# THE HOMECOMING PROJECT:

# Wisconsin's Nursing Home Transition Demonstration



July 17, 2002

This report is one of a series of Appendices which are included in the report "Final Report of the Nursing Home Transition Demonstration Grants Case Study," available from the HHS Office of Disability, Aging and Long-Term Care Policy's website (<a href="http://aspe.hhs.gov/daltcp/home.shtml">http://aspe.hhs.gov/daltcp/home.shtml</a>).

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The office develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

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# The Homecoming Project: Wisconsin's Nursing Home Transition Demonstration

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# Introduction

Across the broad spectrum of public policy, American society is increasing opportunities for persons with all types of disabilities, including people with the physical disabilities and frail older persons, to live lives of their own choosing, in places of their own choosing. Recent policy initiatives in civil rights, health and long term care, income assistance, employment, and housing have a common objective--to create systems of supports and services that allow persons with disabilities, even the most severe impairments, to live independently in accordance with their own choices and decisions. President Bush's New Freedom Initiative provides additional impetus for the continued expansion of community-based supports and services and continued reduction of the nation's reliance on institutional models of care for persons of all ages with disabilities.

# Nursing Home Transitions Demonstration

The Centers for Medicare & Medicaid Services (CMS), in association with the Assistant Secretary of Planning and Evaluation (ASPE), sponsored the **Nursing Home Transitions Demonstration Program.** Under the Demonstration program, CMS and ASPE awarded grants to 12 states between 1998 and 2000 to help nursing home residents move to the community. CMS and ASPE selected The MEDSTAT Group to evaluate the Demonstration Program. The evaluation methodology employed is a case study approach, based upon site visits to nine Demonstration states. The case studies will provide useful information to other states as they begin or continue nursing home transition programs, particularly the states that received 2001 and 2002 Systems Change Grants for Community Living from CMS to affect Nursing Facility Transitions.<sup>2</sup>

#### The Homecoming Project

The Wisconsin nursing home transition program, called the Homecoming Project, awarded funds to Wisconsin's eight Centers for Independent Living (CILs) to facilitate transitions. During a site visit conducted in August 2001, MEDSTAT interviewed staff from the State of Wisconsin Department of Health and Family Services (DHFS) who coordinated the project, as well as staff

<sup>1</sup> In 1998, Colorado, Michigan, Rhode Island and Texas were awarded grants of between \$160,000 and \$175,000 each. In 1999, New Hampshire, New Jersey, Vermont, and Wisconsin received grants of \$500,000 each. In 2000, Arkansas, Florida, Pennsylvania and Nebraska received grants of \$500,000 each.

<sup>&</sup>lt;sup>2</sup> For more information on the Systems Change Grants for Community Living, see the following website: www.hcfa.gov/medicaid/systemschange.htm.

from one of the CILs that implemented the program. MEDSTAT interviewed staff from two additional CILs during conference calls soon after the site visit. MEDSTAT staff also interviewed six consumers who left nursing homes with the help of the Homecoming Project and staff from a county agency responsible for approving the home and community-based services many consumers used after leaving nursing homes. The CILs' final reports for the project and several unpublished reports from the state also informed this case study.<sup>3</sup>

The report begins with a description of Wisconsin's Homecoming Project, followed by a summary of the program's results. The report then discusses how project staff responded to barriers to nursing home transitions, how nursing home transitions continued after the Demonstration project ended, and how the project informed requests for 2001 Systems Change Grants for Nursing Facility Transitions from CMS. Key observations that may be particularly helpful for states that are planning to implement nursing home transition programs of their own conclude this report.

# **Program Description**

Wisconsin received a \$500,000, one-year Nursing Home Transition grant in September 1999 to fund the Homecoming Project. Wisconsin's Department of Health and Family Services (DHFS) contracted with Centers for Independent Living (CILs) to transition nursing home residents in their service area to community settings. The state established goals to help 150 people leave nursing homes, and to help an additional 150 people begin the transition process and possibly transition after the grant period ended. An additional objective was to facilitate the development of a greater role for CILs in long-term care by improving the relationships between CILs and counties, which provide local administration for home and community-based services programs.

Wisconsin provided \$10,000 to each CIL for staff time related to nursing home transitions. Table 1 lists the eight CILs and the cities in which they are located. CILs facilitated most of the transitions under the project, but some of Wisconsin's 72 counties also facilitated transitions under the project. The counties, which administer the state's home and community-based services programs, did not receive grant funds for staff time. The state reserved over \$325,000 of the \$500,000 Demonstration grant for transition expenses with no other identified funding source. Wisconsin hired a project coordinator to develop the contracts with the CILs, provide training and technical assistance, and approve the use of the Homecoming Project funds for transition expenses.

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<sup>&</sup>lt;sup>3</sup>References for these reports can be found in the bibliography at the end of this report.

TABLE 1. CILs Funded by the Homecoming Project		
CILs	Location	
Access to Independence	Madison	
Center for Independent Living for Western Wisconsin	Menomonie	
Great Rivers Independent Living	La Crosse	
Independence First	Milwaukee	
Midstate Independent Living Consultants	Rhinelander	
North Country Independent Living	Superior	
Options for Independent Living	Green Bay	
Society's Assets	Racine	

# The Role of Centers for Independent Living

Each CIL designated a Regional Homecoming Coordinator to work with nursing home residents who wanted to live in the community. According to state staff, the state encouraged CILs to hire consumers. At least two of the coordinators interviewed for this report have a disability. Some CILs used Homecoming Project funds to hire a new part-time person specifically responsible to facilitate transitions. Other CILs used the funds to pay for part of a current staff person's time, so that person could spend a higher percentage of his or her time facilitating transitions.

Wisconsin did not develop a standard process for facilitating nursing home transitions. Each of the eight CILs devised its own process for facilitating transitions. The three CILs interviewed for this report differed in the level of formality applied to the process. Before the grant period, one CIL with prior experience facilitating transitions had already developed an assessment tool to identify items the consumer should consider or address before moving, including housing, service, and transportation needs and preferences. This CIL's coordinator preferred consumers complete this assessment themselves as much as possible. The other two CILs did not have an assessment tool, but identified similar needs using the expertise of their Regional Homecoming Coordinators, one of whom had moved from a nursing home and had experience helping other people move.

In addition to the Regional Homecoming Coordinator, other CIL staff supported people leaving nursing homes in the course of their normal responsibilities. Many residents received independent living skills training (which covers a wide range of activities, including budgeting, shopping, food preparation, and using public transportation) and peer support to help them

prepare for living in the community and adjust to living with a disability in the community. One CIL created a peer support group comprised exclusively of former nursing home residents, enabling Homecoming consumers to help each other through their common experience. CILs also offered benefits counseling, the support of a housing specialist, and a loan center for assistive technology.

Some CIL staff indicated a key challenge was setting realistic consumer expectations. Some consumers and family members reportedly underestimated the level of assistance they would need in their own home or apartment. According to one Regional Homecoming Coordinator, some people initially expressed preferences for non-essential household items like entertainment equipment and later realized a table and cookware may be more urgent needs. One CIL staff person stressed the importance of working with, not ahead of, the consumer. For example, she encouraged consumers to develop a long-term goal, even if she believed it was unrealistic, and then helped them identify intermediate steps toward attaining that goal.

Consumers interviewed by MEDSTAT staff highlighted several aspects of the CILs' assistance that were important in helping them leave nursing homes. Several consumers had worked toward moving before the CIL was involved, but were unable to pay for necessary goods and services (e.g., apartment deposits, furniture) or were not able to find housing on their own. One consumer said developing a plan for moving was important. Another cited the moral support from CIL staff.

CIL staff said they continued to support consumers for several months after they had moved back to the community. The amount of time consumers and CILs kept in touch depended on the consumers' needs and preferences. CILs made its other services, including peer support and independent living skills training, available to former residents. Peer support was particularly important for many consumers. For some consumers, leaving a nursing home was a first step to further independence. Some consumers interviewed for this report were taking steps to enter the workforce and one was enrolled in college.

# Role of State Project Coordinator

Wisconsin hired a project coordinator to develop contracts with the CILs, provide training and technical assistance, and approve the use of the Homecoming Project funds for transition expenses. The project coordinator worked in the state's Office for Persons with Physical Disabilities (OPPD) within the Bureau of Aging and Long Term Care Resources, the state

agency that manages home and community-based services for elderly people and people with physical disabilities.

The state project coordinator's principal strategies for orientation and training of the Regional Homecoming Coordinators were video conference calls and site visits. During the monthly videoconferences, all eight CILs updated the state and each other on their progress and discussed effective strategies. CIL staff with less experience facilitating transitions reported learning from other CILs' experiences, while CIL staff with more experience did not find the conference calls valuable. CIL staff provided few comments on the site visits, in which the project coordinator visited each CIL to learn more about local differences in the project and to provide technical assistance.

# Transition Expense Payment Process

Wisconsin set aside most of the \$500,000 grant, \$325,000, for one-time transition expenses. Table 2 describes the process by which CILs and counties applied for transition expenses on a consumer's behalf. For each transition expense, the CIL or county faxed a completed form, along with either receipts or cost estimates, to the state project coordinator. Wisconsin contracted with Age Advantage, an Area Agency on Aging based in Madison, to act as a fiscal intermediary. After the project coordinator approved the expenses, she authorized the fiscal intermediary to issue a check to the CIL or county. This arrangement allowed the state to bypass the state purchasing requirements and reimburse CILs based on receipts submitted.

TABLE 2. Original Transition Expenses Payment Process		
Agency	Action	
CIL or County	Sends request to use Homecoming funds.	
State	Approves or denies payment.	
CIL or County	If state approves payment, purchases item(s) and sends receipt to state.	
State	Forwards receipt to Age Advantage.	
Age Advantage	Sends payment to CIL.	

The approval and reimbursement process did not work as efficiently as the state planned. During the grant, the state adjusted the approval process. The state allowed CILs and counties to obtain advance approval based on undocumented cost estimates (e.g., \$500 for items necessary to set up a household) and then follow up with documentation for each item purchased.

#### Identifying Candidates for Nursing Home Transition

The state targeted the Homecoming Project funds to Medicaid-eligible residents who had been in a nursing home at least three months. One CIL reported that several people interested in Homecoming were not eligible because they were not eligible for Medicaid. The Homecoming Project focused on people with disabilities under age 65. Due to the short time frame of the project, however, the state did not set an age limit and encouraged CILs and counties to help as many people as they could regardless of age.

CILs reported they did not deny transition assistance based on level of disability or on any other criteria. Due to the short duration of the project and the high demand for assistance, some Regional Homecoming Coordinators focused on people who they perceived as "ready to move". Indicators of readiness included:

- an ability to live safely in the community without skilled services (e.g., registered nurse, therapist),
- an ability to signal for help,
- an existing support system, either through family or social service agencies,
- cooperation from the nursing home discharge planner,
- the consumer's progress toward making a transition before the CIL became involved, and
- the consumer's willingness to do his or her share of the work required to move.

Some CIL staff considered the last two criteria particularly important, because they believed consumers would be more satisfied with the transition and more likely to continue living independently if they performed much of the work necessary for transition themselves. For example, one CIL provided a consumer a list of apartment buildings with accessible, affordable apartments, but the consumer was responsible for calling the apartments, visiting them, and choosing an apartment.

Wisconsin publicized the Homecoming Project in newsletters sent by the Office for Persons with Physical Disabilities and through a pilot project called Family Care. The state also sent a memo about the Homecoming Project to county, tribal, and Area Agency on Aging staff. State staff presented the project to nursing home ombudsmen, including specific instructions on how to refer a consumer to the project. State staff also sent a press release to local media, which led to newspaper articles about the project.

In addition to statewide outreach efforts, Wisconsin required CILs to perform an outreach mailing to nursing homes in the CIL's service area. The state provided a memo and brochure

for the CILs to mail to nursing home administrators or discharge planners. Some CILs performed additional outreach. A CIL in a rural area received some response from local newspaper articles and advertisements; this CIL had little success with radio announcements and flyers that were made available in libraries, grocery stores, and other public places. One CIL gave presentations to discharge planners and nursing staff in each nursing home in its thirteen-county service area as an outreach activity. The staff person who gave these presentations believed these face-to-face presentations were the most effective form of outreach.

Two of the three CILs interviewed for this report received more requests for transitions than they could serve. CILs learned about transition candidates from the candidates themselves, family members, nursing home ombudsmen, nursing home discharge planners, hospital discharge planners, and county agencies that manage home and community-based services.

#### CILs' Relationships with Nursing Homes

CIL staff reported that nursing homes were generally cooperative with the project, especially once informed that people have a legal right to leave. For some rural nursing homes, extensive effort was required to convince nursing homes that they could not legally prevent CIL staff from visiting a resident who had invited the CIL staff into the home. According to CIL staff, nursing home discharge planners were particularly cooperative and a good referral source and nursing home rehabilitation professionals sometimes helped the consumer and CIL prepare for transition.

Some consumers indicated more resistance from nursing homes. Other consumers said nursing home staff were willing to help but did not know how or had limited time to do so. One consumer recommended additional outreach with nursing home discharge planners, which may also increase awareness of community options among nursing home staff.

#### CILs' Relationships with Community Long Term Care Programs

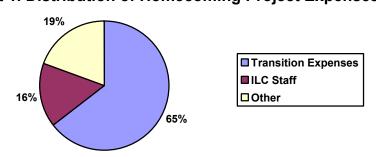
One of the state's goals for the Homecoming Project was to improve the relationship between CILs and counties. Wisconsin's 72 counties and one American Indian tribe are responsible for authorizing public home and community-based services. Most consumers accessed supportive services through the Community Options Program Waiver, a Medicaid home and community-based services (HCBS) waiver for people with disabilities and older people. County staff determine eligibility for home and community-based services and help consumers select their

services. According to state staff and some CIL staff, the CILs have often had adversarial relationships with counties, due to the CILs' advocacy role and the counties' role in providing home and community-based services. However, one CIL staff person reported good relationships with the counties in its service area before the grant.

The Homecoming Project required CILs and the counties to work together to ensure community housing and services were available as soon as consumers left the nursing home. Three months into the project, Wisconsin began requiring that county staff conduct assessments of Homecoming Project consumers *before* they left the nursing home. This required cooperation between CILs and counties, gave Homecoming Project consumers quicker access to services, and addressed the concern of some counties that people may be leaving nursing homes without adequate services. If the resident was eligible for the HCBS waiver, county staff also visited the resident one or two days after the move to develop a plan of care for waiver services. In addition to working with CILs, some counties also facilitated transitions on their own. Most people assisted by county staff were either on the county's waiting list for Medicaid waiver services or residents of a nursing home scheduled to close.

# **Demonstration Results**

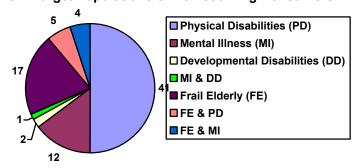
The \$500,000 Demonstration grant served people from October 1, 1999 through December 31, 2000. The grant was originally a one-year grant, but CMS approved Wisconsin's request for a three-month, no-cost extension. As shown in Chart 1, about 65% of grant funds were allocated to transition expenses, including home modifications, rental deposits, and household items. Wisconsin paid 16% of the grant to CILs to cover staff time. The remaining funds were used to cover the costs of the fiscal intermediary and the state project coordinator's salary and expenses.



**Chart 1. Distribution of Homecoming Project Expenses** 

During the 15-month federal grant period, 81 nursing home residents transitioned to community living. CILs facilitated transitions for 56 of these people. Counties helped an additional 25 people relocate from nursing homes using Homecoming Project funds. An additional 85 residents worked with CIL staff toward moving from a nursing home. Several nursing home residents continued to prepare for transition after the grant period ended. The number of people who left nursing homes was well short of the state's goal of 150 people, but is comparable to the number of people relocated by other Demonstration states.

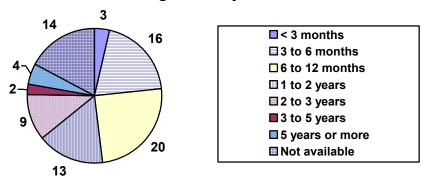
The Homecoming Project focused on people under the age of 65 with physical disabilities. As Chart 2 shows, about half of the 81 people transitioned during the grant period were within this target population. An additional 15 former nursing home residents were under age 65 with a diagnosis of mental illness and/or developmental disability. Thus, more than two-thirds of transitioned residents were under age 65. By comparison, in 1999 only 7% of Wisconsin nursing home residents were under age 65 (Wisconsin Bureau of Health Information, 2000).



**Chart 2. Target Populations of Homecoming Consumers** 

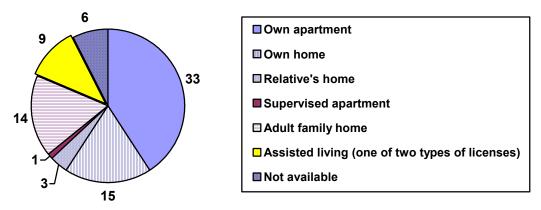
Nationally, nursing home residents are most likely to leave in the first three months of their residency (Gabrel and Jones, 2000). In contrast, Wisconsin focused the Homecoming Project on people who had been in a nursing home three months or longer. The state intended to focus resources on persons less likely to leave the nursing home without assistance. Only three consumers had been in a nursing home for less than three months. Chart 3 presents nursing home length of stay data, which were available for 67 consumers. A majority of Homecoming Project consumers (36) had been in a nursing home for three to twelve months. Twenty-eight consumers had been residents for more than one year, and the longest length of stay was almost 18 years. These data suggest that the program was successful in targeting nursing home residents who probably would not have returned to the community without special assistance.

Chart 3. Homecoming Consumers' Nursing Home Length of Stay



Of the 75 people for whom living arrangement data were available, nearly two-thirds of consumers moved to their own home (15) or apartment (33). As shown on Chart 4, other consumers usually moved to congregate living facilities, either adult foster care homes or assisted living facilities. People who moved to a congregate living facility were more likely to have been helped with their transition by county staff.

Chart 4. Homecoming Consumers' Living Arrangement After Transition



None of the Homecoming Project consumers returned to a nursing home during the grant period. At the time of the site visit, the three CILs interviewed for this report had helped 41 people leave nursing homes (28 during the grant period and 13 after the grant period). At that time, between 3 and 18 months after discharge, three of these 41 people had returned to a nursing home.

The Homecoming Project did not measure the overall cost of facilitating a transition because it did not measure the staff time to assist residents in transition. The project did measure the cost

of one-time items and services purchased to help a person transition. The cost for these transition services ranged from \$0 to \$38,104. For the 65 people that used Homecoming Project funds for transition expenses, the average cost was \$4,722. The most expensive transition services were home modifications.

State staff and some CIL staff indicated that relationships with counties and CILs generally improved as a result of the Homecoming Project. One CIL indicated it had good relationships with counties before the project. According to state staff, county staff became more aware of the wide variety of services and resources offered by CILs, in addition to their advocacy function. However, CIL and state staff indicated tense relations remained between some counties and some CILs. One CIL staff person reported rural counties and counties far away from a CIL were more resistant to the CIL's involvement because county staff perceived CIL staff as outsiders.

# **Barriers to Community Transition and How Addressed**

State staff and most CIL staff interviewed for this report said the two most significant barriers to transition were: (1) a lack of affordable, accessible housing; and (2) a low supply of home and community-based services.

#### Housing

State staff and the CIL serving Milwaukee reported a lack of affordable, accessible housing was the most significant barrier to community relocation. People often had to wait several months for subsidized housing or looked for non-subsidized housing because the wait was so long. Housing was even more difficult to find because most consumers required accessible residences. Some consumers did not require accessible residences because their primary diagnosis was mental illness. According to one CIL, many consumers had financial histories that made it difficult to obtaining private housing. Credit card debt was most common, either from medical bills or basic living expenses. Delinquent phone and utility bills also complicated the housing search.

One Regional Homecoming Coordinator reported home modifications were often delayed due to a lack of reliable contractors with the knowledge and skills to make modifications in compliance with the Americans with Disabilities Act. Indoor modifications were particularly difficult to complete in the summer and fall because contractors wanted to complete their outdoor work before winter.

Housing was not the most significant barrier for all geographic areas and target populations. One CIL serving several rural counties reported housing was a less significant barrier than securing home and community-based services, but it was still a significant barrier. One CIL staff person said elderly people were more likely to prefer moving to a child's home, which made housing a less significant barrier if the child was willing and able to live with the consumer. Publicly financed assisted living was not available for younger people with disabilities in Wisconsin, which further limited housing and service options for that population.

<u>How addressed:</u> CILs interviewed for this report employed a variety of methods to help residents obtain housing. These methods included:

- employing housing specialists to connect consumers with public and private housing resources,
- providing home modification assessments and coaching people to work with landlords to allow home modifications,
- financing home modifications with Community Development Block Grant funds or the U.S. Housing and Urban Development Department's Home Investment Partnerships Program (a.k.a. the HOME program),
- working with a developer to dedicate housing units to people leaving nursing homes,
- referring consumers with poor credit to the Wisconsin Coalition for Advocacy, a source for attorneys doing pro bono work, so the consumer could start bankruptcy proceedings to reduce his or her debt burden, and
- negotiating with the local phone company to settle delinquent claims for phone services.

#### Home and Community-Based Services

Most Homecoming Project consumers required home and community-based services (HCBS) after their transition, and most accessed services under a Medicaid HCBS waiver. In most counties, there are waiting lists for the state's largest waiver program, the Community Options Program Waiver (COP-W). The average time that new waiver applicants spend on a waiting list varies by county. CIL and state staff estimated that the time spent on a waiting list ranged from two to seven years.

CIL staff also indicated that few service providers were available even when financing was available. Several home health agencies and personal care agencies went out of business in 2000, and there was a general shortage of direct service workers. One CIL staff person said a lack of confidence in the home and community-based services infrastructure made some family members and consumers less likely to choose a return to the community.

How addressed: Two state programs that preceded the Homecoming Project helped address the shortage of home and community-based services. The Community Integration Program II (CIP II), administered within a Medicaid home and community-based services waiver, is specifically designed for people who leave nursing homes. Under CIP II, every time a nursing home closes and a former nursing home resident moves to the community, additional funds are allocated to the CIP II to support one consumer living in the community. These funds are initially available to the person leaving the closed nursing home. If this person does not use waiver services, these funds are then available for other people leaving nursing homes.

Wisconsin reserved some CIP II openings for people served by the Homecoming Project. Some county and CIL staff criticized this practice because it allowed Homecoming Project consumers to receive waiver services before other waiver applicants who had been waiting longer. At least one person was concerned that this arrangement, if continued over the long-term, would create an incentive for some people to enter nursing homes.

Wisconsin had also implemented a pilot project called Family Care. In the five counties in which all components of Family Care are available, home and community based services are considered an entitlement and these counties do not have waiting lists, enabling quick access to services. Family Care is also operated as a managed care model, which gives counties a financial incentive to help people leave nursing homes, since the counties are financially "at risk" for the total costs of long term care services provided in the county. One CIL said that Family Care counties were more willing to help relocate consumers. On the other hand, another CIL considered Family Care an obstacle during the Homecoming Project because CIL and county staff started the project in a newly changed system with new rules they did not yet know how to follow.<sup>4</sup>

#### **Transportation**

According to CIL staff, public transportation is not readily available in Wisconsin, particularly outside Milwaukee County. CIL staff reported transportation services specifically for older people and people with disabilities can be unreliable, insufficient, and expensive. CIL staff reported transportation was a barrier both before and after a person left a nursing home. For

<sup>&</sup>lt;sup>4</sup> For a more complete discussion of the initial implementation of the Family Care Demonstration, see the *Wisconsin Family Care Implementation Process Evaluation Report*, which can be found at the following website: http://www.legis.state.wi.us/lab/Reports/00-0FamCaretear.htm

example, arranging for peer support was difficult because usually either the peer or the consumer needed accessible transportation.

<u>How addressed:</u> CILs tried to improve access to transportation in several ways. One CIL typically accompanied people when they visited a potential apartment to be sure the consumer considered proximity to public transportation. One CIL bought a van to meet their staff, volunteers, and consumers' transportation needs; however, this CIL believed most CILs in Wisconsin could not afford vans. One consumer used a motorized scooter to run errands, and recommended it for other people. Several community and church fundraisers paid for a van with a lift for another consumer.

#### Guardianship

Depending upon individual circumstances, guardians could be either a barrier or an advantage for a person trying to leave a nursing home. Consumers, state staff, and CIL staff mentioned several examples of guardians who resisted nursing home transition, usually due to safety concerns. Resistant guardians reportedly were often corporate guardians or family members who were informal caregivers when the consumer was in the community. Some family members, who reportedly were burned out from their caregiving responsibilities before nursing home admission, were characterized as reluctant to put themselves at risk of burn out again if consumers were to return to community living. Also, the shortage of personal care workers and lack of nearby medical services in rural areas caused guardians to be concerned about potential health and safety risks.

<u>How addressed:</u> One CIL connected guardians who were reluctant to support transition with guardians who had been involved in successful transitions. Some guardians were reportedly willing to support transition after learning about a successful example.

# Summary of Methods to Address Barriers

Table 3 summarizes methods to address transition barriers encountered in the Homecoming Project.

TABLE 3. Addressing Barriers to Nursing Home Transition		
Barrier	How Addressed	
Housing	Housing specialist to identify resources	
	Home modification assessments	
	Funding home modifications through other federal sources	
	Legal assistance in bankruptcy proceedings to reduce debt burden	
	Settling delinquent phone bill claims	
Shortage of Home and	Home and community-based services program specifically for people	
Community Services	leaving nursing homes	
	Pilot project in which home and community-based services are an	
	entitlement, with incentives to help people leave nursing homes	
Transportation	Encourage consumers to consider transportation availability when	
	selecting housing	
	Motorized scooter for consumers	
	Community fundraisers for accessible van	
	CIL purchase of van to help staff and volunteer transportation	
Guardianship	Connect guardians reluctant to support transitions to guardians who	
	have allowed successful transitions	

# **Next Steps for the Nursing Home Transition Program**

Wisconsin did not continue funding the Homecoming Project after the federal grant period ended in December 2000, but nursing home transitions continued nevertheless. CILs continued to facilitate nursing home transitions, although at a reduced level, since no funding was available for transition services or CIL staff time. Counties also continued transitions because more nursing home closures were occurring. State staff anticipated more closures because companies which owned an estimated 10% to 15% of Wisconsin's nursing homes were in bankruptcy.

Late in 2001, the state set aside approximately \$1.9 million to pay for one-time transition expenses and for ongoing home and community-based services for people leaving nursing homes. Wisconsin set aside an additional \$1.3 million in 2002 for the same purpose. The money included Medicaid HCBS waiver funds for ongoing services and state funds for services that are not covered by a Medicaid HCBS waiver. Wisconsin added any money spent on ongoing services to its home and community-based services programs budget in future years, so the money would be available as long as the former residents lived in the community. Using this money and the Community Integration Program II mentioned in the "Barriers" section, 153 people left Wisconsin nursing homes in 2001. Both CILs and counties facilitated these transitions.

Both the state and the CILs used their experience in the Homecoming Project to develop proposals for the Nursing Facility Transition Grants under the Systems Change Grants for

Community Living program in the spring of 2001. Wisconsin submitted two proposals for Nursing Facility Transition Grants, one from the CILs and one from the state. In September 2001, CMS awarded the state a \$800,000, three-year grant and the CILs a \$450,000, three-year grant.

The state grant will continue transition funding for people with physical disabilities and older people while expanding transition efforts to people with mental illness and people with developmental disabilities in intermediate care facilities for people with mental retardation. Wisconsin will also use the grant to start initiatives to increase the supply of direct support workers and affordable, accessible housing. The state's grant, like the Homecoming Project, set a goal of improving the relationship between a non-profit advocacy group and the publicly funded long-term care system. According to state staff and some CIL staff, the Homecoming Project successfully improved relationships between CILs and counties, and the state proposed to replicate this experience with another target population and advocacy organization. For the second grant, the state plans to partner with Grassroots Empowerment, an advocacy organization for people with mental illness, and increase its involvement in the long-term care system for people who are dually diagnosed with developmental disabilities and mental illness.

The grant to the CILs is similar to the Homecoming Project. One difference is that Great Rivers Independent Living Services in La Crosse (now Independent Living Resources, Inc.), the CIL managing the grant, will distribute most of the grant funds directly to the CILs. Instead of requiring a central project manager to approve expenditures, CILs can use grant funds both for staff and for transition services without prior approval. CILs will also use the grant to improve outreach efforts and to provide more peer support to nursing home residents.

# **Discussion**

In summary, the one-year Wisconsin Homecoming Project helped 81 residents leave nursing homes and return to community living. The state relied primarily on the existing infrastructure of its eight Centers for Independent Living to identify potential candidates for transition and to work with home and community-based service program staff to plan the activities necessary for a nursing home resident's successful transition back to community life.

State and CIL staff considered CILs to be good organizations to facilitate transitions due to their experience in deinstitutionalization and their knowledge of the social service system. CILs believed facilitating transitions fit well within their organizational mission. The CILs' core services--advocacy, peer support, information and referral, and independent living skills training

--complemented the efforts of Regional Homecoming Coordinators. Consumers who left nursing homes often used one or more of these services before their transition.

While CILs continue to help consumers transition from nursing homes to community settings, Wisconsin's counties also make important contributions to nursing home transitions. Counties facilitated almost one-third of the transitions during the grant period. Counties do not provide most of the services CILs provide that support transition efforts--although counties offer information and referral--but counties have a strength Wisconsin's CILs do not have. Counties determine eligibility for publicly funded home and community-based services and provide ongoing case management required in the state's HCBS programs. Since they do not need to coordinate with another organization, counties are well suited to quickly facilitate transitions. During the grant, counties were more likely to facilitate transitions when a nursing home was closing--a situation that required a quick response.

# **Key Observations**

Two elements of Wisconsin's experience in the Nursing Home Transition Demonstration Program may offer lessons for other states: the use of CILs as transition facilitators, and the system for payment of transition services.

#### CILs as Transition Facilitators

Like several other states awarded Nursing Home Transition Demonstration grants, Wisconsin contracted with Independent Living Centers to be the lead facilitators of nursing home transitions for the Demonstration. The rationale for contracting with CILs to take the lead in facilitating transitions is an obvious one--the entire mission of CILs is to promote community living for persons with severe disabilities, and the staff of CILs, many of whom have lived in nursing homes at some point in their lives, have "real world" experience of what it really takes to assist someone to move back to community life.

However, the level of resources allocated to the CILs under the Homecoming Project was limited (\$10,000 each). CIL staff report that they spent far more on nursing home transition efforts during the project than they were awarded under the Demonstration grant. Most of the CILs were involved in nursing home transition efforts prior to the grant, and all continued their activities after grant was over. Thus, the grant simply provided additional resources, and a renewed focus, on nursing home transitions to the community.

While CILs were a logical choice for leading nursing home transition efforts, they also have limited capacity. There are only eight CILs in Wisconsin. The high demand for community placements in Wisconsin, particularly due to nursing home closures, was a factor in the state's decision to shift resources for transition services to county long-term care agencies.

#### Payment for Transition Services

Wisconsin reserved the majority of Demonstration funds (about two-thirds) for transition expenses directly attributable to individual placements. Instead of allocating these transition expenses directly to the CILs, the state retained these funds in a centralized pool, which CILs could access as placements were made. The advantages of this approach were: (1) transition funds could be allocated directly in accordance with where nursing home transitions were occurring, in case some CILs were more successful in facilitating transitions than others; and (2) the state retained greater control over how transition expenses were utilized, rather than delegating these decisions to the CILs. Although there were initial slow-downs in the reimbursement process, the state managed to speed up the reimbursement time with feedback from CILs.

# **Bibliography**

Alexander, Julie. "Nursing Home Transition Needs Survey" Independence *First*: Milwaukee, Wisconsin, February 21, 2000.

Eiken, Steve; Burwell, Brian; and Asciutto, Anthony. "Michigan's Transitioning Persons from Nursing Homes to Community Living Program" The MEDSTAT Group: Cambridge, Massachusetts, unpublished draft.

Gabrel, C and Jones A. "The National Nursing Home Survey: 1997 Summary" National Center for Health Statistics *Vital and Health Statistics* 2000 July; 13(147).

Johnson, Steven. "Final Wisconsin Homecoming Project Report" Great Rivers Independent Living Services, Inc.: La Crosse, Wisconsin, December 22, 2000.

Pinchar, Midge. "Independence First Homecoming Project Final Report" Independence First: Milwaukee, Wisconsin, December 29, 2000.

Wisconsin Bureau of Health Information. *Wisconsin Nursing Homes and Facilities for the Developmentally Disabled* Wisconsin Department of Health and Family Services, Division of Health Care Financing: Madison, Wisconsin, November, 2000.

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