomplishments and Outcomes

- The grant's extensive activities opened lines of communication and improved relationships between and among community and housing service providers, individuals with disabilities and their families, housing specialists, advocates, and nursing facility staff, including discharge planners. These outreach activities resulted in better

coordination between the housing and service sectors, which improved the timeliness, effectiveness and efficiency of transition services, while supporting individual choice.

- Many transitioned individuals subsequently participated in a wide range of advocacy and transition efforts, including conducting outreach and peer mentoring at the nursing facility where they previously resided.

- The project transitioned 193 individuals, exceeding its initial target by 43. The average transition cost per person was $210 less than the $1,200 originally budgeted, in part because only 69 percent of transitioning individuals requested assistance with transition expenses, such as security deposits, furniture purchases, and utility hookups.

- To locate, obtain, and develop appropriate, accessible, and affordable housing for individuals transitioning, grant staff from the Department of Human Resources, a housing coordinator, and transition specialists under contract with CILs established collaborative working relationships with the Department of Housing and Community Development (DHCD), state and local public housing authorities, and other housing providers. As a result, landlords reported upcoming vacant apartments and set aside vacant rental units for individuals transitioning to the community with waiver services. Grant staff also developed a State Registry for Affordable and Accessible Housing.

- Grant staff and partners participated in a wide range of housing initiatives, some instituted by the Governor. One of these initiatives led to the development of the Bridge Subsidy Demonstration Project, which will be implemented in early 2006. The purpose of the pilot is to provide short-term rental assistance for 75 to 100 individuals annually, for up to 3 years, while the individuals await permanent housing assistance such as a Section 8 Housing Choice voucher.

Enduring Systems Changes

- DHCD 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 Department recently instituted a new requirement for developers to have a marketing strategy and to work with disability organizations to assure outreach to persons with disabilities for these units.

  DHCD also requires that set-aside units 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.

- Housing authorities in some counties changed their priority criteria on housing voucher set-asides to allow a person in a nursing facility who is on the housing voucher list to move to the top of the list when they become eligible for waiver services.

- The State enacted legislation (generally referred to as the *Nursing Home Access Act*) stating that employees or representatives of protection and advocacy agencies and of

CILs shall have reasonable and unaccompanied access to residents of public or private nursing facilities that receive reimbursement under the Medicaid program. Access is to be granted to provide information, training, and referrals to programs that address the needs of people with disabilities, including those that enable individuals with disabilities to live outside the nursing facility. The legislation also requires nursing facilities to provide all newly admitted residents with information about home and community service options.

- The State enacted the *Money Follows the Individual Act* (2003) and, subsequently, *Money Follows the Individuals Accountability Act* (2004), which ensures that individuals eligible for Medicaid who reside in a nursing facility have the right to apply for waiver services even if no waiver slots are available. It also requires the review of quarterly assessments to identify individuals indicating a preference to live in the community.
- The State also added transition services to the Living at Home: Maryland Community Choices waiver program and a housing specialist position was created within the waiver's case management agency. Regulatory, policy, and program changes were made to implement the new provisions.
- Consumer direction and control, key components of the independent living philosophy, have been incorporated into transition planning by the CIL staff and waiver case managers.

Key Challenges

- At the beginning of the grant, some nursing facilities refused to permit CIL staff to speak with residents. To address this problem, grant staff engaged in outreach, education, and a successful effort to enact legislation assuring access. Although the new law improved access in some regions, at the end of the grant period, CIL staff in other regions still reported some difficulty entering nursing facilities to speak with residents.
- Maryland CILs focused their NFT-ILP Grant on providing outreach and education. As a result, caseloads increased quickly and, to keep pace with the demand, grant staff focused on identifying housing and community services. Consequently, monitoring and evaluation of outcomes were initially hindered but were completed during the no-cost extension period.
- The lack of accessible and affordable housing was the major challenge for individuals transitioning from nursing facilities. Contributing factors include: (1) 2- to 3-year waiting lists for subsidized housing programs such as Section 8 housing, (2) a shortage of rental subsidy vouchers, (3) a low vacancy rate and high demand for apartments, and (4) no requirements or incentives for property owners to update the Housing Registry with vacancies. In some instances poor credit histories or a criminal background made it more difficult to obtain housing.

  Grant staff addressed these challenges by establishing relationships with housing authorities and private landlords and by staffing and participating in various housing

committees, task forces and work groups, which provided a means to facilitate housing conferences, education, and training. For example, the Prince George's County CIL established a Housing Coalition for Persons with Disabilities in concert with another disability services provider and a nonprofit housing developer. The Coalition sponsored two trainings on the requirements of the *Fair Housing Act* as applied to people with disabilities.

- A number of challenges hindered transition, such as the high turnover of nursing facility social workers/discharge planners, which necessitated retraining efforts. Another obstacle was nursing home reluctance to purchase equipment such as motorized wheelchairs, which residents needed to look for community housing. Additional obstacles include: conflicts between the individual transitioning and family members or legal representatives; delays in Social Security payments; transitions occurring prior to the establishment of community supports; lack of public transportation and attendant care services; and service hour needs not matched by programs.

  Grant staff were able to address some barriers by helping to identify programs and resources, and mediating with families. Others, such as Social Security payment delays, could not be directly addressed, but when such delays occurred, staff identified other temporary resources to meet immediate needs.

- Project staff had considerable success in procuring existing housing for transitioning clients, but found the development of new housing to be a more challenging and lengthy process.

Continuing Transition Barriers

- The variability in the administration of housing subsidy policies and practices by public housing authorities (PHAs) makes it very difficult to address the housing needs of people with disabilities. For example, PHAs can have different priority groups and eligibility criteria. Lack of a data collection capability also makes it difficult to plan for future housing needs and to support funding requests.

- Section 8 voucher policies exclude individuals with criminal histories, which limits their housing options. This policy treats criminal histories differently than does the State's Medicaid program, which deals with criminal records of potential providers on a case-by-case basis. Medicaid allows some individuals with criminal histories to become providers after considering the nature of their crime and how long ago it occurred. HUD should explore a similar policy.

Lessons Learned and Recommendations

Collaboration between housing and services programs and professionals promotes efficient and effective transition services. States may need to enact legislation to remove transition barriers; for example, covering transition services in waiver programs and enacting a Money Follows the Person policy, while HUD should set aside rental assistance vouchers for individuals transitioning from nursing facilities.

Key Products

Outreach and Educational Materials

Using Connecticut's transition guide as a template and incorporating elements of Maryland's NFT-ILP Grant's *Moving Home* guide, grant staff prepared a draft transition guide called *Supporting Home Choices,* which lists local and state resources and contact information. The guide's purpose is to assist people with disabilities to remain at home or to transition from a hospital or nursing home back to a home or other community residence. It provides basic information on how to identify needs, seek services, and plan transitions back to the home and community. The Maryland Department of Disabilities is interested in working with consumers, advocates, and state departments to assure a comprehensive review of the guide prior to finalizing it. Once finalized, the guide will be posted on their website and strategies for distribution will be explored.

Staff also developed a fact sheet and registration form for persons interested in transitioning. The fact sheet provides information about the NFT project, including CIL contact numbers. The registration form records information about the individual's personal situation, vocational, educational and day activity preferences, housing preferences, accessibility requirements, housing assistance needed (e.g., deposits, furniture, assistive technology, accessibility modifications), and other needs. The form also includes a signed consent from the nursing home resident giving permission to the transition specialist to assist in their discharge planning process and the transition from the nursing facility to the community.

MASSACHUSETTS

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to improve community capacity for long-term care and partner with housing providers and agencies to enable eligible individuals in nursing facilities to transition to and live safely in the community. The grant, which conducted activities in the Worcester area, had four major goals: (1) to increase access to and the availability of community services and supports for individuals who want to transition; (2) to increase access to and the availability of affordable, accessible, and safe housing for individuals who are transitioning; (3) to help nursing home residents and their families become more knowledgeable about community services and supports, as well as their options for community involvement by (a) addressing concerns nursing home residents may have about transitioning, and (b) motivating consumers and stakeholders to participate in transition efforts; and (4) to implement monitoring and evaluation mechanisms to measure the effectiveness and sustainability of transition strategies.

The grant was awarded to the Department of Mental Retardation, which is part of the Executive Office of Health and Human Services.

Role of Key Participating Partners

- An important feature of the grant's implementation was interagency leadership. While the Department of Mental Retardation was the grantee, representatives of seven state human service agencies served on the grant's Interagency Planning and Steering Group. This group was established in Year One to focus on system issues. Agency representatives provided their agency's perspective and helped facilitate transition activities affected by their agency's regulations, policies, or practices. Agencies included mental health, public health, mental retardation, elder affairs, vocational rehabilitation, Medicaid, and Health & Human Services. These agency representatives developed recommendations for cross-agency, systemwide changes in policy and practice.

- The Division of Medical Assistance (DMA)—the Commonwealth's Medicaid agency—was the primary partner in project implementation. DMA facilitated outreach to nursing facilities and provided cost and service data for nursing home residents transitioning to community settings.

- Key local partners were the Aging Services Access Points (ASAP) program, the local Independent Living Center (ILC), and nursing facility staff. ASAP staff were responsible for screening nursing facility residents to determine their eligibility for home and community services. ASAP staff were the most knowledgeable resource for information on both nursing facility and community services in the demonstration area. Nursing facility staff worked closely with grant staff to plan and implement transitions. The local Geriatric Social Workers Association provided a forum for discussion and continues to focus on improving discharge planning in the demonstration area.

- Local charitable, faith-based, and other nonprofit organizations hosted outreach activities and provided funding, staff, food, and household items. They also assisted consumers to establish community networks for recreation and support.
- The Executive Office of Human Services and the Grant Manager invited the CMS-funded technical assistance team to convene a "Connect the Dots" process to coordinate this grant with seven other Real Choice System Change and Medicaid demonstration grants.
- Representatives of a wide range of state and local agencies, service providers, advocacy groups, legislators, nonprofit organizations, and private citizens served on the grant's Citizens Advisory Board, Discharge Planning Task Group, and Housing Workgroup.

Major Accomplishments and Outcomes

- The project assisted 34 nursing home residents to relocate during the grant period. Staff provided additional assistance to 12 of the 34 who later moved to settings that better matched their preferences or who were seeking employment. Grant staff also conducted education and outreach activities with over 80 additional nursing home residents and their families who were planning moves and worked with at least 18 nursing home residents who, after evaluating their options, decided not to transition.
- Responding to requests from partner agencies, hospitals, and individuals, grant staff provided assistance, information, referrals, and advocacy to help divert nine persons from nursing facilities. Staff also assisted 15 grant consumers who, after moving, experienced a medical emergency or hospitalization. All but one was able to remain in or return to their homes.
- Partners and providers have increased knowledge about home and community services, housing, public benefits, key components of the transition process, and the importance of involving consumers in service planning and in the development of policy.
- Under the direction of the Grant Manager, grant staff, agency partners, and consumers designed and tested the "Aging and Disabilities Resource Locator," a Web site to help consumers and providers identify community long-term care (LTC) resources. This Resource Locator is part of the Executive Office of Health and Human Services' Virtual Gateway Web site. It provides a common access point to trusted resource information, a standard process and easy-to-use format. Consumers, families, nursing facility staff, and discharge planners enter search criteria and receive results from multiple sources to locate community LTC resources. A checklist of types of support the grant determined essential for community living (e.g., transportation, help with chores, help with finances) guides users' search for providers in their geographic area.

Enduring Systems Change

- Based in part on increased awareness and discussions that resulted from grant activities, the Commonwealth added transitional support as a service under the Elderly and Mental Retardation/Developmental Disabilities (MR/DD) waivers. These supports include those

determined to be necessary in locating and securing accessible, affordable housing and developing community skills that will facilitate an individual's transition from an institutional residence to a community living arrangement. Examples include moving-related expenses (e.g., security deposits, furnishings, deposits for utility or services access, pest eradication, allergen control or one time cleaning prior to occupancy), and costs for recruitment, screening, and training of staff who will support the individual in the community.

- In part a result of the interagency focus on nursing facility transition, as of July 2005, the Executive Office of Elder Affairs instituted a statewide Comprehensive Screening and Supports Model for nursing facility residents. Local Aging Services Access Points (ASAP) staff now provide face-to-face screening of nursing facility residents to insure that facilities begin discharge planning at the time of admission.

Key Challenges

- Barriers to finding housing and community supports included: (1) lack of affordable and accessible housing and a lack of knowledge about how to find it; (2) lack of rent subsidies; (3) lack of transportation to support community living; (4) poor credit histories that made it difficult for individuals to obtain housing and utilities, or a criminal record that made it difficult to obtain housing and employment; and (5) reluctance by some landlords and service providers to serve individuals with mental illness, especially those on psychotropic drugs, and others with fluctuating chronic medical conditions.

- The Commonwealth's LTC system has multiple programs and initiatives that provide services to discrete target populations. Each program has its own eligibility rules, service names, and definitions. It is difficult and time consuming for consumers and service planners to navigate this complex system, particularly when an individual has multiple disabilities or co-occurring health conditions. When planning or seeking services, duplicative applications and documentation requirements often lead to service delays.

- A large number of nursing home residents who wanted to transition had chronic diseases characterized by episodic flare-ups and remissions (e.g., mental illness, diabetes, Multiple Sclerosis). Their fluctuating needs for LTC services made it very difficult for them to consistently meet service eligibility criteria and maintain supports.

- Relocation assistance (aka "targeted case management") is available to only a few Medicaid-eligible consumers. Even for those covered under existing Home and Community-Based Services (HCBS) waivers (MR/DD, Elderly, Traumatic Brain Injury), relocation supports are limited. There is no HCBS waiver program for persons under age 60 who have only medical needs and/or physical disabilities. No single agency addresses their needs or provides case management. Without the relocation assistance/case management provided by grant staff, it was difficult for this population to put together a comprehensive service package that would meet their needs. In addition, once in the community, the responsibility for monitoring and maintaining services is totally the consumer's.

Continuing Transition Barriers

- All of the challenges cited above continue to be major transition barriers.
- While case management is available to all elderly persons, not just those eligible for waiver services, it is not at the level needed to plan and implement a move. Targeted case management is available under the state plan only to young persons with DD under the age of 18 and to persons with MR of all ages whether or not they are under the waiver. However, the targeted case management benefit is also not at the level needed to plan and implement a move. Consequently, both elderly persons and younger adults with DD receiving case management also need "relocation assistance," which is a much more intensive level of assistance to assure that all supports and resources (not just those funded by Medicaid) are in place to enable the person to return to and/or remain in the community.
- The local Aging Services Access Points (ASAP), ILCs, and nursing facilities do not have the resources to continue providing the type of relocation assistance provided through the grant. While there are some resources for developing a transition plan, there are very limited resources to assist consumers to implement that plan.
- Community providers are not reimbursed to participate in planning meetings prior to discharge and often cannot complete an assessment until a firm discharge date is given.
- Many programs have a "payer of last resort" policy. Consumers must expend considerable time and energy documenting their inability to obtain services from other programs.
- Consumers cannot obtain equipment they will need in the community until after they transition. As a result, the opportunity is lost to use the equipment with the assistance of nursing facility staff, including occupational and physical therapists. Similarly, a person is not eligible for community services until after their move. This delays receipt of essential services such as medications and personal care while eligibility is being determined and services authorized. The resulting delays can result in medical emergencies and a return to the nursing home.
- There is a lack of accessible and affordable housing, a lack of rental subsidies, and a lack of a full continuum of supportive housing (e.g., group homes, assisted living, supported living, and other residential options).
- The eligibility criteria for personal assistance services under the state plan are too stringent. To qualify, a person must need physical assistance with at least two activities of daily living (ADLs). Although meal preparation and medication oversight and reminders were the most common support needs for many consumers, these needs are not counted when determining eligibility. Meal preparation was considered an ADL at the beginning of this project, but since 2002 it has been considered an independent activity of daily living (IADL).
- Resources for financial management, surrogate decision-makers, guardians, and representative payees are extremely limited and many consumers without family

support are forced to take on these tasks themselves even though their skills and history indicate that financial management is a key support need.

Lessons Learned and Recommendations

General

- Serving all nursing home residents who wanted to transition—regardless of their eligibility for specific programs—highlighted system barriers and service gaps that would not otherwise have been apparent had we served only those who met the criteria for a specific program, such as the Elderly waiver. This approach—combined with the work of the Interagency Planning and Steering Group—led to systemwide partnerships that increased effectiveness and the possibility of sustaining transition programs.
- Matching those transitioning with peer mentors proved to be challenging because people wanted to make their own friends and preferred to receive advice from professionals or from persons they knew. Matching individuals based on their ages and lifestyles would have been preferable, but this was not possible given existing resources and the limited grant period.

State

- Although the Commonwealth recently added coverage of certain transition services under the Elderly and MR/DD waivers, coverage is very limited even for those eligible. Many nursing facility residents do not qualify for existing HCBS waiver services. The Commonwealth should provide relocation assistance for all Medicaid-eligible persons who are navigating a return to the community. Relocation assistance is intensive case management and is not to be confused with ongoing case management or as funding for one-time transitional expenses such as rent and utility deposits. The term is used to distinguish the type of case management needed for transitioning from other types of case management provided for different populations.
- The Commonwealth should establish a “fast track” process for eligibility determinations and service approvals for nursing facility residents who are transitioning.
- The Commonwealth needs additional housing rent subsidies and/or interagency collaboration to develop funds to subsidize rents for individuals transitioning.
- Transition programs need to involve nursing facility staff as full partners both in individual transition efforts and in any rethinking and redesign of the current LTC system.
- The Commonwealth needs to establish specific guidelines and protocols for planning and implementing nursing home transition. In particular the roles and responsibilities of the transition planning team must be clear and specific, including not only hospital and nursing home discharge planners but also community support providers who will implement the plan.

- The Commonwealth needs to design and mandate a single application form for supports and services (including housing). At a minimum, demographic and eligibility information should be required only one time and in one universal format.
- The Commonwealth should count the need for meal preparation and medication cueing as ADL needs when determining eligibility for state plan personal care services.
- The Commonwealth should provide flexible funding options for Medicaid services. At a minimum, flexible funds are needed during transition. Relocation planning is unique for each individual. For example, flexibility could enable individuals to address the service gaps during the critical period 4 to 6 weeks postdischarge when Medicaid community LTC supports are not in place.
- The Commonwealth should provide the same financial protections for spouses of individuals in the community as is provided to individuals in nursing facilities.
- Vocational rehabilitation agencies and providers should routinely conduct outreach and provide services to nursing facility residents who wish to return to work and who see vocational options as a key piece of their transition planning.
- The Commonwealth should provide benefits counseling specific to persons who are interested in transitioning from nursing facilities.

Key Products

Outreach Materials.

Fact sheets, PowerPoint presentations, and brochures, including an illustrated "Road Map to the Community" were distributed to consumers and their families as well as to multiple private and public entities with an interest or stake in transition activities.

Educational and Training Materials.

Consumers, staff, and partners developed (1) a manual and PowerPoint presentation titled *How to Conduct A Housing Search in Worcester*, summarizing the steps to finding rental housing in Worcester; (2) a *Transition Guidebook* that gives practical guidance about living in the community; and (3) several planning tools such as sample budget materials and checklists for persons planning to transition.

Technical Materials.

Grant staff and partners developed an array of data management tools, including a database to track transitions; "clinical profiles" to describe those transitioning and general cost trends; and templates for tracking the amount and allocation of case management time and relocation funding assistance.

Reports

Consumer Satisfaction and Quality of Life Report. As part of its evaluation, the Nursing Facility Transitions Project contracted with the Shriver Center at the University of Massachusetts to provide an independent assessment of consumer outcomes, including

satisfaction and quality of life. Information in this report was gathered through structured interviews of a sample of consumers, family members, and staff from nursing facilities and community agencies. Interviews occurred 3 to 28 months after consumers moved.

A Look at Housing Resources in the Worcester, MA Area. Prepared by the Clark University International Development, Community & Environment Department, the report identifies housing resources and barriers to obtaining housing within greater Worcester. Interviews were conducted with 17 agencies and with nursing home residents moving to community settings.

Massachusetts Bridges to Community Nursing Facility Transition Project: Summary of Project Outcomes and Findings. March 2006. This summary report describes findings of project studies of costs and benefits of transition activities, consumer outcomes and satisfaction, discharge planning, and housing. The report describes obstacles and recommendations. The report includes as appendices the following internal reports:

- *Study on Discharge Planning: Review & Synopsis of Relevant Regulation & Policy Affecting Discharge Planning.* Bridges to Community Nursing Facility Transition Project, 2004.
- *Obstacles to Nursing Home Transition: Synopsis of Obstacles Identified and Planning Group Recommendations for Addressing Obstacles.* Bridges to Community Nursing Facility Transition Project, 2003.

MICHIGAN

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to enhance existing housing and waiver programs to better support nursing facility transitions. The grant had four primary goals: (1) to enhance Michigan's capacity to reach out to nursing home residents who want to live in the community and support their transition; (2) to establish a model to divert individuals from potentially permanent nursing facility placement; (3) to provide education and training on specific aspects of the transition process to community organizations, health care professionals, and project partners; and (4) to provide an evaluation of the program and a study of the comparative cost-effectiveness of community living versus institutional living.

The Division of Community Living within the Department of Community Health implemented the grant in close partnership with the University of Michigan Turner Geriatric Clinic.

Role of Key Participating Partners

- Hospital staff affiliated with the University of Michigan Turner Geriatric Clinic conducted diversion activities for persons being discharged from the hospital.
- The Corporation for Supportive Housing managed the $100,000 transition fund for direct support of transition expenses not covered by other resources.
- Grant staff worked closely with two Area Agencies on Aging (AAAs) and two Centers for Independent Living (CILs) to transition individuals from nursing facilities.
- The Michigan State Housing Development Authority provided housing vouchers and worked with relocation coordinators to find suitable housing.

Major Accomplishments and Outcomes

- Grant staff successfully transitioned 258 nursing facility residents with widely varying levels of need. For the 41 percent of transitioned individuals who required no Medicaid or state-funded services post-transition, the State's annual per-person costs were reduced by 90 percent. (The remaining 10 percent was for health-related costs including prescription drugs and physician visits.) For those who enrolled in the MI Choice waiver program for elderly and disabled persons, costs were reduced by 60 percent, and for those receiving services through other state-funded programs, costs were reduced by 76 percent.
- Of 118 inpatients diverted from nursing facilities, 51 were still living at home at the end of the study.
- Grant staff developed a comprehensive diversion model for use statewide.

- The Grantee developed a comprehensive training and education program to inform staff in nursing facilities, CILs, and housing agencies about the transition process, how to conduct transitions, and resources to facilitate transition.
- Outreach efforts have created a heightened awareness of housing challenges, especially for persons with disabilities under 55 years of age. The Michigan State Housing Development Authority, which is developing its 5-year plan, is considering set-asides of Section 8 vouchers for individuals who are transitioning.

Enduring Systems Changes

- The State added nursing facility transition (NFT) as a service under the MI Choice waiver program. Waiver service providers are authorized to furnish up to $3,000 of transition services. Plans projected to total more than $3,000, which includes both transition and support/coordination costs, must be pre-approved. Allowable transition costs include those for (1) one-time deposits to secure housing or obtain a lease; (2) utility hook-ups and deposits; (3) furniture, appliances, and moving expenses; and (4) one-time cleaning expenses, including pest eradication and allergen control.
- The State has authorized new Home and Community-Based Services (HCBS) waiver slots for persons who are transitioning. Grant staff requested additional waiver slots for individuals transitioning and the State now has a policy to provide a waiver slot to anyone who has been in a nursing facility more than 6 months. Exceptions to the 6-month rule may be granted in a limited number of circumstances; for example, if a person is 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.
- Entities that administer the waiver program—called waiver agents—and CILs are continuing outreach and education activities so that all nursing facility residents have the opportunity to transition to the community using the MI Choice waiver.
- The Grantee developed a permanent fund to reimburse transition costs not covered by other sources. It is funded with civil monetary penalties levied on nursing facilities for violations. The fund is now administered by the state Medicaid Agency.
- The grant permanently expanded the number of waiver agents and CILs available to assist in the relocation of nursing facility residents back to the community.

Key Challenges

- The MI Choice waiver was closed statewide for the first 2 years of the grant, which made it difficult to transition individuals who needed waiver services. Assistance with activities of daily living (ADLs) is available through the Medicaid state plan, but the eligibility determination process for these services is complex and time consuming.
- The lack of affordable and accessible housing in the counties where transitions were planned was a major obstacle that was difficult to overcome.

- The State lacked sufficient Section 8 vouchers for people over 62 years of age. This problem was addressed by utilizing regular Section 8 vouchers and other affordable housing options for individuals of all ages.
- Lack of home and community services due to lack of funding.

Continuing Transition Barriers

- Lack of affordable and accessible housing.
- The lack of global budgeting for all of the State's long-term care (LTC) services is a barrier to serving consumers in the community setting of their choice.
- In most areas of the State, agencies are only eligible for $3,000 per person for transition services and transition program growth is slow. Paying more than $3,000 per person to cover start-up and training costs would provide an incentive to start transition programs across the State. Michigan spends only 14 percent of its LTC budget on home and community services.

Lessons Learned and Recommendations

General

To convince the State to fund transition expenses and waiver slots, you need data that demonstrate cost savings.

State

- To implement a successful statewide transition program, you need a combination of political will and adequate resources.
- To assure that everyone in a nursing home who wants to live in the community can do so, the State needs to enact a Money Follows the Person policy.
- To assure that people receive the services they need in the setting of their choice, the State needs to enact policies that ensure person-centered planning.
- More funding is needed to increase the availability of housing options and to make home repairs and modifications.
- Coordinate nursing home transition activities with HCBS waiver programs. This will eliminate the administrative costs of a separate, stand-alone transition program and utilize the extensive experience of waiver case managers who work with people who need LTC services and supports and housing. It will also allow faster start-up because much of the infrastructure is already in place, from computers to Medicaid billing systems.
- The State should establish a state-level integrated information system to help people identify transition resources, to support coordination, and provide cost data.

- The State should establish an adequately staffed statewide single point of entry that will divert people from nursing homes, prevent long nursing home stays, and transition people out. A bill to establish such a system has been introduced in the legislature. Currently, the Aging and Disability Resource Centers (ADRCs) are only proposed for four areas of the State.
- Waiver programs should cover counseling services specifically designed for people transitioning to explain the process and educate them on issues involved in a successful transition.
- Add a question to the MDS Resident Assessment Instrument (RAI) that asks residents if it is okay for the facility to release information to another party, either a caregiver, a transition program, an ADRC, single point of entry staff, or other designee. Without this authorization, once the MDS data are in the CMS repository, it is necessary to get data use agreements.
- Move question Q1a up to the beginning of the MDS RAI so that people are asked immediately when being assessed if they wish to return to the community. Also add a housing question so that transition programs know the individual's housing status, which can then be more quickly maintained or developed.
- The State needs a better information system that allows for collaborative care planning. It is necessary to link transportation providers, housing providers, and LTC service and supports providers with consumers to develop and initiate successful transition plans.

Federal

HUD needs to provide additional Section 8 vouchers.

Key Products

Outreach, Educational and Technical Materials

Grant staff developed a Web site, brochures, and a toll-free number to provide information about nursing facility transition. Grant staff also developed (1) an education program containing vignettes of program participants for CILs and MI Choice waiver agents; (2) a DVD and brochure titled *A Better Choice* to raise awareness about the realities of transition among care managers, consumers, and their families; and (3) a user guide on the use of the Michigan Client Information System for NFT participant service planning and reporting.

Reports

Grant staff developed a report on the diversion component of the grant titled *Nursing Facility Diversion: Mobilizing Residents, Families and Resources to Facilitate Return to Community Living*.

NEW HAMPSHIRE

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to ensure stable community residence for older adults with complex, multiple problems who are currently residing in nursing homes or receiving a nursing home level of care in the state psychiatric facility. The grant had four major goals: (1) to identify potential transition participants in one region and determine their needs for housing and services; (2) to develop "Wrap Around Services" teams for transitioning older adults with mental illness from institutional settings to community settings; (3) to secure funding to expand services and ensure the continuation of the project; and (4) to improve the overall state infrastructure to support people with disabilities in their homes, and provide the necessary support to persons with mental illness moving from institutions to the community.

The New Hampshire Nursing Facility Transition Grant is the only such CMS grant focusing exclusively on transitioning individuals with mental illness.

The grant was awarded to the Department of Health and Human Services, Bureau of Behavioral Health and was implemented by the Bureau's Older Adults Mental Health Administration.

Role of Key Participating Partners

- The Dartmouth Psychiatric Research Center developed an evaluation plan as part of the original grant application and modified the plan as needed throughout project implementation. The evaluation team attended regular meetings with the project team to discuss the best ways of meeting the program's objectives, participated in formative evaluation activities, developed and maintained the project's database, and developed and conducted a consumer satisfaction survey.
- The University of New Hampshire Institute on Disability hired a project coordinator to oversee the implementation of all grant objectives. They also initially recruited a housing specialist, funded by the grant project, to help locate housing resources and to provide technical assistance/guidance and training.
- The Riverbend Community Mental Health Center, which has an existing relationship with nursing homes in the target area, provided a psychiatric nurse case manager who was already employed in the Center's Elders Program to work half time on the project. She identified potential transition participants, advocated for consumers and families to explore and consider transition procedures, provided intensive case management services, and oversaw wrap-around team activities.
- The New Hampshire Housing Finance Authority initially served on the project's advisory committee and worked with the project's housing specialist to identify designated rental assistance vouchers for individuals with mental illness transitioning to the community.

- The Real Choice Consumer Advisory Council (RC-CAC) provides advice to all three of the State's Systems Change Real Choice Grants. Grant staff met regularly with the RC-CAC as well as another consumer advisory group—the Mental Health and Aging Consumer Advisory Council. These two councils provided input, oversight, and support for grant activities. Staff participation in the RC-CAC meetings facilitated the coordination of grant activities with those of the other Systems Change grants, and also helped to assure that grant activities were coordinated with other relevant state- and privately-funded initiatives addressing the needs of older adults with mental illness.

Major Accomplishments and Outcomes

- Grant staff assisted 15 older adults with mental illness to transition from nursing facilities and the state hospital to the community, exceeding the grant's original goal of 10 transitions. None have returned to an institution.
- The Elder Wrap Around Team in the grant's pilot area of Concord is now well established and is a model of inter-agency collaboration. More than 20 regular members from public and private agencies attend the Team's monthly meetings, and more than 90 members are available to meet as needed. Some members participate as part of their job responsibilities and others are volunteers. The success of the model has led to team development in other regions of the State. Grant staff of the FY 2004 Real Choice Grant to integrate housing and long-term supports are now providing technical assistance and training to enhance the development of each of the Elder Wrap Around Teams.
- The grant also contributed to the establishment of a state-level wrap around team called the Cross-Bureau Team, which addresses systems issues identified by the regional Elder Wrap Around Teams. The Cross-Bureau Team comprises the Bureaus of Behavioral Health, Elderly and Adult Services, and Developmental Services, and is charged with identifying ongoing unmet needs and developing policy and planning responses to address them.
- The Bureau of Behavioral Health is using state general funds to continue transitioning nursing home residents and to divert individuals from unnecessary nursing home admissions in the pilot region. The funding will cover a full-time psychiatric nurse case manager to work on nursing home transition and diversion activities, through a contract with Riverbend Community Mental Health. Inc. It will also cover transition costs not reimbursable through other sources.
- Through their participation on several public and private housing task forces, grant-related staff representing the needs of persons with disabilities helped to ensure that people with mental illness transitioning to the community were given priority for Section 8 vouchers. They also secured a memorandum of understanding between the New Hampshire Housing Finance Authority and the Department of Health and Human Services, Bureau of Behavioral Health that will enhance communication and a positive working relationship between the two entities in order to identify and secure subsidized housing for older adults with mental illness.

Enduring Systems Changes

- The State has made a commitment to continue funding the transition of individuals with mental illness using state general funds. The Bureau of Behavioral Health annually assesses whether funding should be continued and the program is now being extended for a sixth year. The allocation includes staffing costs and flexible support and service dollars to support the transition process, which was key to the project's success. This commitment is compatible with the State's GraniteCare program to reform the Medicaid system, which aims to increase home and community services and decrease reliance on nursing homes. The State is considering proposals to expand the project to other areas of New Hampshire.
- As was recommended by grant staff, beginning January 2006, the State is requiring a face-to-face consultation for every Medicaid eligible individual seeking nursing home placement or home and community services to ensure that community options have been explored. Nurses employed by the State's Aging and Disability Resource Center will conduct the consultations using the Medical Eligibility Determination process.
- When the grant project began, only five Elder Wrap Around Teams in the State met regularly; now there are 10, including the grant project team. The state-level Cross-Bureau Team is also meeting regularly on an ongoing basis to address unmet needs at a policy level.
- Grant staff were trained and then introduced a person-centered planning approach in the service planning process for older adults with mental illness participating in the Concord Elder Wrap. This approach is now being encouraged with all the Elder Wrap Around Teams.
- Grant activities have improved access to services by improving communication between multiple service systems, including the Bureau of Behavioral Health and the Bureau of Elderly and Adult Services. Persons with multiple disabilities can have difficulty obtaining services because the systems that provide them are generally "siloed." Prior to the grant, this was particularly the case for individuals with mental illness who applied for waiver services. With improved education for field staff, persons with mental illness who meet the level-of-care criteria now face fewer barriers to obtaining waiver services.

Key Challenges

General Project Challenges

- Due to significant turnover at the Department of Health and Human Services and the need to re-educate each new administrator about the grant, there was less than optimal Department involvement in publicizing and emphasizing the project's importance and in eliciting the cooperation of all nursing homes in the pilot region to refer transition candidates to the project.
- Some transitioning residents did not receive community support services in a timely fashion due to a shortage of direct service workers.

- Project staff did not have access to the MDS or other information to help identify potential transition candidates. Therefore, the project had to rely on voluntary referrals from nursing facility or psychiatric hospital staff or the residents themselves. The psychiatric nurse case manager and other Riverbend staff also identified potential candidates based on their knowledge of nursing home residents.

Personal Challenges

- Residents' medical needs, mental health needs, and logistical and personal care needs presented significant challenges. Some participants were unable to follow a treatment plan or had a lack of insight into their illness. Others' needs exceeded available community resources, including housing, staff support, and waiver services.

- Sometimes participants' desires did not match their needs or proved unrealistic. Many were not familiar with the different types of housing, or feared or resisted unfamiliar situations, such as group homes or adult medical day care. Some candidates did not want a "roommate" yet needed live-in assistance.

- Opposition or lack of support from families totally impeded transition in some cases, regardless of the person's potential or desire for transition.

Systems Barriers

- There is a significant lack of community living options for older adults with mental illness. Even if appropriate housing can be located, it is often too expensive. In one instance, the project team had located two accessible apartments for two transitioning residents only to have Section 8 housing vouchers withdrawn by HUD in a statewide funding reduction just before the transition date. Also, many residential care settings that might be suitable have specific resident admission requirements that some individuals cannot meet, such as the need to be continent and able to self-manage medications and self-administer insulin injections.

- Lack of transportation affected housing options for some candidates, and having a limited number of guardians for indigent residents delayed or slowed the transition process. The eligibility determination process for waiver services sometimes took several months and other service arrangements needed to be made before waiver services were authorized. Some individuals had such complex needs that they required 24-hour in-home supports or supervision, but the State has limited numbers of licensed community residential beds.

- Arranging all of the necessary services and supports in a timely and coordinated manner was extremely challenging; for example, establishing eligibility for services, arranging for guardians, establishing a representative payee, and obtaining information release forms required by HIPPA. In some cases, it was also difficult to obtain a consultation for individuals with multiple co-occurring conditions, including developmental disabilities, substance abuse disorders, acquired brain injury, and complex medical conditions. In some cases "turf" issues or lack of staff expertise regarding individuals' specific needs caused delays.

Continuing Transition Barriers

- State funding of long-term care (LTC) services continues to have an institutional bias.
- Services funded through the Elderly and Chronically Ill waiver have not typically served the needs of persons with a mental illness even when the mental illness is chronic.
- The State's nursing home and waiver level-of-care eligibility criteria require applicants to have a medical need, which excludes many individuals with LTC needs, including those with mental illness.
- Lack of parity for mental health benefits, particularly in Medicare, and lack of a wellness and recovery treatment approach for older adults with mental illness in the community prevent transition because individuals with mental illness often cannot obtain the treatment and other services they need to successfully transition to and remain in the community.
- The lack of affordable housing and residential care options to address the varied needs of persons with disabilities as they age is a continuing transition barrier. This is particularly a problem for individuals eligible for the SSI program.

Lessons Learned and Recommendations

- It is essential to have a source of flexible funds to cover transition costs such as household items, security deposits, and transportation, which are not reimbursable through other sources. Flexible funds are also essential to provide "bridge" funding when coverage of essential services and supports is delayed.
- Having a dedicated psychiatric nurse case manager with geriatric experience was essential to overcome transition barriers facing older persons with mental illness.
- A "top-down" approach eliciting the involvement and support of the leadership of key agencies to reduce barriers and urge cooperation should be combined with a "bottom-up" approach of fostering cooperative staff relationships in the field to ease referrals and address case specifics. For example, some nursing home staff were reluctant to refer individuals for a variety of reasons, including financial disincentives and fear that residents would not have their needs met in the community. When grant staff developed relationships with nursing home staff and addressed their concerns, they were more likely to make referrals.
- To increase referrals of potential transition candidates by nursing facilities, it can be helpful if agency directors communicate with them about the State's transition goals.
- The Wrap Around Team model has been essential to provide ongoing support for older adults with mental illness to successfully transition to and remain in the community. The concept involves addressing psychiatric, medical, and social care needs by coordinating or "wrapping" the needed services and supports around the individual, and the key to the success of this model is the inclusion of the consumer and family members in service plan development. In addition to regional teams, key agency leaders should expand the

role of the Cross-Bureau Team to address cross-agency system barriers to transition. Such a group is a means of short circuiting the sometimes lengthy process of meeting various categorical program requirements and agency procedural requirements.

- Consumer involvement and advocacy are essential components of a successful transition program.
- To remedy the limitation of relying on voluntary referrals, other recommendations include: (1) have all persons applying for nursing facility entry, including persons undergoing a Pre-Admission Screening and Annual Resident Review for eligibility due to mental illness, be assessed for community living options as a formal process; (2) consider implementing an annual level-of-care review process whereby all residents are reviewed to determine their continuing need for a nursing home level of care and their desire to remain in the facility; (3) consider seeking a waiver to allow, with appropriate "gate keeping" and eligibility mechanisms in place, for Money to Follow the Person so that adequate funding of supports is available wherever a person needing a nursing facility level of care resides.
- The State should (1) continue to shift the focus of LTC policy and funding from institutions to home and community services; (2) provide flexible funding to support people with disabilities in the community in ways not traditionally funded by Medicaid, by paying in a timely manner for items such as rental security deposits, transportation to nonmedical appointments, and essential furniture; and (3) improve communication between primary care and mental health providers serving persons with mental illness in the community.

Key Products

Outreach and Technical Materials

Grant staff developed a brochure called *Home Choice* to inform nursing home residents in the pilot area of Concord about the grant transition project. Grant staff also developed screening and eligibility materials for use during initial contact meetings, and the evaluation team developed a participant database tracking sheet and consumer satisfaction survey for those who had relocated to the community with the assistance of the grant.

Reports

The New Hampshire-Dartmouth Psychiatric Research Center, with input from the project staff, prepared a report titled *New Hampshire's Nursing Home Transition Project Evaluation Report* that summarized the findings of the grant project.

TEXAS

Nursing Facility Transitions—Independent Living Partnership Grant

Primary Purpose and Major Goals

The grant had four major goals: (1) to expand outreach efforts to identify potential candidates to transition from nursing facilities into the community; (2) to train state agency staff, consumers, volunteers, advocates, and service providers on how to address transition barriers; (3) to build lasting partnerships between Centers for Independent Living (CILs) and the State's long-term care agency staff to support CILs' efforts to provide transition services; and (4) to identify and recommend changes in state long-term care policy to support transitions.

The Austin Resource Center for Independent Living, Inc. administered the grant on behalf of the Texas Independent Living Partnership, a cooperative effort of the Texas Association of Centers for Independent Living, the Health and Human Services Commission, and the Department of Human Services.

Role of Key Participating Partners

The Texas Independent Living Partnership and its Consumer Task Force assisted with grant planning and implementation.

Major Accomplishments and Outcomes

- To increase awareness of community service options among consumers, state agency staff, and local service providers, the Austin Resource Center for Independent Living, Inc. (ARCIL) sponsored three annual conferences on relocation practices, developed transition assessment and service planning materials to use with transitioning clients, and engaged in other outreach activities.
- To develop transition expertise among CIL staff, consumers, advocates, and state staff in relevant departments (e.g., long-term care, aging, and vocational rehabilitation), ARCIL provided training and technical assistance.
- In order to ensure staff capacity to administer the State's new rent assistance program targeting transitioning individuals, ARCIL persuaded the State to increase funding for program administration.
- To develop a lasting resource for ongoing systems advocacy and program development related to long-term care systems change for state agencies, CILs and other interested parties produced a report, *Rebalancing the Texas Long Term Care System: A Blueprint for Systems Change.* The report was developed with input from each CIL and other project partners, and recommendations were forwarded to the Promoting Independence Advisory Board, the State's Olmstead advisory group.

- Grant staff presented recommendations contained in the report to the Promoting Independence Advisory Board at regular meetings during the 3-year grant period. The Promoting Independence Advisory Board developed a package of "Promoting Independence" legislative initiatives and budget items—incorporating many of the same recommendations—that was passed, in part, by the Texas Legislature in 2005.

Enduring Systems Changes

- State agency staff, CIL staff, and other stakeholders have increased knowledge about best transition practices and how to develop community services infrastructure.
- CILs in other states are using the transition assessment and service planning materials developed under the grant.
- Transition training materials developed under this grant were used by the State's Real Choice Systems Change Money Follows the Person (MFP) Grant (FY03) to develop a structured, consistent process for regional coordination of transition activities. Regional coordination groups include the contracted relocation services providers, state agency regional supervisors, and the MFP grantee, and they address specific transition problems or issues at an individual and systems level.
- The State amended the Aged and Disabled waiver (called Community Based Alternatives) to cover transition assistance services such as rent and utility deposits, basic household goods, and moving costs.
- The State Vocational Rehabilitation Agency created a new policy to allow payment for relocation assistance as part of an individual employment plan.
- The Texas Legislature authorized the continuation of the State's MFP policy.
- The State issued a Request for Proposal to provide relocation services statewide and all four contracts were awarded to CILs. The CILs were able to win these contracts in part due to the knowledge and experience gained under the grant.

Key Challenges

Grant staff identified potential challenges in advance and developed the grant's work plan to address and resolve them so they would not impede progress. For example, anticipating that it might be difficult to garner broad support for policy recommendations, they worked with the CILs and other stakeholders to develop policy recommendations that addressed specific issues of concern to them, such as how to obtain an exception to individual cost caps in waiver programs. They also developed recommendations that were consistent with CILs' and stakeholders' values and built on and refined already-formulated policy goals.

Continuing Transition Barriers

- The State's current MFP provisions do not apply to institutions other than nursing facilities and should be extended to do so.

- Texas currently has four contracts with CILs to provide relocation services statewide. Relocation services are more like intensive case management and include assessment of community needs, identification of housing, coordination of medical and personal care needs, transportation, financial supports, and completing the move to a community residence. About 10 percent of individuals who transition need these services because they have extensive and/or complex needs that are not addressed by the waiver or other state case management services. However, relocation services are funded by state general revenue funds and are capped.
- Lack of accessible and affordable housing remains a major barrier to transitioning.

Lessons Learned and Recommendations

- To assure the availability of relocation services for all who need them and to maximize use of state dollars, the State should cover these services either as a Medicaid administrative expense through the waiver program or through the targeted case management option.
- Policy changes that would help individuals find housing include: (1) targeting housing vouchers for individuals who are transitioning such as was done under the title Project Access; (2) redirecting funding from the development of age- and disability-segregated housing to tenant-based rental assistance programs; (3) targeting housing assistance to people at the lowest income levels; (4) providing funding for environmental modifications such as ramps, grab bars, and widening doors; and (5) expanding HUD's capacity to monitor and enforce accessibility standards.
- Due to staff turnover, educating state agencies and state legislature staff about transition issues is not a one-time effort. CILs must be prepared to provide transition education on an ongoing basis.
- An increase in the federal match for waiver expenses to 100 percent for a period of 12 months following a transition from an institution to the community would provide a major incentive for states to initiate policies to transition more people.

Key Products

Educational Materials

Grant staff developed the *Housing Search Guide: Relocation from Nursing Facilities to the Community, 2003* to assist professionals who have a role in "relocation" of people with disabilities from nursing facilities to community living arrangements with appropriate services and supports. The purpose of the *Housing Search Guide* is two-fold: to provide practical information to assist in the location of appropriate housing, and also to convey a philosophical basis for systems advocacy in housing.

Technical Materials

Individuals seeking to transition may undergo assessments by multiple service providers and have several service plans. Grant staff produced an *Inventory of Community Service*

and Support Needs for Transition from Nursing Facilities to Community that was designed to consolidate this information. It includes eight assessment areas and is a working document that needs to be updated regularly.

Reports

Grant staff produced a report, *Rebalancing the Texas Long Term Care System: A Blueprint for Systems Change*, which summarizes the policy recommendations of the Texas Independent Living Partnership over the 3-year grant period and contains detailed long-term recommendations for systems change. The report is a resource to Texas state agencies, CILs, and other interested parties for ongoing systems advocacy and program development.

WASHINGTON

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to make living in community settings a realistic and viable option for a wide range of persons in the long-term care system. The grant had three major goals: (1) to strengthen the capacity of independent living service providers to furnish technical assistance and support regarding independent living, consumer direction, and nursing facility transition; (2) to expand access to accessible, affordable housing for individuals who are transitioning; and (3) to improve the provision of assistive technology services needed for community living.

The grant was awarded to the Department of Social and Health Services, Aging and Disabilities Services Administration, who contracted with Centers for Independent Living and other independent living providers to work with state grant staff on grant activities.

Role of Key Participating Partners

- The State contracted with providers of independent living services to implement the grant. They were key partners, working closely with local case managers to facilitate the transition of long-term nursing facility residents.
- Grant staff reported on grant activities to various statewide consumer advocacy groups—the State Independent Living Council, the Governor's Committee on Disability Issues and Employment, the Disability Initiative Advisory committee, and the Developmental Disabilities Council—and relied on their input to inform grant implementation.

  For example, the State originally limited eligibility for grant-related services to nursing facility residents under age 65, but included residents of any age after receiving feedback from these groups. The State also hired a local Center for Independent Living (CIL) to work on housing issues with the local housing authority in response to the groups' advice that CILs needed a financial incentive to become more active in local housing issues.

Major Accomplishments and Outcomes

- Through education, training, and the establishment of collaborative relationships, local case managers are now more knowledgeable about and accepting of the role that independent living providers can play in facilitating transitions. In the eastern part of the State, a CIL has developed a strong working relationship with local case managers and is now able to provide transition support in more remote rural areas.

- 1,399 residents were transitioned from nursing facilities to the community during the grant period. Over half went to residential care settings, in part because they needed services to be available on a 24-hour basis.

- Project staff advocated with HUD to clarify Project ACCESS rental assistance voucher requirements and worked with a local public housing authority to establish a process and memorandum of understanding for utilizing 50 Project ACCESS vouchers for persons who were transitioning. As a result, nursing facility residents in two counties had access to these vouchers without having to join a waiting list; 45 persons leaving nursing facilities were issued Project ACCESS housing vouchers and 24 were used by the end of the grant period.

  People who didn't get vouchers either returned to their own home, moved in with family, or—most of them—moved into a community residential care facility such as assisted living or adult family homes. These facilities provide a readily available housing option and a straightforward transition process from the case manager's perspective.

- Direct service grant funds were used to obtain assistive technology services and equipment necessary for nursing home residents to move to the community. Approximately $297,000 was spent to buy equipment not covered by the State's Durable Medical Equipment program (e.g., lifts, and bariatric beds) or to rent it until program approval was obtained post-transition. An additional $116,000 was spent for environmental modifications, such as widening doorways and installing an external elevator.

Enduring Systems Changes

- The independent living network has traditionally been involved in providing independent living services to individuals living in the community. The grant has built the capacity of this network to facilitate and support nursing facility transition, particularly for long-term residents. Independent living consultant services are now a valuable and legitimate resource for local case managers in transition planning. Prior to the grant, independent living services were rarely utilized in transition.

- The State has amended the Aged, Blind, and Disabled waiver to cover NFT services, including environmental modifications, independent living consultation services, adaptive and assistive technology, and consumable supplies such as incontinence pads. Waiver funding leverages state general revenue funds earmarked for nursing facility transition to expand the types of supports that are available and to increase access to services.

- State-employed case managers have broadened their scope of work to include the transition of long-stay as well as short-stay nursing facility residents, and are focusing their efforts on persons of all ages rather than primarily on those age 65 and older.

- The Spokane Housing Authority has designated individuals leaving nursing facilities as "homeless," enabling them to bypass a 2-year waiting list for Project ACCESS vouchers.

- An independent living center 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.
- A multidisciplinary housing team established during the grant period is continuing its work after the grant ends. The team includes housing authority staff, home and community services social workers, representatives from developmental disabilities (DD) service agencies and veterans affairs, and mental health advocates. The team meets monthly to work on a range of issues, including streamlining the housing voucher application process, arranging for intensive housing searches for nursing facility residents when needed, and coordinating with the relevant community service system to ensure appropriate services and supports are in place at the time of transition and thereafter.

Key Challenges

- Case managers have a limited time to spend on transition activities and generally work on short-term resident discharges because they are required to prioritize newly admitted Medicaid-eligible residents for discharge and transition. Short-term residents typically have current housing and strong connections to their family and other community supports—key factors assuring a successful transition. Because long-term residents lack housing, often have weakened community connections, and can be dependent on the institutional environment, their needs can exceed case managers' ability and time to address them. The collaboration between case managers and independent living providers who were able to provide intensive supports for these residents was critical to their successful transition.
- Transitioning long-term residents with complex medical needs or who need assistance or supervision available 24 hours a day proved to be very difficult due to inadequate budgets for home and community services. For some individuals, grant staff were able to address these constraints by leveraging funds from multiple sources.
- Initially, transitions were not occurring in the planned time frame. Grant staff identified the reasons for the delay and changed the process for using grant funds for one-time transition expenses so local case managers had direct access to these funds. Up to $800 per transition was available but higher amounts could be approved on a case-by-case basis.
- The ability of Washington's six CILs to support nursing facility transition statewide is constrained by a large geographic area to cover as well as a lack of community services. For example, there is a waiting list for DD waiver services and other community residential supports. Undertaking transitions is especially challenging in the State's remote rural areas where there are few community resources.
- Securing affordable housing continues to present challenges statewide, in both rural and urban areas. Many individuals who transitioned had to live with family members or in community residential settings due to the difficulties in finding private housing. Although

grant staff were successful in having housing authorities set aside vouchers for transitioning residents and had set up procedures to permit independent living providers to assist in the housing search, the capacity of these providers is insufficient to meet the need.

- Although it was beneficial to secure Project ACCESS rental assistance vouchers without a waiting period, challenges remain in finding accessible apartments with affordable rent, and landlords in a very competitive rental market who are willing to accept vouchers and have environmental modifications made. An additional barrier is the HUD requirement for a clear credit history and no criminal background, which excluded some nursing facility residents.

  Successful housing searches in a competitive market require a swift, rigorous, and thorough approach. Staff resources—independent living specialists—were insufficient to carry out such searches and limited accessible transportation added to the challenge.

- Budget shortfalls have prevented an increase in funding for transition services.

Continuing Transition Barriers

- The lack of affordable and accessible housing remains a transition barrier.

- The implementation of person-centered transition planning was not as successful as planned. Person-centered planning (PCP) requires specific skills and sufficient time. Some case managers failed to recognize the value of PCP and maintained practices using their professional judgment to develop service plans. Others were influenced by pressures to move people quickly in order to meet regional goals for transition.

  Additional training and exposure to PCP is needed but likely will have little impact until: (1) there is a cultural shift in LTC service delivery that recognizes clients as capable, competent, and contributing citizens with potential strengths, and (2) regulations provide the flexibility to furnish personalized supports needed to realize those strengths.

- Federal policy continues to promote institutional care as the preferred strategy for long-term care.

Lessons Learned and Recommendations

- States should have dedicated Medicaid case management staff to move transitions at a faster pace.

- Medicaid staff and case managers need to develop a solid understanding of the use of Project ACCESS rental assistance vouchers to facilitate nursing facility transition.

- Some issues are better addressed at the local level rather than through a statewide effort. For example, it may be easier for independent living providers to form collaborative relationships with local case management providers than to institute these

relationships at the state level through the Medicaid agency. This is particularly true when working on issues that can vary statewide, such as housing and transportation.

- Federal policy and regulations should emphasize and promote community living as the "gold standard" of long-term care and require waivers for institutional/ nursing facility services.

Key Products

Outreach Materials

CIL staff and LTC ombudsmen use *The Right to Choose* flier when meeting with nursing facility residents. It provides information and instructions with contact numbers for anyone wishing to move from a nursing facility.

Educational Materials

Brochure for Personal Assistant Recruitment and Retention—a primer for individuals on consumer direction.

WEST VIRGINIA

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

The grant's primary purpose was to enable eligible individuals residing in nursing facilities or other segregated environments, or who are at risk of segregated placements, to transition to or remain in the community, and to participate in its social and economic life to the extent desired. The grant had four major goals: (1) to increase the availability of information about community resources, supports and services for persons with disabilities or long-term care needs to enable them to make informed choices for community living; (2) to identify persons who wish to transition from nursing facilities into the community and identify necessary services and supports; (3) to identify operational and system barriers to community living and recommend changes to address them; and (4) to implement transition support models and evaluate their cost-effectiveness as well as consumer satisfaction with them.

The grant was awarded to the Department of Health and Human Resources, Bureau for Medical Services (Medicaid) and was managed by the West Virginia University's Center for Excellence in Developmental Disabilities Education, Research and Service.

Role of Key Partners

The grant program, called *Transitioning to Inclusive Communities*, partnered with all potential stakeholders, including consumers and consumer advocacy groups, state agencies, the Long-Term Care (LTC) Ombudsman, the Behavioral Health Ombudsman, the Olmstead Coordinator, the nursing home industry, home and community service providers, and organizations providing legal assistance to persons with disabilities.

- Stakeholders served on the grant's Consumer Oversight Committee and provided oversight, direction, and technical assistance for grant activities. They also (1) helped to develop solutions to address transition challenges and barriers, (2) reviewed proposals for the funding of community projects under the grant, (3) assisted in the training of service providers and the LTC Ombudsman, (4) assisted with meeting service and support needs for those transitioning, and (5) developed recommendations for sustainability.
- Centers for Independent Living (CILs) distributed State Independent Living Council funds for individuals being served under the grant to pay for non-Medicaid-funded supports and services. The CILs provided transition navigator services and also collected and stored furniture and appliances to lessen the expenses for those transitioning. The Northern West Virginia CIL was instrumental in educating policy makers about specific policy changes needed to ensure successful transitions.
- The West Virginia Assistive Technology Services program provided information and referral services regarding home modifications.

- The Behavioral Health Ombudsman participated in transition planning for individuals with behavioral health needs.
- Grant staff collaborated with the State's Community-Integrated Personal Assistance Services and Supports (CPASS) Grant staff to improve recruitment of direct care workers and to promote a new self-directed option in the Aged and Disabled (A/D) waiver by educating state policy makers and state agency staff. They also collaborated with the State's Real Choice Grant staff on several goals related to housing, transportation, and the nurse practice act.

Major Accomplishments and Outcomes

- Grant staff provided technical assistance and information on community resources, services, and supports to over 3,000 people, including consumers and family members, faith-based groups, advocacy groups, CILs, senior centers and other senior service providers, Medicaid providers, and Ombudsmen. In particular, this information helped individuals on the waiver waiting list obtain personal care service through the State's personal care program.
- Grant staff provided education regarding person-centered planning and the transition process to over 3,214 professionals, 259 family members, and 588 persons with disabilities in 28 counties at nursing homes, state hospitals, provider agencies, conferences, and during individual team meetings.
- The grant transitioned 74 persons from a nursing or psychiatric facility, and diverted 64 persons who were either in the community or in the hospital and at risk of facility placement. Individuals served included people of all ages with all types of disabilities. Grant staff also identified six children residing in nursing homes and provided information to their families about other service options.
- Grant staff identified transition challenges and recommended policy, procedure, and practice changes to address them.
- Grant staff developed *A Navigator's Guide to Community Inclusion* and distributed the guide to the LTC Ombudsman, the Olmstead Director's Office, nursing home social workers, and CILs. They also provided training on the guide to 27 persons representing consumer and provider groups, the LTC Ombudsman, Aging and Disability Resource Centers, as well as CIL staff.
- Grant staff developed a data base and methods for collecting transition/diversion data.
- Grant funds were provided to local community groups and organizations to develop and implement initiatives to provide supports for individuals transitioning. They include: (1) a Readiness Assessment and Recovery Education Center for persons with mental illness who are transitioning, developed by the West Virginia Mental Health Consumers Association; (2) the Golden Rule Assistance Dog program, which trained and placed six assistance dogs, enabling persons with disabilities to remain in their communities; and (3) the provision of training to hospital staff in one area of the State about supporting

individuals with traumatic brain injury in the community, conducted by the Brain Injury Association.

- Grant staff helped to establish the Legal Resource and Representation Group and organized a meeting of key legal aid organizations to promote communication, collaboration, and coordination on legal issues and actions on behalf of persons with disabilities and others with LTC needs. Staff also developed a booklet on legal representation and legal resources for persons with disabilities who need assistance to access and sustain community living arrangements.
- Grant funds were used to purchase a nationally certified Personal Assistant Services training curriculum for West Virginia State University's Extension Department. Grant staff developed a memorandum of understanding to encourage the University to provide the curriculum at no cost to agencies who want to offer training to current or prospective employees.

Enduring Systems Change

- Prior to the grant, the state plan offered more personal assistance hours than did the waiver program's "homemaker" benefit (defined to include help with activities of daily living and instrumental activities of daily living. Waiver participants who needed more personal care than provided under the waiver were not allowed to get additional hours through the state plan program. The grant staff's recommendations for addressing transition barriers led the State to change the regulations so that A/D waiver participants now can obtain personal care services through the state plan if they need more hours than the waiver will cover.
- The State expanded the use of targeted case management (TCM) for persons transitioning from nursing homes from 30 days pretransition to 180 days. The TCM option is only available for people with mental illness, but the State is considering covering additional eligibility groups.
- Based in part on the recommendations and work of grant staff and the CPASS grant staff, the State instituted a consumer-directed option under the A/D waiver. This option can facilitate transitions when an individual is having difficulty obtaining authorized services due to workforce shortages. Representatives of the Office of Behavioral Health Services are interested in adapting this model for the Mental Retardation/Developmental Disabilities (MR/DD) waiver.
- State agencies, providers, and advocacy groups continue to use outreach and educational materials developed with grant funds.
- Person-centered approaches developed under the grant continue to be used to develop service plans for individuals transitioning, which help consumers to be actively involved in planning their discharges.
- The Commissioner for the Bureau of Senior Services requested and received $3.6 million of state funds for new waiver slots to reduce the waiting list for the A/D waiver. CIL staff

are prepared to provide Navigator services and supports as soon as the funding is available.

- Partnerships formed under the grant are continuing after its end: (1) CILs and the LTC Ombudsman meet monthly to identify transition resources and to address transition barriers, (2) CIL transition navigators continue to meet semimonthly to share best practices and provide transition/diversion information to the Olmstead office and state agencies, and (3) the Legal Resource and Representation Group is meeting on a regular basis.
- Grant staff assisted in the development of memorandums of understanding (MOUs) among protection and advocacy agencies and other public and private legal entities to encourage collaboration among them and responsiveness to Olmstead issues. These MOUs will help to assure that people with disabilities are able to exercise their civil and due process rights to transition to and remain in the community.
- The Northern West Virginia CIL has assumed responsibility for continuing data collection on transitions and diversions, which they will share with the Olmstead Director, the Medicaid agency, waiver program staff, and advocacy and consumer groups.

Key Challenges

- A general lack of home and community services exacerbated by waiver waiting lists and freezes on waiver slots prevented individuals from transitioning in a timely manner. A prior court decision prohibiting the prioritization of individuals on a waiting list for the MR/DD waiver prevented discussions about prioritizing the A/D waiver waiting list for nursing home residents wishing to transition.
- The goal of using staff from CILs as transition navigators was not realistic given varying abilities to assume this role, and the fact that CILs did not serve all areas of the State. As a result, grant staff had to identify other entities to partner with and other sources for navigators, for example staff from grant programs serving specific populations, such as traumatic brain injuries and spinal cord injuries. Grant staff also worked with the West Virginia Mental Health Consumers Association to help transition individuals with mental illness.
- Other transition challenges included: (1) the lack of affordable and accessible housing, (2) difficulty finding community placements for children with complex medical needs residing in nursing homes, (3) the lack of workers to provide authorized services, (4) difficulty finding placements for individuals with behavioral issues, and (5) resistance by community providers to serve individuals with antibiotic-resistant bacterial infections.

Continuing Transition Barriers

- Those cited immediately above.
- The State has a major institutional bias. The majority of LTC funds go to institutions, there is a freeze on waiver slots, and there are waiting lists for both waivers. Due to

legal issues related to waiting lists, the State is not able to prioritize the waiting list to give precedence for waiver slots to individuals who are transitioning.

- Although MDS data show that over 2,000 persons in the State's nursing homes indicated a desire to transition, nursing home-specific MDS data are not available to navigator staff or advocates in West Virginia to target outreach activities.
- Some nursing home residents do not meet either the waiver target group criteria, financial eligibility criteria, or the stringent level-of-care criteria. Some who meet all the criteria need services not provided under the waiver, such as ventilator care.
- Denial of and lack of timely access to home modifications, durable medical equipment, and assistive devices are significant transition barriers.

Lessons Learned and Recommendations

- Comprehensive data are needed to thoroughly document a transition program's cost effectiveness. Technical assistance to develop methods for data collection and analysis is needed.
- A shortage of direct care workers can result in individuals not receiving authorized services. To decrease the risk that transitioned individuals will return to the nursing home due to unmet needs, waiver service providers must ensure that individuals receive their authorized services.
- Planning to introduce or change policies or practices should involve individuals who will be affected by the changes.
- To increase synergy and the likelihood of bringing about sustainable systems change, staff of each Systems Change grant should meet semiannually to share their experiences and develop strategies to promote the achievement of their goals.
- Educating community groups about independent living principles and promising practices and providing them with small grants leverages limited resources to serve a greater number of individuals. It also helps to ensure that initiatives will be specific to the needs of the population and/or the geographic area and will be sustained.
- Grant staff should utilize technical assistance provided by outside sources to learn about best practices and seek information from other states to identify solutions to common challenges.
- Having a quality assurance framework for transition activities and home and community services as well as technical assistance prior to implementation enhances project activities and can save time by helping projects stay on track towards their goals.

Key Products

Outreach Materials

Grant staff produced a brochure about the grant's activities, and over 1,000 were distributed along with other transition information materials, such as fact sheets about the A/D and MR/DD waiver programs, and flyers about training materials on person-centered planning, transition options, and readiness assessment for nursing home staff. All printed materials are available in Braille, electronic format, cassette tape, and large print. The materials were distributed to consumers, providers, nursing home and hospital staff, service providers, and other stakeholders.

Educational and Training Materials

Staff developed a *Navigator's Guide to Community Inclusion*, which provides information about assessment, legal resources, and a readiness assessment tool for individuals in institutional settings, including psychiatric facilities. The guide is being used by the Olmstead Director, CILs, the LTC Ombudsman, and nursing home social workers.

Staff also developed a person-centered transition planning curriculum, a person-centered checklist manual for consumers and navigators, and other PowerPoint presentations and materials on person-centered planning and the transition process. These materials were used in education and training activities.

Reports

Grant staff submitted a preliminary report on Targeted Case Management (TCM) to the Bureau for Medical Services (Medicaid), the ADA Director, the Olmstead Director and other interested parties. The report described the Medicaid TCM option as a means to assist with transition/diversion from nursing facilities and recommended that TCM be available for up to 180 days for anyone transitioning.

WISCONSIN

Nursing Facility Transitions—Independent Living Partnership Grant

Primary Purpose and Major Goals

The grant's primary purpose was to create effective methods to reduce and eliminate barriers that limit or prevent persons with disabilities or long-term illness from living in the community. The grant had four major goals: (1) to establish a consistent outreach process to identify people who want to move from a nursing facility to the community; (2) to enhance the existing independent living center peer support program that provides transition assistance for consumers, families, and guardians; (3) to develop methods to increase housing options for people who are transitioning; and (4) to facilitate successful transitions from nursing facilities to community placements for up to 210 persons during the grant period.

Independent Living Resources, Inc., one of Wisconsin's eight Independent Living Centers (ILCs), administered the grant, which was a statewide collaborative effort of all the ILCs working with the Department of Health and Family Services and other local and state resources.

Role of Key Participating Partners

- While the grant did not have a consumer advisory committee, some members of ILC Boards of Directors and several transition staff had once resided in nursing homes and provided valuable input on a range of transition issues.
- To facilitate transitions, staff collaborated with the transition coordinator in the Department of Health and Family Services and worked regularly with state and county Medicaid staff. They also worked with several organizations and programs, including Wisloan—a low interest loan program for assistive technology—and the Telecommunication Equipment Purchasing Program to obtain items that consumers needed to transition.

Major Accomplishments and Outcomes

- Grant staff successfully transitioned 184 consumers during the grant project. At the time the grant ended, 27 additional consumers were preparing to transition within the next 6 months, thus achieving the grant's target of transitioning 210 persons.
- ILCs enhanced and expanded their existing peer support program enabling transitioning consumers throughout the State to have access to peer support from someone who had already transitioned. If no peers live within travel distance, transitioning consumers are given prepaid phone cards to enable them to communicate with peers in other parts of the State.

- The Wisconsin Coalition of Independent Living Centers, which includes all of the State's eight ILCs, has acquired a greater understanding of the resources needed to support ongoing transition services and is committed to working to assure funding for these services. Some Coalition members are working at the national level to encourage the Department of Education, Rehabilitative Services Administration, which funds ILCs nationwide, to add transition services as a fifth core service provided by ILCs.

Enduring Systems Changes

- The State now covers transition services under the Aged and Disabled (A/D) waiver program. This funding enables nursing home residents to pay for security deposits and other transition expenses.
- The Governor has instituted a *Community Relocation Initiative* within the State's waiver program with the goal of transitioning 1,400 individuals. The initiative allows individuals who have been in a nursing home longer than 90 days to obtain transition funds and is providing a means to continue the activities instituted under Wisconsin's Nursing Facility Transitions (NFT) State Program Grant.
- Awareness about the need for nursing facility transition has increased statewide. Grant staff established a consistent outreach process and all of the State's ILCs now have staff trained in nursing facility outreach and transitioning strategies.
- ILCs are now part of the State's recommended transition teams. Although the State has not allocated funding to cover their services, ILCs continue to provide a greater amount of transition services than they did before the NFT-Independent Living Partnership (ILP) Grant. Nursing facilities and county staff view ILC staff as a resource for transition activities and are more willing to work with them, and ILCs are receiving increased referrals for transitions from a variety of sources. Involving ILCs in transitioning provides consumers with peer support, skills training, and advocacy services that they would otherwise not receive.
- The Wisconsin Coalition of Independent Living Centers has amended its Vision Statement to include a commitment to transition services, and all of the State's ILCs will continue providing transition services after the grant ends.

Key Challenges

- A major challenge was the lack of a systematic method to identify individuals who want to transition. The State would not allow ILCs to use MDS data, which can contribute to the timely and accurate identification of residents with transition potential. The State said it was prohibited from doing so by HIPAA regulations. The ILCs continue to pursue collaboration with state staff to use MDS data, but so far have not been successful.
- Nursing home residents are not fully informed of their rights and options to live in the community, either at admission or later, and the ILCs did not have the resources to conduct outreach to all of the nursing home residents who potentially could transition.

To expand outreach efforts, the ILCs trained more of their own staff, as well as peer supporters, volunteer care givers, counselors, nurse administrators for personal care programs, and families about a wide range of transition issues, community service options, and the transition process. They also provided tools to use when discussing transition with nursing home residents.

- Transitions were delayed by several factors, including long waiting lists for home and community services in most counties and the lack of affordable, accessible housing. Long waiting lists for Section 8 rental assistance vouchers and landlords' refusal to accept vouchers exacerbated the housing problems. Additionally, some housing providers and private landlords were reluctant to rent to people with disabilities, particularly those with mental illness, because they viewed them as a problem group. ILCs addressed delays on an individual basis but were not able to address them on a systems level.
- Grant staff did not establish the level of collaboration with the housing sector that they originally envisioned. Because the association linking the State's 124 public housing authorities (PHAs) was not responsive to overtures from the ILCs, it was not possible for grant staff to establish working relationships with all of the PHAs throughout the State. A few individual ILCs and PHAs, however, were able to work together successfully. ILCs also tried to establish a coalition of local housing providers, PHAs, and businesses, but ended the effort due to lack of interest.

Continuing Transition Barriers

- Until all states enact Money Follows the Person (MFP) funding, people with disabilities will not be assured a choice between home and community services and institutional care.
- Some individuals with multiple diagnoses require services from more than one waiver, which can be very complex to arrange and coordinate. Combining waiver programs would simplify the system for these individuals.
- Allowing states to offer waiver services on a less than statewide basis creates inequities in access to home and community services for nursing home residents seeking transition.
- There is no formal mechanism to connect nursing home residents who identify an interest in transitioning to community living to an advocate (independent of the state or county) to assist them in this process. Such a mechanism could possibly be formalized through the Ombudsman or Independent Living Programs.
- The lack of affordable, accessible, integrated housing is a major transition barrier and the ILC network remains committed to continued advocacy on this issue.
- Budget shortfalls and low reimbursement rates have a negative impact on the availability of workers and community services. Home and community services continue to be poorly funded relative to nursing homes. The lack of transportation services;

affordable, accessible, integrated housing; and workforce shortages make it more difficult for people with significant disabilities to live in the community.

- The lack of an effective statewide nursing home diversion program and a long waiting list for waiver services results in many people being unnecessarily institutionalized and losing their homes. Once in a nursing home, SSI and SSDI eligible residents may only keep a personal needs allowance of about $65 a month, making it impossible to save enough to transition back to the community without government assistance.

Lessons Learned and Recommendations

- Education of paid and volunteer transition staff as well as families, judges, and guardians about the rights of individuals in nursing facilities and the availability of home and community services helps to assure the success of outreach activities. Undertaking education activities early in the transition process also helps to decrease resistance to transition based on negative preconceptions, and encourages broad involvement in transition planning processes at an early stage.
- Adoption of an MFP approach is an effective strategy for dealing with a lack of services due to waiver program waiting lists.
- The grant laid the groundwork but much more advocacy work and state commitment and action is needed to provide home and community services to all nursing home residents who want to live in the community.
- Allowing a higher personal needs allowance for nursing home residents who are actively planning transitions would improve their financial situation

Key Products

Outreach Materials

Independent Living Resources produced a two-page *Nursing Facility Transition* flyer that provides basic information about consumers' right to be supported in the community as well as a clear description of the NFT-ILP Grant project, including contact information for obtaining assistance.

Educational Materials

Grant staff produced a residents' rights brochure, which was used for consumer education, and materials about the rights of individuals in nursing facilities were used in training ILC staff, peer supporters, families, and others. The materials included information about the *Americans with Disabilities Act* and the Olmstead decision, as well as relevant Medicaid regulations.

Technical Materials

Grant staff developed a *Needs Assessment Survey* and a *Furnishings Checklist* to assist transition planning.

WISCONSIN

Nursing Facility Transitions—State Program Grant

Primary Purpose and Major Goals

Wisconsin's nursing facility transitions project, titled *Homecoming II*, is built on the experience of a previous Nursing Facility Transitions grant received in 1999. The original *Homecoming* project focused on individuals with physical disabilities and frail elderly persons living in nursing homes, and developed relationships with Independent Living Centers as partners in outreach and relocation support.

The grant's primary purpose was to develop statewide systematic processes for the ongoing identification and relocation of institutionalized individuals who want to live in a less-restrictive setting, giving special emphasis to those who have developmental disabilities or serious mental illness. The grant had two major goals: (1) to facilitate the transition of approximately 400 individuals from nursing facilities to a successful community placement during the project period, and (2) to increase the flexibility and responsiveness of the current system so that available resources can be redirected to enable persons with long-term care needs to be served in the least restrictive setting appropriate to their needs.

The grant was awarded to the Department of Health and Family Services (hereafter the Department) and implemented by its Division of Supportive Living (now called the Division of Disability and Elder Services) in collaboration with Wisconsin's Nursing Facility Transitions–Independent Living Partnership (NFT-ILP) Grant that was awarded to Independent Living Resources, Inc., one of Wisconsin's eight Independent Living Centers.

Role of Key Participating Partners

- Independent Living Resources, Inc. and the other Independent Living Centers (ILCs) identified individuals who wanted to relocate to the community and provided one-time transition services. To facilitate transitions, the ILCs collaborated with the Department's transition coordinator, worked regularly with state and county waiver staff, and provided ongoing peer support.
- The State's county human services departments, which administer Home And Community-Based Services (HCBS) waiver programs, identified individuals in their communities for relocation, made funding available, and provided care coordination.
- The Stockbridge–Munsee Band of Mohican Indians, the Community Care Organization, NewCAP, Independent Living, Inc., and the Foundation for Rural Housing worked on initiatives to expand the availability of affordable, accessible housing which were funded by the grant.
- The Department contracted with Independence First of Milwaukee, an ILC, for a relocation coordinator to assist with the high volume of nursing home closures in that area. The relocation coordinator worked with state and county partners to develop a

cross-agency team to ensure that residents in closing facilities were given the option to move to the community prior to being moved to another nursing facility.

Major Accomplishments and Outcomes

- The Department and its partners assisted 471 nursing home residents to move into their own homes or other community settings using an individualized care planning process. Eighty percent of the individuals relocated from 2002–2004 were still in the community after 1 year. Consumer satisfaction interviews with a sample of those relocated indicated that almost all were pleased with the move and with their new living situation.
- Data collected by the Department that demonstrated savings to the Medicaid budget for relocated individuals helped convince the legislature to enact a Money Follows the Person (MFP) policy and provided support for the Governor's Community Relocation Initiative.
- In addition to contracting with Independence First of Milwaukee for a relocation coordinator, the Department also hired a state-level relocation coordinator who worked with staff of the NFT-ILP Grant on individual relocations and developed a positive working relationship with all of the ILCs. She also worked with mental health staff hired by the State's Real Choice Grant to develop a strategic plan to resolve systems problems that present service barriers for people with mental illness. In this capacity, she worked with the Real Choice Grant staff to relocate some individuals with serious mental illness from nursing homes. Initially funded by the grant, the state relocation coordinator is now a permanent position.
- The project's workforce coordinator conducted a review of workforce projects funded by the Department from 1999 through 2002 to identify their accomplishments and conducted a county survey to learn about the current status of the direct care workforce. She also assisted a local organization to apply for and receive a U.S. Department of Agriculture grant to plan the development of a worker cooperative in one county.
- The housing grants funded through the grant increased the availability of housing options for people with disabilities. Local agencies completed five housing projects that included: (1) assistance with home repairs and accessibility modifications, (2) a project to convert senior housing units to assisted living apartments, (3) an assessment and survey of housing accessibility and safety among elders of a Wisconsin tribe, (4) the development of a cooperative for elderly housing in a rural area, and (5) planning and site selection for an elderly housing cooperative in Milwaukee.

Enduring Systems Changes

- The most significant and enduring outcome was the enactment of an MFP policy for individuals in nursing homes and intermediate care facilities for persons with mental retardation and other developmental disabilities. The State has a long waiting list for waiver slots and this policy will enable individuals in these institutions to move to a community setting without having to wait for a waiver slot or for an institutional bed to

close. Prior to the implementation of this policy, the state budget allocated a certain number of slots to the Department and additional slots could only be generated if a person left a nursing home that was closing or downsizing and the bed was closed.

- The Governor has instituted a Community Relocation Initiative within the State's waiver program with the goal of transitioning 1,440 individuals. The Initiative allows individuals who are Medicaid eligible nursing home residents to obtain transition funds and is providing a means to continue the activities instituted under the grant.
- The State amended its HCBS waiver for elderly persons and persons with physical disabilities to include relocation services.

Key Challenges

- The main transition challenge was the lack of home and community services and Medicaid budget shortfalls that precluded the appropriation of additional funds. However, because the grant documented savings for nursing home residents who relocated to the community, the legislature enacted a policy allowing the State to move funds from the nursing home budget to the community budget for persons able to transition.
- Although a specific goal was to transition persons with serious mental illness and developmental disabilities, it was not possible due to a lack of funding for home and community services for these populations at the time the grant was implemented. However, the new MFP policy will provide a source of funding for these services and the State is using the Systems Change MFP grant it received in FY 2003 to work on transitioning persons with developmental disabilities. The Real Choice Grant staff have applied for a 1915(c) waiver for persons with mental illness who are in nursing facilities.
- The project was not able to fully address issues related to workforce shortages and the grant's objectives in this area were not fully achieved due primarily to staffing issues. Additionally, because the State does not employ direct care workers, efforts to address workforce issues are dependent on multiple local and private agencies over which the Department has only minimal control. The Department is continuing to work on workforce recruitment and retention issues as part of its Comprehensive Systems Change Grant and continues to provide grant funding to counties to work on these issues as well.

Continuing Transition Barriers

- Although local care managers have been creative in finding solutions on a case-by-case basis to address workforce shortages and a lack of accessible affordable housing and transportation, these issues continue to be major transition barriers.
- The Council on Long Term Care Reform's Residential Options Committee acts in an advisory capacity to the Department and made recommendations for strategies to address a wide range of housing and residential care issues. However, the recommendations have not been implemented due to the differing and often conflicting

interests and perspectives of stakeholders, which include nursing home operators, community residential care home operators, housing officials, consumers, and advocates. The fragmentation of the public housing and residential care sectors is also a factor impeding implementation of the recommendations.

Lessons Learned and Recommendations

- It is vital to have a person coordinating nursing home relocation activities. This ensures that relocations receive priority and are expedited.
- Relocations need to be under the overall auspices of a state's HCBS waiver program(s). Relocation activities must be visible, but cannot be operated in isolation of ongoing programs. The county staff who operate Wisconsin's waiver programs have skills and resources that could not be duplicated by a dedicated group of care managers who only work with relocations.
- Having information to document the success of relocations is critical to achieving enduring change. Data is important, but policy makers also respond to stories. Projects need to ensure there is a "face" to relocations.
- It is important to have a funding source like Wisconsin's Community Options Program that can be used flexibly to fund transition costs that cannot be covered under Medicaid waivers.
- Policy changes to allow for more seamless funding of long-term care regardless of the setting would enable people who need care to choose options without the limitations imposed by funding sources.

Key Products

Reports

- To gain a better understanding of the current structure and availability of the long-term care workforce, an online survey was conducted during July 2004. The *Long-Term Support Direct Care Arrangements in Wisconsin Counties: Survey Results, 2004* report summarizes the information collected through the survey and provides an overview of the ways in which counties purchase direct care and support services for elderly people and people with disabilities under the state-funded Community Options Program (COP) and HCBS waiver programs. The report represents an important initial step in documenting Wisconsin's direct care and support arrangements in order to assist county and state-level program and policy planning.
- Starting in 1999, funding has been available to county COP lead agencies to initiate closer links with employment and volunteer resources in an effort to address weaknesses in the long-term care provider networks in their areas. Counties were invited to initiate efforts, called Community Links Workforce Projects, to strengthen or expand the workforce for the long-term care population in their communities.

The counties form local coalitions to identify strategies to address worker shortages, determine approaches that will be most successful in their communities to address the issues, and apply for grants to implement their project ideas.

Wisconsin's Community Links Workforce Projects—Four Year Summary 1999–2002 provides an overview of home and community care and the workforce through a review of all the Community Links Workforce projects. Each county description includes the name and contact information for one or more key people.

- A report titled *Interviews With 2001, 2002, 2003 Wisconsin Nursing Home Relocation Project Participants* summarized interviews with persons who relocated under the NFT project. The report was prepared by the Department's quality assurance contractor for the COP-Waiver Program, who conducted interviews with 49 persons relocated under the NFT project between 2001 and 2003.