

Promoting Community Living for Older Adults Who Need Long-term Services and Support

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Executive Summary

Most older adults¹ who need long-term services and supports (LTSS)² live in the community, often with the help of family and friends, and some receive paid services. Many older adults receive help through Older Americans Act-funded meals and in-home services. Those older adults with few financial resources often rely on Medicaid to pay for their LTSS because this program is the primary public payer for these services. About half of older Medicaid beneficiaries receiving LTSS do so in their homes and communities, where older adults prefer to live. In contrast, 80% of beneficiaries receiving LTSS under age 65 do so. The disparity that older Medicaid beneficiaries experience persists, despite the fact that their home and community-based services (HCBS) costs are relatively low compared to other categories of beneficiaries.

The high rate of institutionalization of older Medicaid beneficiaries receiving LTSS continues more than 15 years after the United States Supreme Court's decision in *Olmstead v. LC*. This decision held that unjustified isolation of people with disabilities violates the anti-discrimination Title II of the Americans with Disabilities Act. *Olmstead* applies to people of all ages who need LTSS, including those who acquire their disabilities after they reach age 65. Many older adults will need assistance with activities of daily living (ADLs)³ at some point in their lives. Although some older adults who need LTSS for assistance with these activities do not think of themselves as people with disabilities, they do meet the legal definition, and the *Olmstead* decision applies to them.

Many states could do more to comply with *Olmstead* because they have a great deal of control over the LTSS that older Medicaid beneficiaries receive. States operate Medicaid under broad federal guidelines and decide: 1) financial and functional eligibility criteria for LTSS, and 2) the range of HCBS that beneficiaries can receive and under what circumstances.

States can use their Medicaid flexibility and extant research results to ensure that older Medicaid beneficiaries receiving LTSS have as much opportunity to live in the community as do younger beneficiaries. For example, states could target their home and community-based services to those most at risk of entering nursing homes. Research shows that older adults with the most risk are those with limitations in 3 or more ADLs, cognitive impairment, or poor health. States could also help ensure that HCBS provide relief to family caregivers because increased caregiver stress is related to more use of nursing homes.

States that heavily invest in HCBS would likely see decreased use of nursing homes. Numerous studies show that increased public spending on HCBS is associated with lower use of nursing

¹ Defined in this policy brief as people who are aged 65 and over.

² Long-term services and supports include nursing home care.

³ Activities of daily living include such things as eating, bathing, and dressing.

homes for older adults. This is true for Medicaid-funded HCBS, and separately for Older Americans Act (OAA)-funded HCBS and meals.

Older adults with dementia are at high risk of using nursing homes due to cognitive impairment. Effective use of proven dementia care interventions for people with the condition and their family caregivers has the potential to reduce nursing home use. Researchers identify five common components of quality dementia care including: 1) formal diagnosis, 2) education of people with dementia and their families, 3) provision of supports and services to them, 4) attention to medication needs, and 5) adjustment of care goals over time.

States vary in terms of their approaches to providing HCBS and many states have the opportunity to provide more of them to older adults with disabilities, including those with dementia. States also have a responsibility to ensure that their nursing homes respond appropriately to their residents' desire to leave the facility and live in their communities. If states take these steps, they can improve the lives of older adults with disabilities and their caregivers.

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Most older adults who need LTSS live in the community, often with the help of family and friends, and some receive paid services. (Freedman and Spillman, 2014). Many older adults receive help through Older Americans Act-funded meals and in-home services. Those with few financial resources often rely on Medicaid, which is the primary public payer of long-term services and supports (LTSS). About half of older Medicaid beneficiaries who receive LTSS live in nursing homes (Eiken and colleagues, September 2015). However, older adults prefer to live in their homes and communities (Keenan, 2010).

Older Medicaid beneficiaries' high rate of institutionalization persists more than 15 years after the United States Supreme Court's *Olmstead v. LC* decision in 1999. The Court held that unjustified isolation of people with disabilities in institutions violates the anti-discrimination Title II of the Americans with Disabilities Act. The Court added that public entities must provide community-based services to persons with disabilities when: (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity (U.S. Department of Justice, 2016).

Olmstead applies to people of all ages who need LTSS, including those who acquire their disabilities after they reach age 65. Many older adults will need assistance with ADLs at some point in their lives. Although some older adults who need LTSS for assistance with these activities do not think of themselves as people with disabilities, they do meet the legal definition, and the *Olmstead* decision applies to them. While *Olmstead* applies to people of all ages with all types of disabilities across the country, progress toward community living varies by nursing home, age, type of disability and state.

This policy brief argues that many states could be providing more home and community-based services (HCBS) to older adults with disabilities and:

1. Documents problems with nursing home residents' access to assistance in leaving their facilities to live in their communities.
2. Documents differences in Medicaid beneficiaries' receipt of LTSS by age and state.
3. Offers recommendations to states for promoting community living for older adults with disabilities.
4. Documents the impact of providing increased HCBS to older adults with disabilities.
5. Describes the special circumstances of older adults with dementia, who are at high risk of nursing home use.

1. Nursing Homes Residents' Access to Assistance

Nursing home residents, including older adults who want to transition to their homes and communities, sometimes do not get the help they seek, according to the U.S. Department of Health and Human Services (Schell, 2016). The Department's Office for Civil Rights examined data from the Minimum Data Set's⁴ "Section Q," which enables individuals to express interest in learning more about opportunities to live outside of the nursing home. When a resident expresses this desire, nursing homes are required to notify a state-designated "local contact agency." These agencies must then contact interested individuals by telephone or in person, and provide information/education about home and community-based options.

The Department found that at least 50,000 nursing home residents from over 7000 nursing homes said they wanted to talk with someone about leaving their facility, but never received a referral to a local agency that could help them. Among the reasons nursing homes cited for their lack of responsiveness were problems with knowing a local agency that could help residents transition to their homes or communities, family not wanting the resident to leave, and the facility's assertion that the resident had too much disability to leave. All of these reasons fail to directly consider the residents' wishes.

States have a role in ensuring that residents have access to information about transitioning from nursing homes. For example, states must make available designated "local contact agencies" to provide information to individuals who live in nursing homes about returning to the community. Depending on the state, "local contact agencies" may be Aging and Disability Resource Centers (ADRCs, or "No Wrong Door" Systems), area agencies on aging, long-term care ombudsman programs, centers for independent living, or other entities. Each of these entities has the expertise to educate individuals who live or work in nursing homes about HCBS options. States can also provide HCBS that can help residents live in the community, if they are willing and able to do so. Family considerations, while important to know, do not obviate the need to ensure that residents' wishes are heard and accommodated to the extent possible.

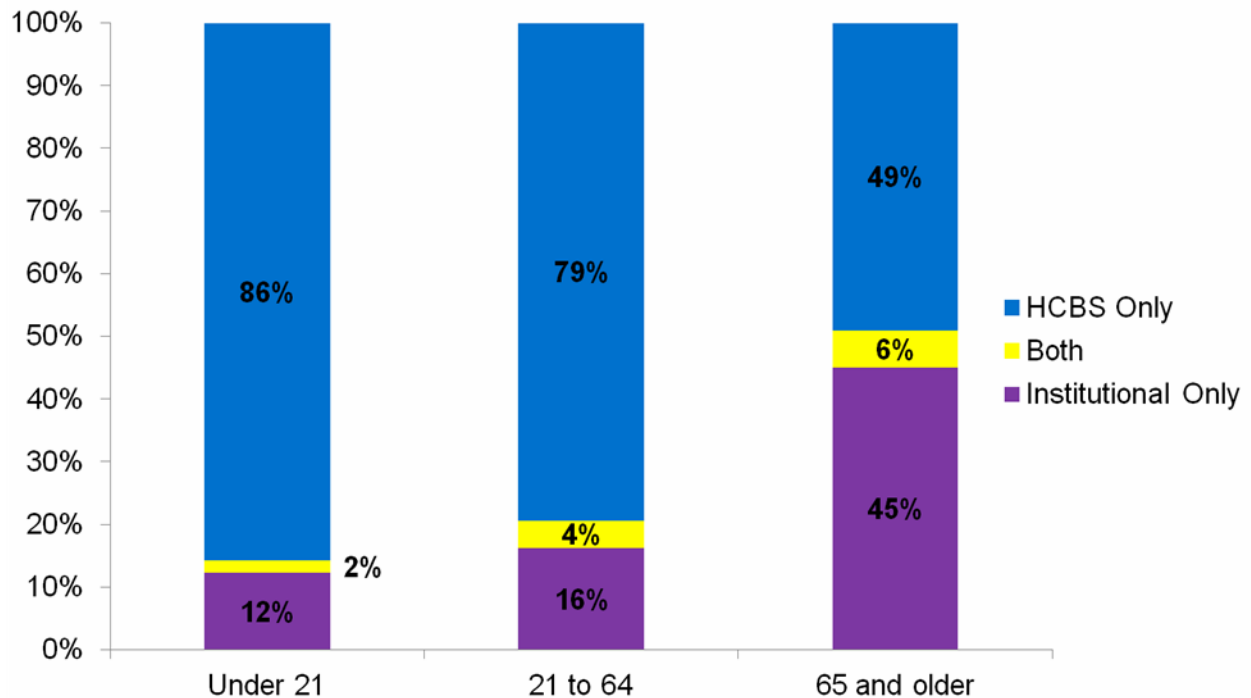
2. Variations in Medicaid Spending on LTSS by Age and State

State policy decisions have resulted in a large disparity in the Medicaid HCBS resources available to older beneficiaries versus those who are younger. Nationally, older Medicaid beneficiaries receiving LTSS are much more likely than younger ones to live in institutions. About half of the 1.9 million older Medicaid beneficiaries who received LTSS in fiscal year 2011 lived predominantly in the community. In contrast, 80% of the 1.7 million non-elderly beneficiaries did so (Reaves and Musumeci, 2015). Figure 1 provides details about the settings in which Medicaid LTSS beneficiaries received services in 2011 by age (Eiken and colleagues, September 2015). Figure 2 shows the large state variation in the percentage of adults receiving Medicaid LTSS who lived only in institutions in 2011. The percentage of adults aged 65 and over receiving Medicaid LTSS in institutions ranged from 12% to 93.9%. Whereas the range for those aged 21-64 was 2.6% to 41.5% (Eiken and colleagues, September 2015). Most states

⁴ The Minimum Data Set is a resident assessment form, which all Medicare and Medicaid-certified nursing homes must use when assessing the needs of their residents.

institutionalized older adults at a rate 2 to 4 times higher than they institutionalized younger adults. The range was 1.7 – 14.3 in 2011.⁵ States can address these disparities by expanding the HCBS available to older Medicaid beneficiaries who receive LTSS.

Figure 1: Percentage of Medicaid LTSS Beneficiaries who Received HCBS by Age Group, 2011



Source: Medicaid Analytic eExtract (MAX). Data were not included for Arizona, Colorado, the District of Columbia, Hawaii, Idaho, Kansas, Maine, Massachusetts, Ohio, Texas, and Wisconsin because these states did not have 2011 data in MAX.

Data do not include LTSS beneficiaries enrolled in comprehensive managed care plans.

Age data were not available for 48,322 beneficiaries, one percent of total beneficiaries.

Source: Eiken and colleagues, September 2015

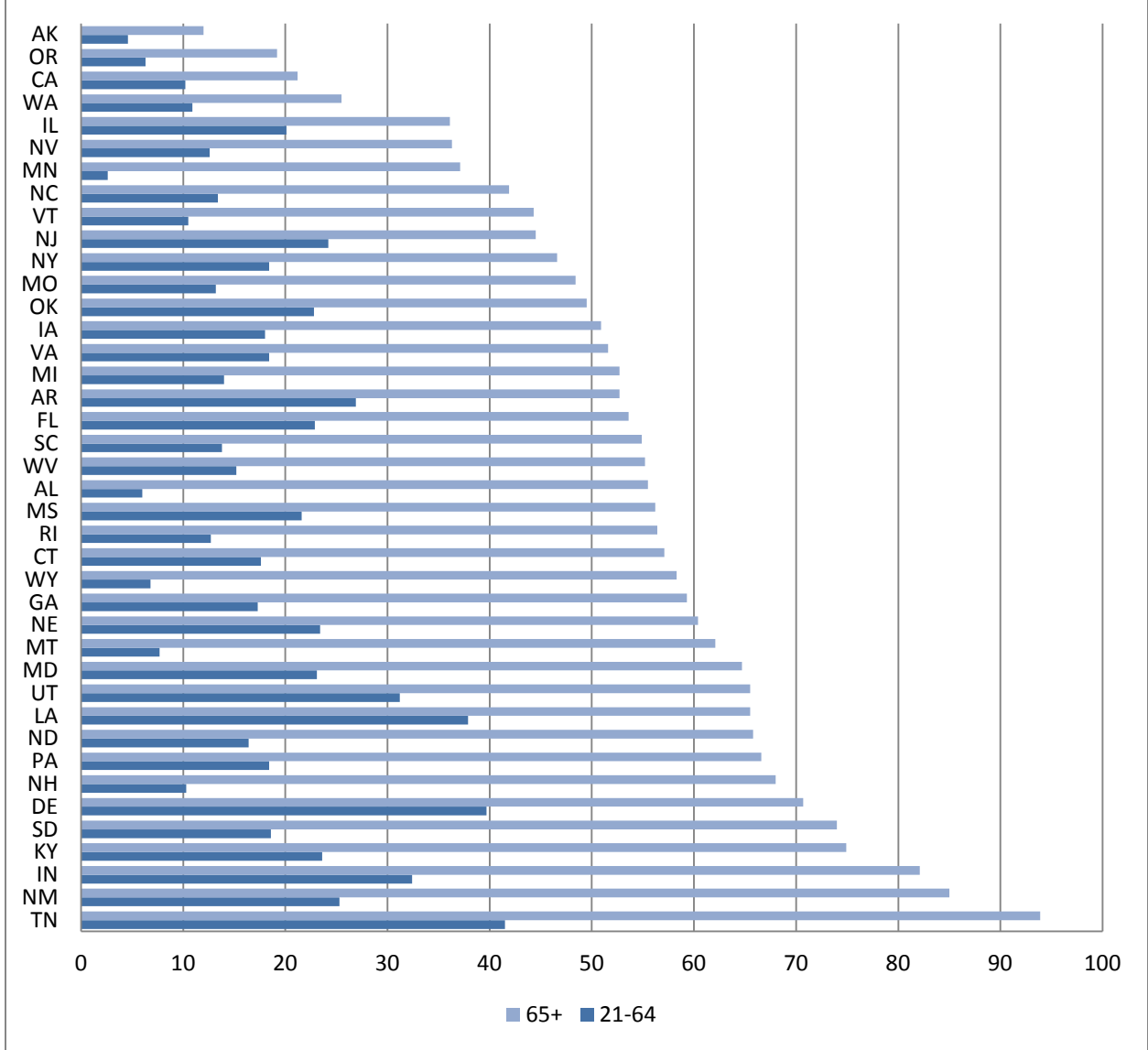
In fiscal year (FY) 2014, over half (53%) of national Medicaid LTSS spending went for HCBS, with the rest going to institutions (Eiken and colleagues, April 2016). These proportions vary markedly by state. In FY 2014, 3 states devoted 1/3 or less of their Medicaid LTSS spending to HCBS. In contrast, 6 states devoted at least 2/3 of their spending to HCBS (Eiken and colleagues, April 2016). Most states have potential to increase the proportion of their Medicaid LTSS spending devoted to HCBS.

Expanding HCBS for older adults is particularly advantageous to states because their per capita HCBS costs are lower than those of other Medicaid beneficiaries. Older Medicaid beneficiaries' HCBS cost 37.4% less on average than other adults. In FY 2012, Medicaid benefit spending per "full-year equivalent enrollee" was \$2590 for "aged" beneficiaries who received HCBS, compared to \$4135 for "disabled" beneficiaries under age 65 (MACPAC, 2015). The disparity

⁵ Author's calculations using data from Eiken and colleagues, September 2015.

that older Medicaid beneficiaries experience related to receiving HCBS persists, despite the fact that older adults are among the least costly Medicaid HCBS beneficiaries.

Figure 2: Percentage of Adults Receiving Any Type of Medicaid LTSS who Lived only in Institutions, by Age and State, 2011



Data Source: Medicaid Analytic eXtract (MAX) Data do not include LTSS beneficiaries enrolled in comprehensive managed care plans. Data do not include Arizona, Colorado, the District of Columbia, Hawaii, Kansas, Idaho, Maine, Massachusetts, Ohio, Texas, and Wisconsin because MAX does not include 2011 data for these states. Please see Appendix A for data table.

Source: Eiken and colleagues, September 2015

Many states have made substantial progress in providing HCBS to their Medicaid beneficiaries who receive LTSS. However, most other states have potential to increase HCBS and likely reduce the proportion of nursing home residents who have relatively low care needs. Centers for Medicare & Medicaid Services' (CMS) data from 2014 demonstrate marked variation in the proportion of people with low care needs by state. In 9 states, the percentage of nursing home residents with no limitations in activities of daily living (ADLs) and mild or no cognitive impairment ranged from 3.5-8.4%. In 10 states the percentage ranged from 13.8-21.4%. (CMS, 2015)

States have many options for increasing the proportion of older adult Medicaid beneficiaries who receive LTSS in their homes and communities. States can do this because they decide: 1) within broad federal guidelines, the financial and functional eligibility criteria for LTSS, and 2) the range of HCBS which beneficiaries receive and under what circumstances (O'Keeffe and colleagues, 2010). For example, states with no Medicaid medically needy program⁶ for HCBS could implement one and enable older adults with costly HCBS to get Medicaid assistance before they seek nursing home admission. States could also provide a wide range of flexible HCBS to Medicaid beneficiaries and ensure that these services support the families that help their loved ones remain at home.

3. Recommendations for Increased Access to HCBS to Older Adults with Disabilities and their Family Caregivers

Many studies reveal statistically significant risk factors related to older adults' use of nursing homes. These factors include: prior hospitalization, symptom burden, limitations in 3 or more ADLs, cognitive impairment, age, and living alone, (Goodwin and colleagues, 2011; Sheppard and colleagues, 2013; Allen and colleagues, 2012; Cai and Temkin-Greener, 2015; Castora-Binkley and colleagues, 2014; Stineman and colleagues, 2012; Wang and colleagues, 2013). Using this information, states can target these groups and provide them with Medicaid HCBS before they enter a nursing home and potentially lose their housing in the community.

In addition to older adults' health and function, their family caregivers' stress predicts nursing home use. Spillman (2014) found that high caregiver stress led to a 13 percentage point increase in the likelihood of nursing home use over 1 year and 20 percentage points over 2 years. The highest sources of stress for family caregivers were physical and financial. Physical stressors may include lifting heavy people or having to stay awake when a person needs help 24 hours a day. Financial stress may result from having to quit a job to care for a loved one.

While Medicaid programs cannot serve family caregivers unless beneficiaries receive LTSS, states' can make choices about their Medicaid programs that can help these caregivers. For example, states can take advantage of opportunities to pay family caregivers of those Medicaid beneficiaries who have family they would like to provide services. States can ensure that adult day centers and respite services are available to beneficiaries in ways that are helpful to family

⁶ Medicaid's medically needy program is a state option that enables people to subtract their medical and LTSS spending from their countable income to qualify for the program.

caregivers. States can offer education and helplines to caregivers who have questions about how to help Medicaid beneficiaries who receive HCBS.

States can also augment their National Family Caregiver Support Programs (NFCSP), which receive funding under the Older Americans Act (OAA) Title III E, and connect these programs with their Medicaid programs. The NFCSP provides grants to states and territories to help family care for their loved ones at home by providing: information, access assistance, counseling and training, respite care, and supplemental services. Data from the Administration for Community Living's (ACL) national surveys of caregivers of older clients show that OAA services, including those provided through the NFCSP, may help caregivers keep their loved ones at home (U.S. Department of Health and Human Services, 2016). Nearly 40 percent of caregivers reported that their family members would be unable to remain at home without services and most said that the care recipient would most likely be living in a nursing home or assisted living. In another caregiver-support-related study, Washington State analyzed the impact of looser eligibility standards for its Family Caregiver Support Program and found that the expansion of services was associated with a statistically significant delay in the use of Medicaid LTSS (Lavelle 2014).

The research supports the conclusion that states could make progress in helping older adults remain in the community longer, if they target HCBS to older adults at risk of nursing home use and provide supports to family caregivers. States could identify the family caregiver(s) of Medicaid beneficiaries, and assess and address their unmet needs for information, education, and supportive services, especially when following the person-centered service plan involves reliance on a family caregiver.

4. Provision of HCBS to Older Adults and its Relationship to their Nursing Home Use

Studies show that increased provision of HCBS is significantly related to lower use of nursing homes. This is true for Medicaid-funded HCBS, and separately for OAA-funded HCBS and meals. Provision of HCBS likely reduces spending on nursing homes by enabling older adults to stay in their communities longer and their family caregivers to potentially experience reduced stress.

Using national Medicare and MDS data for skilled nursing facility (SNF) users, researchers studied the impact of state HCBS spending on dual eligibles⁷ with nursing home stays exceeding 100 days. The authors controlled for beneficiaries' clinical, demographic, socio-economic, and geographic characteristics and tested the impact of state SNF and Medicaid HCBS policies and spending. Dual eligibles experienced less risk of long stays in nursing homes as their states' Medicaid HCBS spending rose (Rahman and colleagues, 2015). Miller (2011) examined the relationship between the percentage of Medicaid LTSS devoted to HCBS and older adults' use of nursing homes, while controlling for their health status and states' nursing home capacity. Over 2000-2007, higher investment in HCBS for older adults was associated with lower use of nursing homes. Those states that increase the proportion of their LTSS devoted to HCBS for

⁷ Dual eligibles are people who are beneficiaries of Medicare and Medicaid at the same time.

their older Medicaid beneficiaries may well realize decreased use of nursing homes for this population.

As spending increases on OAA Title III services, which are primarily HCBS and meals, older adults have significantly lower use of nursing homes. Thomas (2014) found that every 1% increase in the population aged 65+ receiving OAA III-B personal care was associated with a 0.8% decrease in the proportion of low care⁸ residents in nursing homes. Thomas and Mor (2013) found that increases in spending on Title III services and the proportion of Medicaid HCBS funding were associated with decreases in the proportion of low care residents in nursing homes. Further analysis found that for every \$25 in additional per capita spending on older adults' home-delivered meals there was a decrease in the proportion of low care nursing home residents of one percentage point. These studies controlled for states' Medicaid HCBS spending.

Using data from a sample of dual eligibles researchers found that increased HCBS spending reduced risk of nursing home use among beneficiaries with new hip fractures and low incomes. Long term nursing home use decreased by 0.17% for each 1 percentage point increase in the proportion of the state's Medicaid LTSS budget allocated to HCBS. (Blackburn and colleagues, 2015)

Two analyses support the connection between HCBS spending and level of nursing home residents' disability. The higher the proportion of Medicaid LTSS spending devoted to HCBS, the higher the functional impairment level of new nursing home admissions and the higher the proportion of long-stay residents who return to the community (Walsh, 2006). State level Medicaid LTSS spending for 1995–2005 shows that states with extensive, well-established HCBS experienced significantly less growth in LTSS spending than states with minimal HCBS (Kaye, 2009).

This research demonstrates that states with low percentages of Medicaid LTSS funding devoted to HCBS could increase such spending and likely reduce older adults' use of nursing homes and help ensure that nursing home use is reserved for older adults with higher disability levels. Those states that are not already providing a relatively high percentage of LTSS to older adults in their homes and communities could consider doing so to reduce nursing home use and serve people where most would like to live.

5. Dementia, Nursing Home Use, and Interventions

Cognitive impairment is a major risk factor for nursing home use and dementia is one of the major causes of such impairment among older adults. Thirty-two percent of adults aged 85 and older have the condition (Alzheimer's Association, 2016) and about 60% of nursing home residents have moderate or severe cognitive impairment (CMS, 2015). Severity of cognitive and physical functional impairment significantly increases the risk of people with dementia using a

⁸ Low care residents are those who do not need physical assistance with bed mobility, toileting, transferring, or eating and are not classified as needing specialized rehabilitation or clinically complex. Research indicates that low care residents have significantly better cognition than other residents (Thomas and Mor, 2013b).

nursing home. So do behavioral symptoms and family caregiver stress (Gaugler and colleagues, 2009).

A longitudinal study of older adult participants in the Medicare Alzheimer's Disease Demonstration (1989-1994) examined the risk of nursing home use for people with dementia. The participants came from 8 sites across the country and were followed for 3 years. All behavioral symptoms predicted nursing home use; the strongest predictors were "danger to self or others, forgets what day it is, loses or misplaces things, wakes caregiver up at night, hides things, and thinks things are not there." For all behavioral symptoms, caregiver stress affected risk of nursing home use (Gaugler and colleagues, 2011).

Since the major cause of cognitive impairment among older adults is dementia, states could benefit from using evidence-based approaches to enable this population to remain in the community longer with the help of family caregivers. There is much research that indicates how to do this and some examples of states that have developed HCBS systems capable of serving those with dementia.

Interventions for People with Dementia and their Family Caregivers

Tailoring services to the unique needs of older adults with dementia and their family caregivers through a "person-centered" approach could help states target their services to the unique needs of this high risk population. Person-centered planning is a process directed by the person with LTSS needs. The person-centered planning approach identifies the person's strengths, goals, preferences, needs (medical and LTSS), and desired outcomes. The role of family, staff, and other team members is to enable and assist the person to identify and access a unique mix of paid and unpaid services to meet their needs, and to provide support during planning and implementation of a service plan.

To help states explore a person-centered approach to dementia services for older adults, this section of the issue brief focuses on the literature that discusses the effectiveness of specialized dementia services. Reilly and colleagues (2015) reviewed case management interventions and found that they can: 1) reduce nursing homes and assisted living use, 2) improve quality of life for family caregivers, and 3) reduce the caregivers' use of hospitals and emergency departments. Ruiz and Spafford (2015) concluded that multi-component dementia care interventions that include education, counseling, respite, environmental modification, skills training, and case management can reduce caregivers' stress and improve their quality of life and delay institutionalization of the person with dementia. Gitlin and colleagues (2015) identified many multi-component interventions that resulted in less caregiver stress and better care for the person with dementia. Van't Leven and colleagues (2013) found similar positive results during their review.

Callahan (2014) describes some common components of quality dementia care interventions. These include:

- Obtaining a formal diagnosis
- Treating any preventable causes of cognitive impairment or disability

- Educating people with dementia and their families about the condition and how to manage its behavioral symptoms
- Referring people with dementia and their families to specialists, if necessary, and community-based services
- Regularly assessing medication needs, including those that may enhance cognition
- Discussing care goals and adjusting them over time
- Managing co-morbid symptoms in the context of dementia

Extant blue prints for dementia care can help states improve their HCBS systems. ACL's Alzheimer's Disease Supportive Services Program has fostered dementia capable HCBS systems and successfully translated evidence-based interventions into community settings.⁹ The experiences of grantees offer guidance to other states wishing to make progress in this area. In addition, CMS has funded several demonstrations of dementia care interventions through its Center for Medicare and Medicaid Innovations (CMMI).

Conclusions

Older adult Medicaid beneficiaries who use LTSS more often live in nursing homes than younger adults, despite the applicability of the *Olmstead* decision to everyone with disabilities. The situation for older adults and others using Medicaid LTSS varies markedly among the states, with many devoting over half of their spending to HCBS and many others doing much less. Thus, some states have much room for improving their LTSS systems by providing more HCBS to those older adults who prefer to remain at home or in the community.

Older adults most at risk of using nursing homes are those aged 85 and over, or who have cognitive impairment, poor health, or have severe disabilities. Studies show that older adults in states with more Medicaid and Older Americans Act spending on HCBS are more likely to be able to avoid nursing homes and there are effective interventions that could help people with dementia and their family caregivers do so. States could take advantage of extant research and their flexibility under Medicaid to target Medicaid HCBS to those most at risk of needing nursing homes and their family caregivers early enough to avoid institutionalization.

Focus on the population with dementia is important because their caregivers experience more stress than those caring for people with disabilities who do not have dementia (Kasper and colleagues, 2015). Further, several recent literature reviews show that case management, and specialized services can reduce caregiver stress and potentially use of nursing homes for this population.

States vary in their approach to providing HCBS and in their functional criteria for nursing home care and most could be doing more to promote community living for older adults. States also can exert more pressure on nursing homes to honor the preferences residents express to leave the facility. In the process, states may realize slower growth in overall LTSS, if they invest heavily in Medicaid HCBS (Kaye and colleagues, 2009)

⁹ More information about this program and its results can be found at: <http://www.nadrc.acl.gov/>.

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Appendix A. Data Table for Figure 2, Percentage of Adults Receiving any Type of Medicaid LTSS who Lived only in Institutions, by Age and State, 2011

State	21-64	65+
TN	41.5	93.9
NM	25.3	85
IN	32.4	82.1
KY	23.6	74.9
SD	18.6	74
DE	39.7	70.7
NH	10.3	68
PA	18.4	66.6
ND	16.4	65.8
LA	37.9	65.5
UT	31.2	65.5
MD	23.1	64.7
MT	7.7	62.1
NE	23.4	60.4
GA	17.3	59.3
WY	6.8	58.3
CT	17.6	57.1
RI	12.7	56.4
MS	21.6	56.2
AL	6	55.5
WV	15.2	55.2
SC	13.8	54.9
FL	22.9	53.6
AR	26.9	52.7
MI	14	52.7
VA	18.4	51.6
IA	18	50.9
OK	22.8	49.5
MO	13.2	48.4
NY	18.4	46.6
NJ	24.2	44.5
VT	10.5	44.3
NC	13.4	41.9
MN	2.6	37.1
NV	12.6	36.3
IL	20.1	36.1
WA	10.9	25.5
CA	10.2	21.2

OR	6.3	19.2
AK	4.6	12

Data Source: Medicaid Analytic eXtract (MAX) Data do not include LTSS beneficiaries enrolled in comprehensive managed care plans.

Data do not include Arizona, Colorado, the District of Columbia, Hawaii, Kansas, Idaho, Maine, Massachusetts, Ohio, Texas, and Wisconsin because MAX does not include 2011 data for these states.

Source: Eiken and colleagues, September 2015