



**Public Policy Issue Brief**

**Nursing Facility Transition Programs Serving  
Older Adults with Cognitive Impairment**

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# **Nursing Facility Transition Programs Serving Older Adults with Dementia**

## **Executive Summary**

Governmental long-term care reforms in recent years have promoted consumer choice, by offering persons with disabilities more opportunities to choose their own services, service providers, and when services are delivered. Medicaid, which is the largest governmental payer for long-term care, has participants who have exercised their choice primarily among home and community services. However, many states have Medicaid nursing facility transition programs that offer residents the choice of leaving the facility to return home or to the community in a more home-like setting.

Many of the transition programs serve persons aged 65 and over, including those who have cognitive impairment. This population is likely to need extra help making the decision to leave a facility, making arrangements for transition to the community, and managing services after transition. Persons with severe cognitive impairment are unlikely to be able to live independently and will need the help of family caregivers or supportive housing.

Since little is known about how transition programs serve older persons with cognitive impairment, we decided to explore this issue. This issue brief begins by providing background information on transition programs and what is known about participation of elderly persons with cognitive impairment. We then report on case studies of four states that have served this population.

The conclusion has specific policy and practice recommendations for those states developing or implementing transition programs that serve older persons with cognitive impairment. The recommendations are crafted to help ensure that everyone who helps an older person with cognitive impairment transition to the community and remain there has sufficient knowledge of that person and the special challenges of serving someone who cannot advocate for him or herself due to cognitive impairment. The recommendations also focus on ensuring that the tools and processes states use during and after transition facilitate successful outcomes and ensure that older persons with cognitive impairment receive quality services. Finally, the recommendations address the needs of family caregivers who often are essential to successful transitions for older persons with cognitive impairment.

## **Introduction**

Governmental long-term care reforms in recent years have promoted consumer choice, by offering persons with disabilities more opportunities to choose their own services, service providers, and when services are delivered. Medicaid, which is the largest governmental payer for long-term care, has participants who have exercised their choice primarily among home and community services. However, many states have Medicaid nursing facility transition programs that offer residents the choice of leaving the facility to return home or to the community in a more home-like setting. Transition programs help a resident leave by providing support during the transition period, in the hope that the resident will experience better quality of life and care after leaving the facility.

Since at least the mid-1990s, several states' Medicaid programs have had nursing facility transition programs designed to help residents move to the community. Major Federal involvement in these programs started in 1998, when the Federal government began offering funding to help states develop and implement transition programs. Since then, about 30 states have taken advantage of this and other opportunities.

Many of the transition programs serve persons aged 65 and over, including those who have cognitive impairment.<sup>1</sup> The number of older adults with cognitive impairment who have transitioned to the community is not known. However, since most nursing home residents are elderly, 70 percent had cognitive impairment in 2006 and about 46 percent had a diagnosis of dementia in 2007,<sup>2</sup> it is likely that transition programs are serving older persons with cognitive impairments.

This population is likely to need extra help making the decision to leave a facility, making arrangements for transition to the community, and managing services after transition. Persons with severe cognitive impairment are unlikely to be able to live independently and will need the help of family caregivers or supportive housing.

We decided to explore how transition programs serve older persons with cognitive impairment broadly, rather than focusing on dementia because states generally do not distinguish among types of cognitive impairment when serving their elderly populations.

This issue brief begins by providing background information on transition programs and what is known about participation of elderly persons with cognitive impairment. We then report on case studies of how four states have served this population. The conclusion

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<sup>1</sup> In this paper, the term "cognitive impairment" describes a wide variety of impaired brain function relating to a person's ability to: think, concentrate, react to emotions, formulate ideas, problem solve, reason, and remember. Cognitive impairment can range from mild to severe. It can be associated with many disabilities and disorders that are present at birth or develop later in life, such as autism, Down's syndrome, traumatic brain injury, dementia, and, sometimes, mental health conditions. Cognitive impairment can be progressive or stable.

<sup>2</sup> US Department of Health and Human Services, Centers for Medicare & Medicaid Services, *Nursing Home Data Compendium 2007 Edition*; American Health Care Association, *Medical Condition –Mental Status CMS OSCAR Data Current Surveys*, June 2007.

makes policy and practice recommendations for those states developing or implementing transition programs that serve this group.

### **Nursing Facility Transition Programs Begin**

The concept of nursing facility transition is not new. In Oregon, this concept has been an integral part of the state's Medicaid long-term care program since the 1980s. Two other programs, New Jersey and Washington, started programs in 1997 and 1995 respectively.<sup>3</sup>

Since the late 1990s, the Federal government has provided financial incentives to encourage states to serve more persons with disabilities in their homes and communities, rather than in institutions. The first program, Nursing Home Transition, which ran from 1998 – 2001, awarded grants to 12 states to move people out of nursing facilities and help them live in the community or their own homes. The next program was the Center for Medicare and Medicaid Services' Real Choice Systems Change Grants; 23 states received nursing facility transition grants in 2001 and 2002.

The Money Follows the Person (MFP) Rebalancing Demonstration, which is part of the Deficit Reduction Act of 2005, is the third Federal grant program. It is designed to create a flexible financing system where Medicaid long-term care funding moves with the person and does not depend on where he or she lives. Central to MFP is a nursing facility transition program, which identifies individuals wishing to transfer from a nursing facility or another institution to the community and helps them to do so. The term "Money Follows the Person" can also include additional concepts such as improving community services, and nursing facility diversion.

Federal MFP Demonstration requirements limit transition funding to persons who have lived in an institution for at least six months; receive Medicaid benefits for inpatient services; and continue to require an institutional level of care. People who meet their state's standards can move into their own homes or a "qualified residence." A qualified residence is:

- (A) A home owned or leased by the individual or the individual's family member;
- (B) An apartment with an individual lease, with lockable access and egress, and which includes living, sleeping, bathing, and cooking areas over which the individual or the individual's family has domain and control; or
- (C) A residence, in a community-based residential setting, in which no more than four unrelated individuals reside.

The Federal Money Follow the Person program allocated \$1.75 billion over 5 years. This includes the increased Federal Medicaid matches for services and supports for MFP participants for one year after leaving a nursing facility, administrative funds to help states manage their MFP program, technical assistance to state grantees and a comprehensive evaluation of program impacts and outcomes. After participating in a competitive bidding process, 31 states received grant awards in 2007. Grants total \$1.4

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<sup>3</sup> Kasper J, O'Malley M, *Nursing Home Transition Programs: Perspectives of State Medicaid Officials*. Kaiser Commission on Medicaid and the Uninsured April 2006.

billion, and about 35,000 Medicaid beneficiaries will be transitioned during the five year grant period.

CMS has taken steps separate and apart from MFP to encourage nursing facility transition by providing increased flexibility for states wishing to reform their Medicaid long-term care systems. For example, CMS has allowed states to:

- Incorporate “community transition services” into their existing home and community-based services programs.
- Use Medicaid funds for one-time expenses related to nursing home transition for items such as security deposits and home furnishings.

To sum up, Federal incentives for transitioning nursing facility residents to the community have been available for many years. States across the country are using these incentives to transition thousands of nursing facility residents to the community.

### **Transition Programs Serve Some Older Adults with Cognitive Impairment**

Unfortunately, the number of older persons with cognitive impairment who have transitioned to the community is unknown. However, we do know from national data that people with dementia can transition out of nursing facilities, even after a few months in a facility. Kasper analyzed data from the 1999 National Nursing Home Survey concerning transitions to the community of people aged 65 and older whose conditions were stable or recovered.<sup>4</sup> About 13 percent of this transition group had dementia and nursing facility stays longer than 90 days. These data indicate that people with dementia who enter nursing facilities are able to return to the community.

Unfortunately, information about how nursing facility transition programs serve older adults with cognitive impairment is sparse. A review of the extant literature, including national reports on Money Follows the Person and Nursing Facility Transition initiatives<sup>5</sup> and individual state reports revealed that Alabama offered the only transition program exclusively targeting persons with dementia, but this program ended in 2007. Other states have programs that serve adults with cognitive impairment, including Texas and New Jersey. In Texas, 40 percent of all persons transitioned had a diagnosed mental illness, which was defined to include dementia, and 20 percent of those aged 65 or over had a diagnosis of dementia.<sup>6</sup> A New Jersey study of nursing facility residents the state

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<sup>4</sup> Kasper J, *Who Stays and Who Goes Home: Using National Data on Nursing Home Discharges and Long-Stay Residents to Draw Implications for Nursing Home Transition Programs*. Kaiser Commission on Medicaid and the Uninsured. August 2005.

<sup>5</sup> Anderson WL, Wiener JM, O’Keeffe J, *Money Follow the Person Initiatives for the Systems Change Grantees Final Report*. RTI International July 2006; O’Keeffe J, O’Keeffe C, Siebenaler K, Brown D, Anderson W, Greene A, Osber D, *Real Choice systems Change Grant Program FY2001 Nursing Facility Transition Grantees: Final Report*. US DHHS CMS, August 2006; O’Keeffe J, O’Keeffe C, Osber D, Siebenaler K, Brown D, *Real Choice Systems Change Grant Program, FY 2002 Nursing Facility Transition Grantees Final Report*. July 2007 RTI; Reinhard SC, Farnham J, *Meeting Summary: Sustaining Nursing Home Transition*. Community Living Exchange, Rutgers Center for State Health Policy. January 2006.

<sup>6</sup> Ormond BA, Sommers AS, Black KJ, *Examination of Texas Rider 37: A Medicaid “Money Follows the Person” Long-Term Care Initiative*, DHHS, ASPE May 2006.

transitioned to the community found that at least 13 percent of them had “confusion,” which the authors said could indicate some degree of cognitive impairment.<sup>7</sup> Reports from other states indicate that transition programs do not target older persons or, if they do, the data about them is sparse or non-existent.

### **Transitioning Older Adults with Cognitive Impairment Can Be a Challenge**

Two reports give some insight about the challenges states may face in transitioning older adults with cognitive impairment. These reports by Kasper and colleagues show that state officials and care managers have concerns about transitioning this population, particularly individuals whose behaviors require extensive supervision.

In the first report, five states’ Medicaid officials gave their opinions about nursing facility transition issues; the states were Florida, Louisiana, New Jersey, Ohio, and Washington.<sup>8</sup> These officials said the most important factors enabling transition are the motivation of individuals and their families and availability of community support. While officials did not see a diagnosis of dementia as precluding transition, they thought that some of the behavioral symptoms that often accompany this condition, could be a barrier.

In the second Kasper study, researchers ask state program officials to identify two care planners, one in a rural area and another in an urban area.<sup>9</sup> Each care planner was presented with three hypothetical scenarios of persons wishing to transition: 1) an older married man with physical disabilities and a catheter; 2) an older single woman with mild dementia who needs some assistance with daily activities; and 3) a 60-year old man with schizophrenia and diabetes, with a need for supervision. Planners were interviewed about how they would help transition these individuals and what barriers would arise.

Care planners considered the people in the last two scenarios, both of whom had supervision needs, to be difficult to move to the community because: 1) they could not live easily on their own; 2) home and community service programs could not provide sufficient supervision hours; and 3) supportive housing programs have some restrictions on taking persons with these kinds of needs.

These studies indicate, that a dementia diagnosis or supervision needs can be transition barriers. Since most persons with dementia will need supervision during the course of their disease, transition planning needs to take this into account.

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<sup>7</sup> Howell-White S, Palmer S, Bjerklie JR, *Transitions to the Community: A Survey of Former Nursing Home Residents Discharged after Community Choice Counseling*, The Center for State Health Policy, Rutgers, the State University of New Jersey, 2001.

<sup>8</sup> Kasper J, O’Malley M, *Nursing Home Transition Programs: Perspectives of State Medicaid Officials*. Kaiser Commission on Medicaid and the Uninsured, April 2006.

<sup>9</sup> Kasper J, O’Malley M, *Nursing Home Transition Programs: Perspectives of Medicaid Care Planners*, Kaiser Commission on Medicaid and the Uninsured, April 2006.

## Research Methods

Despite the challenges that cognitive impairment or dementia may pose, there is no question that some individuals with these conditions participated in transition. The goal of our study was to identify the issues that can surface for these individuals before and after transition. We conducted a qualitative exploration of the issues by discussing the topic with transition program officials at the state and local levels.

We used two methods to identify states for participation in our case studies. The first included online searches for available national and state reports on nursing facility transition programs and peer reviewed articles. We found 27 reports summarizing these programs nationally or addressing special issues related to them. In addition, we found 37 individual reports on transition programs in 20 states. We reviewed these reports to identify states that had transition programs in place for several years, appeared to have served older adults with cognitive impairments, and had at least a basic description of key programs elements. The second method was to contact members of our advisory committee and asked them to identify states that they knew had served older adults with cognitive impairment, and had transition programs in place for several years.

We identified five states that met our criteria for inclusion in our case study – Alabama, New Jersey, Oregon, Texas, and Washington. We tried to contact each state’s program director and give him or her a written description of our study and the guides for our telephone discussions. State officials in Alabama said that its dementia-specific transition program ceased when the Federal nursing facility transition grant ended, and that they had no contact information for the former program director. Washington State officials chose not to participate in the study. Program directors in New Jersey, Oregon, and Texas agreed to participate in individual discussions and to allow some of their transition specialists to participate in separate discussions.

To develop our discussion guides for state officials and specialists, we reviewed two reports on the key elements of nursing facility transition programs.<sup>10</sup> Reports by Blume and by Reinhard and Farnham cover this topic for persons with developmental disabilities and general populations respectively. Combining the relevant items from these lists and considering their relevance for older adults with cognitive impairment, we decided to address the following topics issues in our discussion guides:

- Program Goals
- Program Outreach
- Eligibility for Transition
- Use of Representatives
- Assessment and Care Planning
- Risk Assessment and Planning

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<sup>10</sup> Blume R, *Money Follows the Person Toolbox: Services for Individuals with Developmental Disabilities*, Community Living Exchange, Rutgers Center for a State Health Policy, March 2007; Reinhard SC, Farnham J, *Meeting Summary: Sustaining Nursing Home Transition*. Community Living Exchange, Rutgers Center for State Health Policy. January 2006.

Dementia Training and Supports  
Available services  
Program Data and Evaluation  
Quality Assurance

In addition, we asked discussants for their opinions about factors creating barriers to transition, methods of overcoming barriers, involvement of family caregivers, supports needed during transition, outcomes of transition programs for participants, program features specific to those with cognitive impairment or dementia, and suggested program improvements for older persons with cognitive impairment.

### **Nursing Facility Transition Programs in Alabama, New Jersey, Oregon, and Texas**

The following section provides an overview of nursing facility transition programs in four states and discusses what, if any, special features these programs offer for older persons with cognitive impairment or dementia and their family caregivers. Alabama's information is limited to what we could glean from one case study report because we could not locate any state officials able to provide us more detailed information about the program, which ended in 2007. Information for the three other states' programs comes from published reports and discussions with state and local officials. It is important to note that the description of Oregon's transition program focuses on a new program the state has started with MFP funding. State officials in New Jersey, Oregon and Texas reviewed this issue brief to ensure that our descriptions of their nursing facility transition programs are accurate.

#### **Program Goals**

All four programs are designed to offer nursing facility residents a choice of settings and services in the community, but they target different populations. The program, *Bringing Alabama's Loved Ones Home*, focused entirely on helping persons with dementia transition into the community. One of the major foci of *On the Move in Oregon* is the population with dementia. The program aims to move people with dementia to settings close to their homes since families in rural areas in Oregon often drive 100 miles or more to visit family members with dementia who live in nursing facilities. Oregon's program also targets persons who have lived in a nursing facility six months or more. New Jersey targets individuals who are on Medicaid or likely to spend down to Medicaid within six months of entering a nursing facility and offers assistance to all nursing facility residents, including those with cognitive impairment or dementia. Texas' program is available to persons with all types of disabilities, but it focuses on residents with complex needs who have lived in a facility six months or longer.

#### **Program Outreach**

All four programs rely on a variety of outreach activities, including educational sessions, to market their programs to nursing facilities and their residents. These activities are conducted by government officials and non-profit agencies, among others. Program

participants are frequently found through referrals from transition specialists, nursing home ombudsmen, Medicaid case managers and eligibility workers, nursing facility staff, family caregivers, and self-referrals from nursing facility residents.

Transition specialists also visit nursing facilities in these states to identify residents who may want to leave the facility.<sup>11</sup> In all states but Texas, the transition specialists are government employees. Texas has contracts with not-for-profit agencies including five Centers for Independent Living and one Area Agency on Aging for the services of relocation specialists. The specialists often are social workers, nurses, or persons who have been trained to work with populations with specific disabilities and who are familiar with community services and supports. Specialists do not determine Medicaid eligibility.

Generally, transition specialists identify nursing facility residents who want to leave, help them do so, and monitor the person's experience after transition for a time period that varies among the states. However, the responsibilities of transition specialists do vary somewhat. New Jersey has a unique approach because its transition specialists do all pre-admission screening for persons who are planning to enter a nursing facility on Medicaid or rely on Medicaid soon. Part of the screening process involves evaluating how long the person will likely remain in the nursing facility and then placing the applicants in one of three tracks. Persons in Track 2 are individuals likely to be able to leave a nursing facility within six months, and specialists try to help this group transition out of the nursing facility. Specialists also get lists of nursing facility residents who answered yes to a question on the standard assessment form (the Minimum Data Set 2.0 or MDS),<sup>12</sup> which asks them whether they want to go home. Texas also uses the MDS in this way.

### Eligibility for Nursing Facility Transition

Each state uses different criteria to determine who is eligible to transition. Alabama required people to have a diagnosis of dementia and a sponsor, who could be a family caregiver, to authorize the transition. Participants also had to have lived in a nursing facility for 21 days, be eligible for the state Medicaid home and community-based services waiver, and be able to transfer to a private home located within the program's two pilot areas. In New Jersey, the participant has to be Medicaid eligible or eligible within 180 days and the costs of his or her care in the community cannot exceed the equivalent cost of care in a nursing facility. In addition, people requiring extensive assistance or supervision due to a cognitive impairment cannot participate unless an informal caregiver is involved in the transition. In Oregon, if the person with dementia has been in the nursing facility at least six months and can have his or her needs met within program service limits, the transition is likely to be approved. Oregon, however, is considering whether to exclude from transition persons on hospice in nursing facilities.

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<sup>11</sup> We chose to use the term "transition specialists" in this paper because each state uses a different term for this function and using all the terms would be confusing.

<sup>12</sup> The Minimum Data Set (MDS) is a standard assessment form that the Federal government requires most nursing homes to use when assessing the health, mental health, and functional needs of their residents. Nursing homes that participate in Medicare and Medicaid must use the MDS upon a resident's admission and quarterly thereafter.

In Texas, the participant must be Medicaid eligible, must be living in a nursing facility have a provider that is available to deliver services, have a place to live, and his or her services must cost less than 200 percent of equivalent nursing facility costs.

### Use of Representatives

Persons with cognitive impairment may need the help of a representative when considering transition and during the transition process. Each state handles this situation somewhat differently, but they usually try to involve family caregivers in the transition, if they are willing and able to be involved. In Alabama's program, which was targeted to those with dementia, a person could not transition to the community without a family caregiver's involvement. In New Jersey, family are only involved in a transition if the resident gives verbal and written permission to a transition specialist. Oregon's program assumes the person requesting transition is legally competent unless he or she has a legally-appointed decision maker. If there is a question about a person's competency and no decision maker exists, the specialist attempts to informally involve family in the transition. In Texas, if the person has capacity to make decisions, he or she decides whether to transition. Family involvement in Texas varies according to the person's capacity and his or her wish to involve family. In all the states but Alabama, the resident's choice has priority over the family's wishes.

### Assessment and Care Planning

To initiate the transition process, each state, except New Jersey, uses its own assessment tool to determine a person's cognitive impairment, functional level, and need for services. New Jersey uses the Minimum Data Set for Home Care, which interRAI developed.<sup>13</sup>

In all states, transition specialists organize planning for the relocation from the nursing facility to the community. Transition planning in the states generally involves the resident, his or her family when the resident agrees, the transition specialist, and staff from the nursing home and from the provider that will be serving the person in the community. When the resident agrees to involve family in the transition, they are a valuable source of information about the resident's history, daily routines, and care preferences. In Oregon, when the transition is to a group home, specialists encourage family to visit the various homes and consider which one would be best for their relative.

In New Jersey, Oregon, and Texas, the transition specialists represent the interests of the resident both to ensure the resident's choices are respected and to protect the resident from harm. For those who want to leave a facility, the specialist works with all parties to ensure that the resident can do so. In one situation described, the nursing facility did not support the request of an individual with cognitive impairment to transition, but the family did. Since the person transitioning was going to live alone, family caregivers received training before discharge and all parties developed a schedule detailing how they would provide care to the person. In another situation, a transition specialist prevented a nursing facility resident who was in a coma from going home with an abusive relative.

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<sup>13</sup> See [www.interrai.org/section/view/](http://www.interrai.org/section/view/) for more information on this home care assessment tool.

Oregon assumes that if the resident can communicate the desire to leave the facility, that his or her choice is what counts most. As an example, one family protested a resident's transition, but the resident insisted she wanted to leave the nursing facility, and she was able to do so with the help of the transition specialist.

During the first year after transition, transition specialists have varying degrees of contact with former residents. In Alabama, specialists visited persons who transitioned once a week during the first month, biweekly in the second month, once a month between three and six months, and had monthly phone contact during the final six months. New Jersey specialists call the resident within two days of transition and again within two to four weeks after transition. Oregon specialists have weekly contacts during the first month and then monthly contacts for the remainder of the year. Texas transition specialists contact persons who transition every week during the first month, every two weeks during the second month, then at 90 days and as needed after that. Contacts may be by telephone or in-person. In all states, if a person receives Medicaid home and community-based waiver services after the transition, then the waiver care manager takes over and follows waiver program requirements related to helping the person and monitoring care.

### Risk Assessment and Planning

To some degree, all states address the risks associated with transition for a person with cognitive impairment through a process that applies to all persons choosing transition. An example of a risk is lack of emergency back up care for a person who needs extensive assistance or supervision. In Texas, risks are evaluated as part of the assessment process. In New Jersey, the resident and family are responsible for considering and specifying how they will resolve risks prior to transition. Oregon has developed at least three tools to help the transition specialist work with the resident and family, and in completing these tools, risks are identified and discussed. The Essential Lifestyle Planning Tool is a guided question and answer process for learning how someone wants to live and then developing and implementing a plan that meets the resident's needs. The Community Mapping Tool focuses on connecting the resident to community resources that can help him or her remain independent. Completing a lengthy transition checklist that identifies risks is required and several program officials must sign it. In Oregon, even if family think a transition is risky, the specialist will work with the resident who chooses to move out of a facility. Texas has individual responsibility agreements where the individual specifies the amount of risk they are willing to take on and the home health agency specifies the types of services it will provide and responsibility it will take on.

### Dementia Training and Supports

The states report that transition specialists do not have mandatory training related to dementia. However, some specialists have continuing education opportunities that they can use to get more expertise on dementia issues. In addition, many of the specialists do have personal and on-the-job experiences with this population that help guide them during transitions for people with cognitive impairment.

Oregon probably attends most to the special needs of persons with dementia in the resources they make available to transition specialists and to providers. The state plans to hold a dementia training session for specialists in 2008, and specialists in some areas have access to geriatric professionals with psychiatric expertise who can help them with difficult behavioral situations. Oregon specialists observed that while dementia expertise is critical and training is very helpful, no amount of training can prepare a person to handle every difficult situation. For this reason, access to geriatric specialists with psychiatric expertise is very valuable. Oregon also has a training program in which all adult foster home providers must participate; the program includes modules on the progression of dementia and behavior management issues. Texas provides consultation opportunities akin to those of Oregon in that it has monthly “scan” calls with transition specialists where they can discuss any issues that have come up including behavioral symptoms of dementia.

### Services Available

All states provide supports and service coordination to those who transition. One time assistance with setting up a home, such as security deposits, is also generally offered. In each state, a wide range of services are available after transition, including personal care, home care, respite, adult day care, and group housing, along with referral to community services such as chapters of the Alzheimer’s Association.

Although states did not have hard data on use of services and settings for care by older persons who transition with cognitive impairment, discussions with state and local program officials revealed some information. In New Jersey, most people with dementia receive homemaker/home health aide services. Medical adult day care is available for individuals who have trouble taking medications or who have chronic conditions, in addition to dementia.

States differ in their use of foster care, assisted living, and group homes. Many assisted living residences in the northern part of New Jersey have dementia units and accept Medicaid, so the state often can transition individuals to these settings. However, the southern part of New Jersey has fewer assisted living facilities that can serve persons with dementia so the state transitions fewer persons with dementia to assisted living. Alternate family care, such as adult foster care, generally is not an option in New Jersey for individuals with cognitive impairment. Officials say that families often are not comfortable with their loved ones being cared for in a family setting when they have not been able to keep their loved ones at home. Oregon officials said that most older residents with cognitive impairment transition into some kind of group home, including adult foster care, residential care homes, and assisted living. State rules require locked doors and kitchenettes in assisted living, so individuals with dementia need special oversight if they are to remain safe and not become isolated in this setting. The state is working with small group homes to help them learn to manage the needs of persons with dementia. In Texas, no data are available about living arrangements for those with cognitive impairment, however, available data suggest that 28 percent of persons

transitioned choose group homes or assisted living. Local staff believe that the majority of persons with dementia go to group homes.

Services for family members caring for their loved ones with dementia are limited. Alabama, New Jersey and Texas have training available for family. In New Jersey the family training focuses on physical assistance. New Jersey and Oregon have respite services available. Oregon appears to have the most generous array of services for family caregivers. Oregon has respite, 24-hour emergency backup for the first year after transition, and a program called Relative Foster Home, in which family care for a relative. The family receives payment for their care, but not as much as licensed adult foster homes. Relative Foster Homes must comply with safety code requirements but they do not have to complete the formal Quality Care Training Program that other foster care providers must.

### Factors Affecting the Success of a Transition

We asked state and program officials to give us their opinions about what factors affect the success of a transition for an older person with cognitive impairment. Officials cited three categories of factors: 1) residents' medical conditions, function, and severity of cognitive impairment, 2) resident, family, and staff attitudes toward transition, and 3) availability of services, resources and housing to meet the resident's needs. Persons with severe cognitive impairment or behavioral symptoms, such as wandering and agitation, are considered harder to transition because placement in a group home is difficult or because family caregivers may not be able to handle these symptoms. An indicator of the difficulty providers have with behavioral symptoms is that Oregon transition specialists found that when nursing facilities gave them lists of people who could leave the facility, these residents often had behavioral symptoms of dementia that the facility considered disruptive or difficult to handle. Finally, persons who have heavy physical care needs in addition to dementia are hard to transition. Along these lines, the Alabama case study report cited acute changes in a resident's or caregiver's condition as being challenging for maintaining a transition to the community.

Attitudes of all parties can affect transition. Some officials said that if people have been in an institution a very long time, they can believe it is their only option, and they need to be educated about the availability of alternatives. All states' officials said family resistance can be a major barrier to transition and that if family support the transition, it is more likely to succeed. Some officials and the Alabama case study report note that some facility staff resist the idea of residents with dementia, who they consider vulnerable, leaving the 24-hour support available in a nursing facility.

Service availability plays an important role in transitions. In Oregon and Texas, officials emphasized that it is not the characteristics of the residents themselves; rather, it is a low supply of services to meet the needs of the residents who want to leave the nursing facility that creates barriers. Every state said that an inadequate supply of supportive housing, direct service workers, or home care providers is a barrier in at least parts of their states. Another barrier in Texas is that the array of home and community-based

services is not broad enough to include comprehensive behavioral supports and that there has not been sufficient coordination with that state's mental health authorities. In two states, officials said that there is an inadequate supply of adult day services providers. Rural areas particularly lack a sufficient supply of providers, partly due to inadequate public transportation options for workers who have to travel to their clients' homes. The Alabama case study report cited residents' need to wait for home modifications before they could move into a home. In Texas, some said that more money managers are needed, particularly for those residents who are in the early stages of dementia and need help paying their rent, utilities and other expenses.

Officials in most states said that low Medicaid payment rates affect providers' willingness to participate in Medicaid and the program's rules can be problematic. In Alabama and Texas payment for home and community services cannot be made prior to a resident's enrollment in the home and community-based services waiver. This poses particular problems for expenses related to home modification and transition. Thus, residents have to wait to leave a nursing facility or there is gap that can occur in providing home and community services.

### Program Data and Evaluation

The programs have relatively little publicly-available data on the experiences of older persons with cognitive impairment or dementia, and the few program evaluations consist primarily of consumer satisfaction surveys. In addition, in some states, it can be difficult to distinguish who has dementia or cognitive impairment because of data compatibility issues.

Some information is available for three of the four states. Alabama's program transitioned 29 nursing facility residents with dementia into the community, and at the end of its program, conducted telephone interviews with 20 of 29 corresponding family caregivers.<sup>14</sup> Results showed that the caregivers appreciated the services and the supports the program offered them and their family with dementia. The caregivers felt they made the right decision to bring the person with dementia home and only three of the 20 believed that the person with dementia would return to a nursing facility. New Jersey contacted 1,975 consumers who had transitioned to the community in 2000.<sup>15</sup> They spoke to 859 consumers, one-half of whom had proxies participate in the telephone interview. Most former nursing facility residents now lived at home, primarily with a relative. Most individuals who transitioned reported high levels of satisfaction with their lives in the community, did not miss the nursing facility, and felt they had sufficient help to remain in the community. The researchers concluded that there were no significant differences in responses between consumers with cognitive impairment and those without. Texas data from 2001 and 2004 show that 8.6 percent of residents under age 65

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<sup>14</sup> *Alabama Nursing Facility Transition Program: Transitioning Alabama's Loved Ones Home, A Final Report.* No date or author given.

<sup>15</sup> Howell-White S, Palmer S, Bjerklie JR, *Transitions to the Community: A Survey of Former Nursing Home Residents Discharged After Community Choice Counseling*, Center for State Health Policy, Rutgers, The State University of New Jersey, 2001.

who transitioned had a diagnosis of dementia; the figure for those aged 65 and over was 20.3 percent.<sup>16</sup> According to the Texas program director, the number of persons who have transitioned to the community has increased so dramatically that data from 2001 and 2004 no longer reflect current usage. No data is available from Oregon as its latest transition program is new. The available evidence indicates that persons with dementia do participate in nursing facility transition programs and can benefit from them. But, the data are far from conclusive.

### Opinions about Transition Outcomes

Given the scarcity of data about transition outcomes for older adults with cognitive impairment, part of our discussions with state and local officials elicited their opinions about outcomes for this group.

Officials generally believe that the quality of life for older persons with cognitive impairment improves when they leave the nursing facility and return to the community. This opinion is based on the assumption that when people transition to their homes or a setting that is home-like, they will have a better quality of life than in a nursing facility. Oregon officials added that behavioral symptoms decrease in small group home settings because staff ratios in that state are one staff person to four or five residents. This ratio allows staff the time to get to know residents, and their likes and dislikes, and how to interact most effectively with them. However, officials in two states did say that people who transition and live alone can be lonelier than when in a facility or a supportive housing setting like assisted living or adult foster homes.

During the discussions, state and local program officials mentioned several situations where persons with dementia were more likely to return to nursing facilities. The circumstances that tended to trigger a return in New Jersey were self neglect such as when a person with dementia does not eat or drink or take medications or when a change occurs in the family caregiver's capacity or willingness to provide care. Officials said that sometimes the family brings the person with dementia home, but then wandering or combative behavior overwhelms the family. In addition, individuals who also have medically unstable conditions are likely to bounce between the nursing facility and the community. Officials in Oregon mentioned that it is important for transitions to occur with enough lead time for the resident to get accustomed to the change; there have been difficulties when nursing facilities have closed abruptly, and transitions had to occur without sufficient time to manage them smoothly.

### Suggested Program Improvements

When officials were asked how their transition programs could be improved for older people with cognitive impairment, several themes emerged, which include additional training, more housing and services, and better systems and payment rates. Most officials mentioned that additional training for transition specialists would help them manage the

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<sup>16</sup> Ormond BA, Sommers AS, Black KJ, *Examination of Texas Rider 37: A Medicaid "Money Follows the Person" Long-Term Care Initiative*, DHHS, ASPE May 2006.

special needs of persons with dementia; specialists need to know the characteristics of dementia, and how to interact with consumers who have the disease. Two states stressed the importance of interoperable data systems, which facilitate analysis of program information and evaluation. Most officials also mentioned development and expansion of the supply of housing alternatives that can accommodate persons with dementia; recruitment of more and better trained direct service workers who have better pay; recruitment of more home care and adult day services providers to the programs, and improving transportation to help persons with dementia or cognitive impairment maintain ties to the community. Two states mentioned that provider payment rates could be increased to facilitate recruitment of providers generally.

### Policy and Practice Recommendations

Much of the discussion above shows that states have not developed separate mechanisms within their programs to provide special assistance to older persons with cognitive impairment or their family caregivers. However, the discussions with state and local officials do point to areas where existing or new nursing facility transition programs could be made more responsive to the special needs of older persons with cognitive impairment or dementia.

In developing the Alzheimer's Association's public policy and practice recommendations on nursing facility transition programs, we relied on our dementia expertise as well as that of the reviewers, the literature, the Alabama case study report, and discussions with state and local officials in New Jersey, Oregon, and Texas. States considering implementing or expanding nursing facility transition programs should consider taking the following steps. These steps are not listed in order of priority.

1. Conduct community outreach and education in nursing facilities to increase awareness that individuals with cognitive impairment can transition to the community.
2. Use the MDS information available on all nursing facility residents to gather information about the resident, including cognitive function, that will help inform the transition process.
3. Use transition assessment tools that measure cognitive impairment and its impact on a person's ability to live successfully in the community. Tools also need to address the potential risks to the person and family during and after transition.
4. Assess family caregiver needs and capability of sustaining care for an older person with cognitive impairment.
5. Include education on dementia in required training materials for transition specialists, service coordinators and other program officials who help persons with dementia transition to the community.
6. Give transition specialists and service coordinators the ability to consult geriatric specialists with psychiatric expertise when helping persons with behavioral symptoms.

7. Provide dementia training to family caregivers as part of the transition process to help them develop the best methods for caring for their family members when they come home from the nursing facility.
8. Refer family caregivers to community organizations and services which offer dementia care information, support groups, adult day services, and respite.
9. Explore modification of Medicaid waiver requirements so that persons who transition have immediate access to waiver services in the community.
10. Expand housing options that are able to serve individuals with cognitive impairment and ensure they have sufficient supports to remain in the community. Ensure that these housing options are suitable for those without involved family members.
11. Require that providers who serve those with cognitive impairment or dementia have the training and experience necessary to meet the special needs of this group.
12. Pay providers appropriately to attract a sufficient supply of qualified workers who are capable of serving people with cognitive impairment or dementia.
13. Develop transportation options in rural areas to support mobility for persons who have cognitive impairment and their home care workers.
14. Collect and analyze data on participation, outcomes, and costs in transition programs for individuals with cognitive impairment to understand any special needs and ways to increase successful transitions. Outcomes should include quality of life, care, health and function. Data should be publicly available while protecting a participant's privacy.