PICKING UP THE PACE OF CHANGE

A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers

Susan Reinhard, Jean Accius, Ari Houser, Kathleen Ujvari, Julia Alexis, Wendy Fox-Grage

AARP PUBLIC POLICY INSTITUTE

longtermscorecard.org

AARP FOUNDATION | The Commonwealth Fund | THE scan FOUNDATION

SCORECARD FINDINGS BY DIMENSION

This section builds on the 2017 *Scorecard* report by providing a detailed analysis and discussion of the five dimensions of performance for long-term services and supports (LTSS): (a) Affordability and Access, (b) Choice of Setting and Provider, (c) Quality of Life and Quality of Care, (d) Support for Family Caregivers, and (e) Effective Transitions.

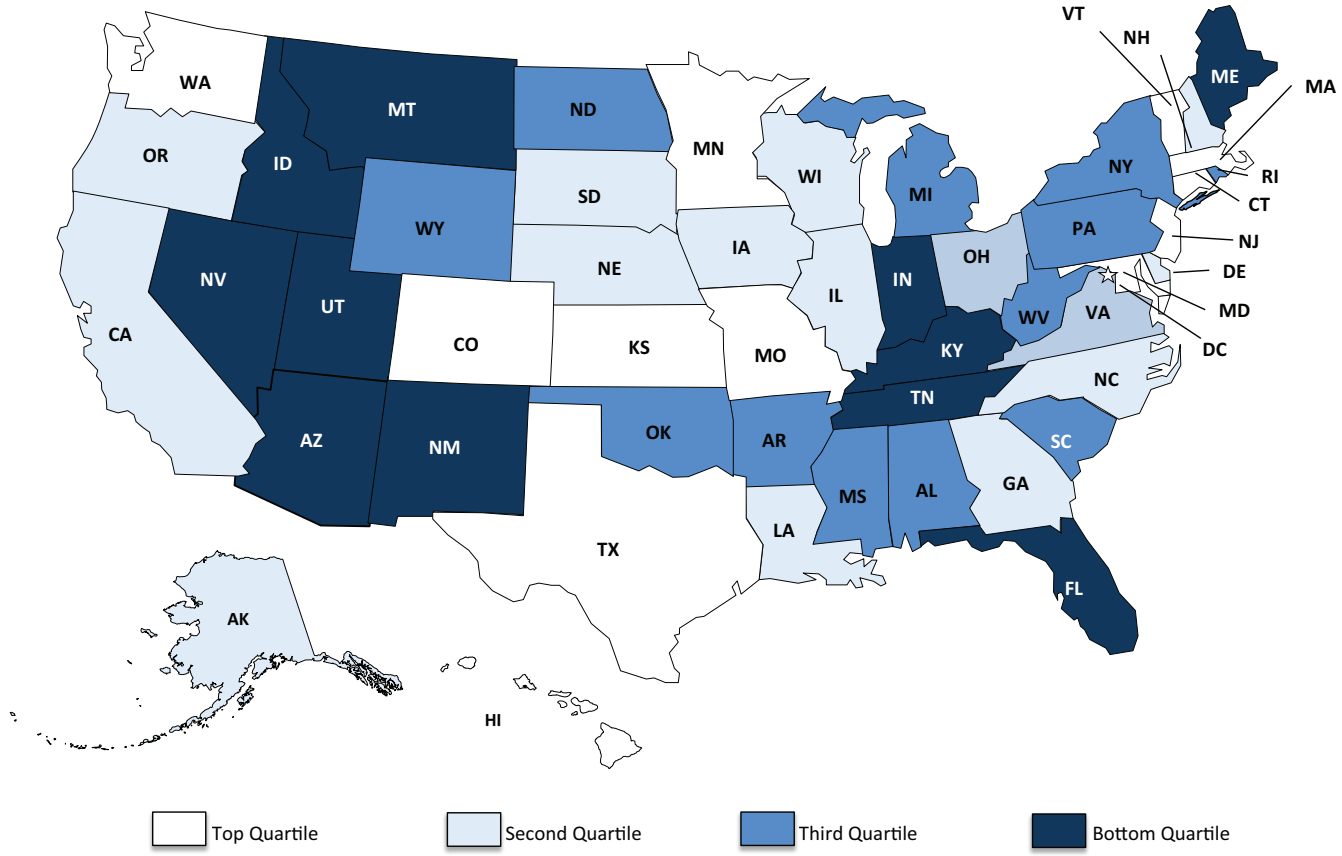
DIMENSION 1 Affordability and Access

This dimension evaluates the affordability of services for people of moderate and higher incomes, how effective the safety net is for those who cannot afford services, and how easily consumers can find the LTSS they need. Everyone faces a risk, but not a certainty, of needing LTSS. About 52 percent of people turning 65 today will develop a severe disability that will require LTSS at some point. About 19 percent are expected to have needs that last less than a year, and 14 percent are expected to have needs that extend beyond five years. Given the aging population, the number of people with a severe need for LTSS is expected to grow from 6.3 million to almost 15.7 million from 2015 to 2065. On average, someone turning 65 today will incur $138,000 in future LTSS costs in his or her lifetime.[1]

Yet most people are not prepared for the risk of needing LTSS or the potential costs they face—now or in the future. Many cannot imagine needing assistance with basic life functions. Others have misconceptions that Medicare will pay for LTSS, when in fact it covers only post-acute care.[2] For many people, the ability to save and accumulate sufficient assets to meet and finance their LTSS needs is hindered by more immediate and often competing financial demands such as housing, transportation, and education.

For people who need extensive services, the cost can be extremely high, far beyond the income and savings of most people. For example, the typical annual cost for a private room in a nursing facility in 2016 was more than $92,000, the base price for assisted living averaged over $40,000, and home care can add up to more than $30,000 per year.[3] According to the US Census Bureau, in 2015 (the most recent year for which data are available) the median household income for a person age 65 or older was $40,971. Thus, the cost of LTSS is a major source of financial risk for middle-class families.

Exhibit 1 **State Ranking on Affordability and Access Dimension**



Source: State Long-Term Services and Supports Scorecard, 2017.

Nursing Home Cost

A consistent finding in this dimension is that the cost of nursing home care is far out of reach for middle-income Americans in every state. There was no meaningful change—typically 10 percent or more—in performance from the 2014 *Scorecard* in 42 states. In 4 states (District of Columbia, Georgia, Nevada, and North Dakota), nursing homes became even less affordable. Five states (Hawaii, Kentucky, Vermont, New Hampshire, and Rhode Island) showed an improving trend. While Oklahoma remained the most affordable state, nursing home costs would still consume 164 percent of the income of the typical older family. The national average is 243 percent of median income.

Top-ranked states on this indicator were Oklahoma, Missouri, Iowa, Kansas, and Utah, where, on average, the cost of a nursing home would consume 171 percent of an older household's median income. While even these states cannot be considered affordable, they are in sharp contrast to the five lowest-ranked states, in which nursing home costs would consume on average 367 percent of income—more than twice as much.

Home Care Cost

Although home care is more affordable than nursing home care, the cost of home care services would consume nearly the entire income of the typical older middle-income family in most states. There was no significant change in performance from the 2014 *Scorecard* in 46 states. Five states (Vermont, Alaska, West Virginia, Utah, and New Hampshire) showed an improving trend, and no states showed a significant decrease in the affordability of home care. The District of Columbia, in which home care cost would

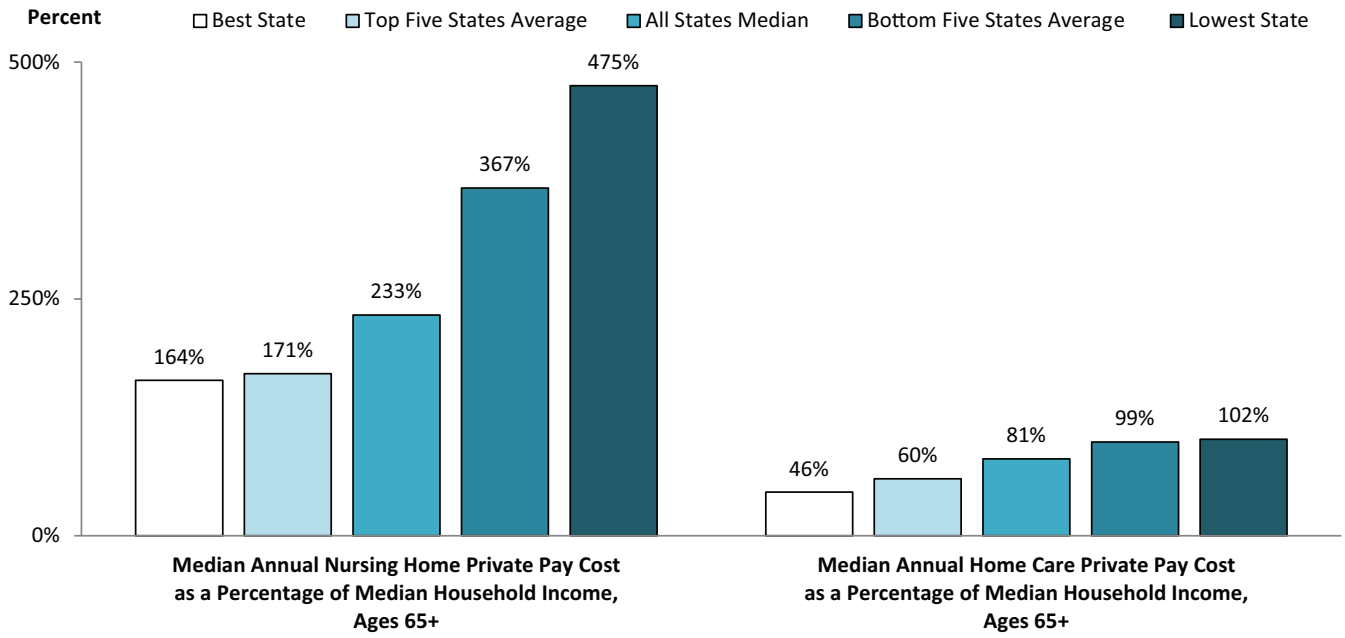
consume 46 percent of median income for an older household, remains the most affordable jurisdiction. The relatively high income of the District of Columbia metropolitan area, coupled with below-average cost of home care, also accounts for adjacent Maryland and Virginia showing relatively more affordable home care—59 and 61 percent of income on average, respectively. The least affordable states for home care were Maine and Rhode Island, where the cost would consume 102 percent of median income. The national average was 79 percent.

Private Long-Term Care Insurance

The private long-term care insurance (LTCI) industry is undergoing transformation. Few consumers have purchased LTCI. The high cost and complexity of LTCI, the mistaken belief that Medicare or Medi-gap covers LTSS, and concerns about rising premiums are some of the factors affecting consumer demand.

On the supply side, most carriers have exited the market. In 2002, over 100 companies were selling private LTCI. By 2015, only 12 remained in the market. Those few remaining carriers are raising premiums, cutting discounts, implementing tougher underwriting requirements, and eliminating products.[4] The current environment is one in which premiums are unaffordable and unpredictable, there are limitations in the amount of protection offered, underwriting is costly and extensive, and consumers are confused and distrustful. However, there are several initiatives occurring at the state and federal levels to improve this product and help older adults and people with physical disabilities maximize their choices.

Exhibit 2 **State Variation: Private Pay Nursing Home and Home Health Cost**



Top Five States	
1 Oklahoma	1 District of Columbia
2 Missouri	2 Maryland
3 Iowa	3 Virginia
4 Kansas	4 Hawaii
5 Utah	5 Utah

Data: AARP Public Policy Institute analysis of Genworth 2016 Cost of Care Survey data and 2015 American Community Survey Public Use Microdata Sample.

Source: State Long-Term Services and Supports Scorecard, 2017.

Not surprisingly, the *Scorecard* found a downward trend in the rate of private LTCI policies per 1,000 people ages 40 and older. The total number of stand-alone and hybrid LTCI policies in effect declined by 3 percent (or 222,298 policies between 2012 and 2015). When factoring in the growth in the 40+ population, it is clear that LTCI policies are not keeping pace with the aging market. Between 2012 and 2015, the total policies per 1,000 in effect for the 40+ population dropped from 53 to 50, roughly a 6 percent decline.

LTCI penetration had broad variation across states. The lowest level was in Nevada, in which 25 policies per 1,000 people ages 40 and older were in the force, compared with the District of Columbia, in which 164 policies per 1,000 were in force (possibly because of the federal government offering this benefit to federal employees), followed by South Dakota, North Dakota, Hawaii, and Nebraska. The national average was 50 policies per 1,000 people ages 40 or older. The range between the top and bottom states was substantial, with coverage in the top five states averaging 129 policies per 1,000 compared with 30 in the bottom five states.

Medicaid: The LTSS Public Safety Net

While the policy climate is dynamic, for more than 50 years Medicaid has served as a critical safety net for millions of people with limited income and resources. It is the primary public payer for LTSS—accounting for 32 percent ($152 billion) of total LTSS spending in 2014.[5] Some 5 million people with LTSS needs—1.6 million in institutions and 3.4 million in the community—get help from Medicaid. Medicaid is a "program of last resort" that requires beneficiaries to have low incomes and few assets. Nearly a third of older people are projected to deplete their savings and turn to Medicaid for vital support.[6]

Many people with low incomes and disabilities also have high out-of-pocket costs for health care. A study found that just over half (54 percent) of people ages 65 and older who spent down to Medicaid eligibility over a 10-year period did so for LTSS; the remaining 46 percent spent down paying for health costs.[7] Therefore, the reach of a state's overall Medicaid program is as important a factor in system performance as the reach of its LTSS program.

Low-Income Adults with Disabilities Receiving Medicaid

Federal and state eligibility criteria determine access to Medicaid coverage. To be eligible, an applicant must meet strict income and asset rules, which vary from state to state.[8] This indicator measures the likelihood that adults with activities of daily living (ADL) disabilities and low to moderate incomes qualify for Medicaid.

The *Scorecard* finds that 15 states showed significant improvement in the number of low-income adults with disabilities receiving Medicaid since 2011. It appears that many of the states that improved were states that expanded their Medicaid program. The Affordable Care Act allows states to provide Medicaid to people under age 65 whose incomes do not exceed 138 percent of the poverty level, a provision of particular benefit to childless adults, who often were precluded from coverage. States are allowed to offer a limited benefit package to the expansion group. Thirty-one states and the District of Columbia expanded their Medicaid program. The remaining 19 states did not adopt Medicaid expansion.

There was a significant decline in performance in four states (Delaware, Montana, Utah, and Oklahoma). The *Scorecard* finds the highest coverage in the District of Columbia, in which 78.1 percent receive Medicaid, compared with Oklahoma, where 38.8 percent of the target population has Medicaid access. The other top states were Alaska, Massachusetts, New York, and Vermont.

Medicaid LTSS Users per 100 People with ADL Disability

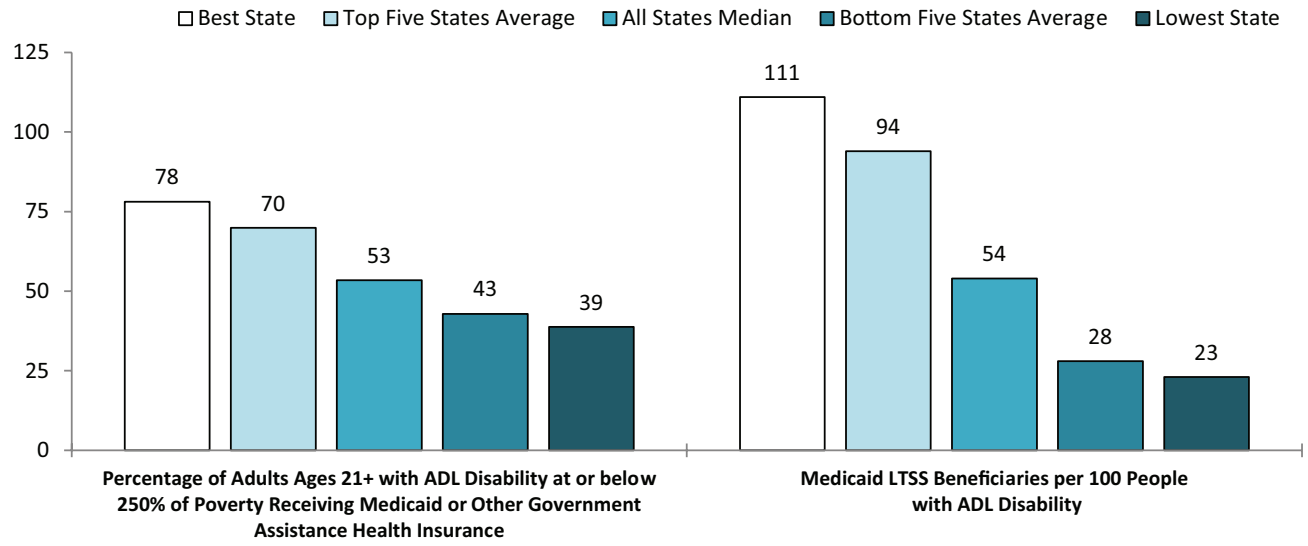
Most Medicaid LTSS users have ADL or self-care disabilities (some without such disabilities have other reasons for LTSS, such as intellectual disabilities or dementia). Because of data limitations, it was not possible to look at the percentage of people with ADL disability. Therefore, in two states (District of Columbia and Minnesota) the number of people of all ages who received Medicaid LTSS in 2012 was greater than the number of people of all ages with ADL disabilities.

States with a relatively low number of Medicaid LTSS participants per 100 people in the target population may impose more restrictive functional eligibility criteria, which could limit the reach of Medicaid LTSS programs or may provide few alternatives other than institutional care.

The *Scorecard* finds that overall there was no significant change in performance at both national and state levels between 2010 and 2012. The top states were the District of Columbia, Minnesota, Vermont, North Dakota, and California, which averaged 94 participants per 100 adults, compared with the bottom five states, with 28 participants per 100 adults—more than a 3 to 1 ratio. The national average was 54.

Exhibit 3 State Variation: Reach of Medicaid Safety Net

Percent and Participant Years



Top Five States

1	District of Columbia	1	District of Columbia
2	Alaska	2	Minnesota
3	Massachusettes	3	Vermont
4	New York	4	North Dakota
5	Vermont	5	California

Data: Percentage on Medicaid - AARP Public Policy Institute analysis of 2014-15 American Community Survey Public Use Microdata Sample. Percentage of Medicaid LTSS Beneficiaries - see Appendix B for a detail description of the data source.

Source: State Long-Term Services and Supports Scorecard, 2017.

Aging and Disability Resource Centers or "No Wrong Door" Functions

In a high-performing state system, consumers of all incomes—including people with disabilities and their families—can readily find information about a broad array of services and how to access them, and there is a coordinated approach to determining eligibility for public programs. The Administration for Community Living, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration have partnered for several years to support states' efforts to develop a single statewide aging and disability resource center (ADRC)/"no wrong door" (NWD) system that provides easy access to information and assistance in navigating the delivery system. These are one-stop, single-entry access points for information and assistance about the full range of services available to people with disabilities, regardless of income or type of disability.

The 2017 *Scorecard* includes a revised ADRC/NWD functions indicator to reflect the five primary functions of a NWD system:

- State governance and administration,
- Populations served,
- Public outreach and coordination with key referral sources,
- Person-centered counseling, and
- Streamlined eligibility for public programs.

Under each function there is a set of measures states can use to assess their progress toward a single statewide NWD system. These measures are designed to help states create a vision for their NWD system and strategically leverage existing resources, establish a basis for meaningful outcome and process measures, help set national guidelines, and improve consistency and quality of NWD systems across the states. This indicator ranks the states on the number and type of functions that ADRCs perform. It does not evaluate how well these functions are performed, or whether they are carried out consistently.

The top-ranking states were Washington, Massachusetts, Minnesota, New Hampshire, and Connecticut.

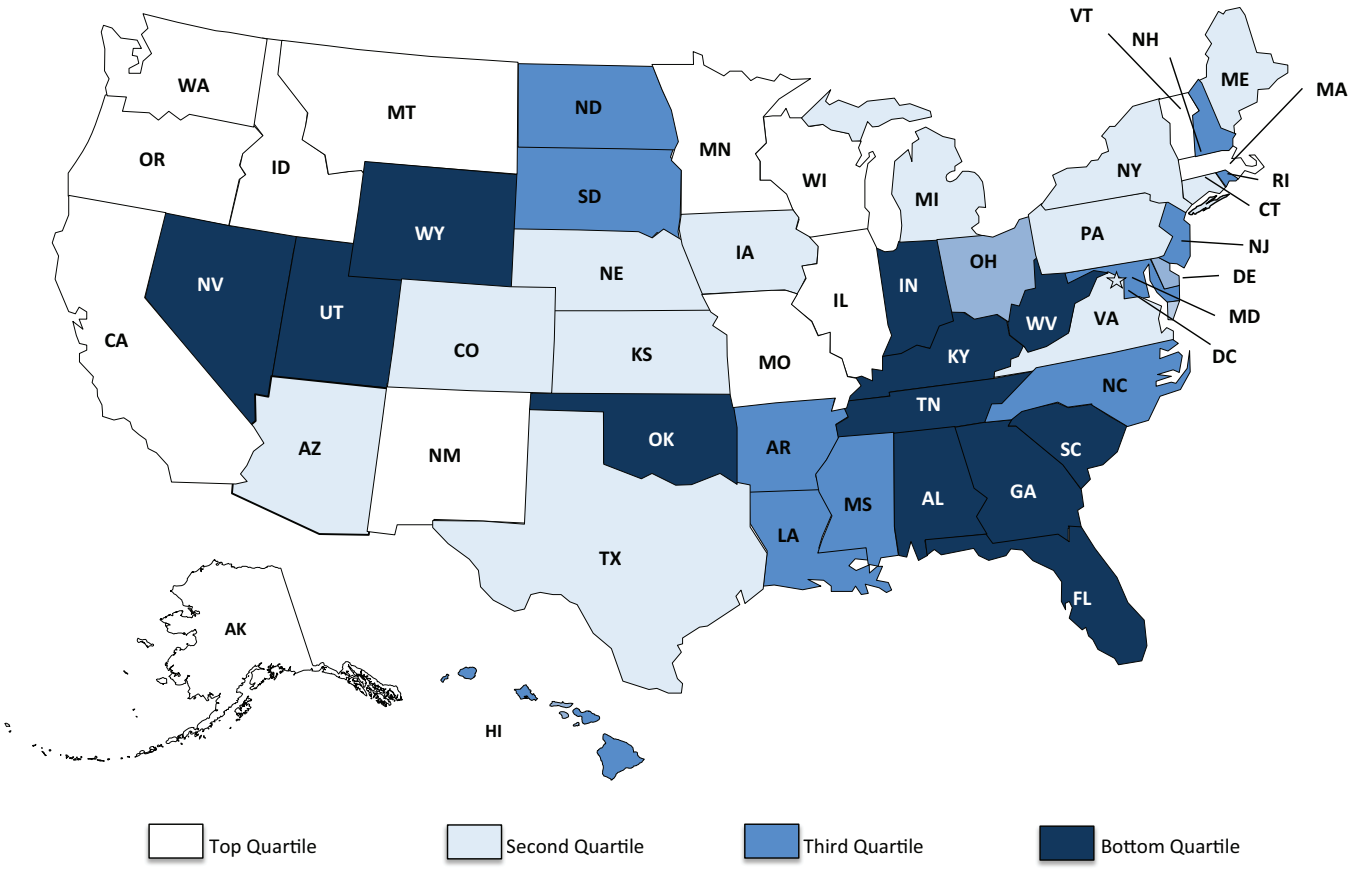
DIMENSION 2 Choice of Setting and Provider

The landmark Americans with Disabilities Act (ADA),[9] passed in 1990, established the civil rights of people with disabilities to participate fully in all aspects of society. It set enforceable standards for preventing employment discrimination and ensuring access to public accommodations and transportation. These fundamental rights of people with disabilities emphasize the importance of the next dimension of a high-performing LTSS system: the ability of people to choose the setting in which they receive services and who provides them. Using the ADA as its basis, the Supreme Court's *Olmstead* decision in 1999 addressed the right of people with disabilities to receive services in the least-restrictive setting.[10] This decision represented a pivotal moment in states' LTSS delivery systems as it addressed the Medicaid program's inadequate supply of home- and community-based alternatives to nursing homes. Calling for states to develop reasonable and appropriate community-based options for people who preferred such settings sent a warning to states that they must address long waiting lists and inadequate options.

Public policy plays a direct role in many aspects of this *Scorecard* dimension. State Medicaid programs are transforming their reliance on nursing homes as the primary setting for delivering services, but the pace of change varies across the states. A "person-centered" approach to service delivery recognizes individual preferences for where services are delivered, who delivers services, how services are arranged, and what community options are available.

Medicaid's central role in delivering LTSS makes it a key area of inquiry in determining how well states offer consumers the choice of setting that is so important to them. Medicaid requires participating states to provide nursing home services to all who qualify, but home- and community-based alternatives remain optional services. While most states have begun to shift the balance of service delivery to offer more home- and community-based services (HCBS), there is still much room for improvement.

Exhibit 4 **State Ranking on Choice of Setting and Provider Dimension**



Source: State Long-Term Services and Supports Scorecard, 2017.

Balance in Medicaid and State-Funded LTSS

For many years, Medicaid "balancing"—that is, bringing the proportion (percentage) of total Medicaid LTSS spending going toward HCBS into balance with strong consumer preference to receive services in the community—has been the primary measure of state progress in LTSS reform. While the *Scorecard* takes a multidimensional approach to overall system performance, state progress in shifting Medicaid spending away from nursing homes and toward HCBS alternatives remains of paramount importance.

This analysis considers the spending balance among older people and adults with physical disabilities—the target populations for the *Scorecard*. In 2014, HCBS accounted for 53 percent of all Medicaid spending on LTSS for all populations. However, this topline figure masks substantial variation, both by state and by demographic groups. While the LTSS delivery system has made significant progress toward offering people more choice and control, it still remains too reliant on costly institutional care, which accounted for the majority of Medicaid LTSS spending for older people and adults with physical disabilities, with only 41 percent going to HCBS for this population.[11]

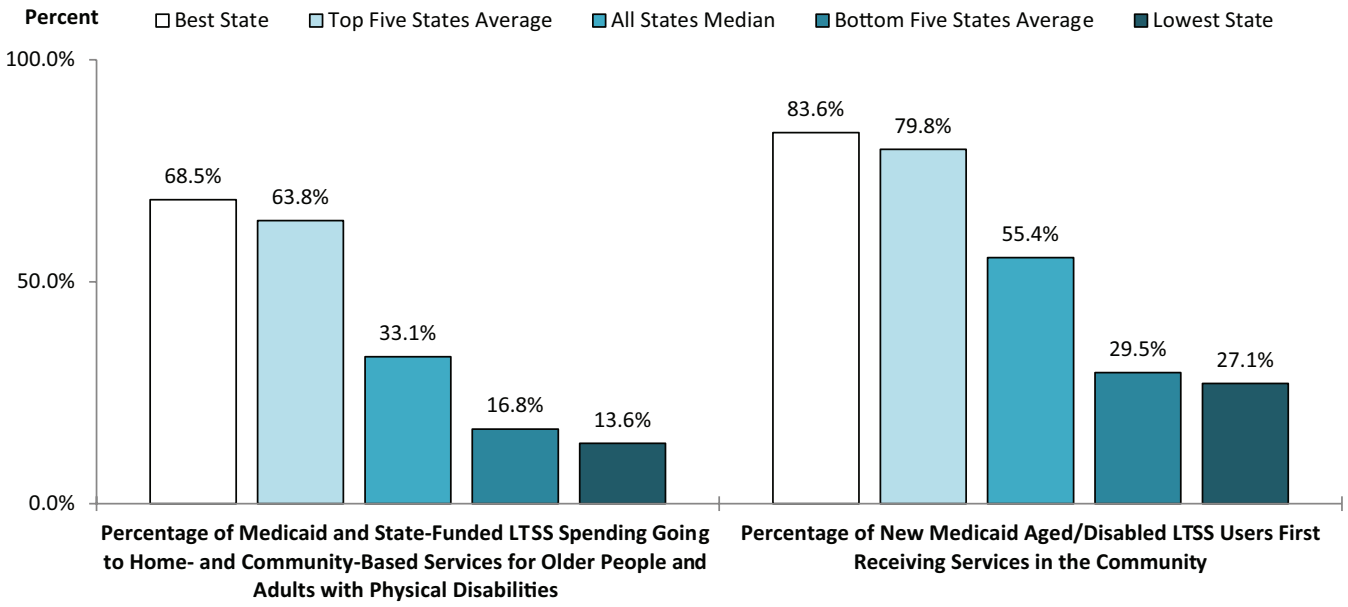
Percentage of Medicaid and State-Funded LTSS Spending Going to HCBS

The *Scorecard* finds that states have made improvements in Medicaid balance, but more work needs to be done. Overall, 17 states significantly increased the proportion of spending going to LTSS and there was a significant decline in 7 states.

The Affordable Care Act included the State Balancing Incentive Program (BIP), which expired on September 30, 2015. It provided grants to qualifying states that would increase a state's Federal Medical Assistance Percentage by either 2 or 5 percentage points, depending on the state's allocation of Medicaid spending for HCBS. The *Scorecard* finds that of the 21 BIP states, only 6 states increased spending balance by at least 10 percent since 2011 (Mississippi, Pennsylvania, Connecticut, Iowa, New York, and Ohio), and 4 states declined (Kentucky, Indiana, Massachusetts, and Nevada). Since BIP was an investment to expand the array of HCBS, the lack of immediate impact is not surprising, and it is possible that more BIP states will improve in the near future.

Minnesota and Washington were national leaders, spending 65 percent or more of their Medicaid LTSS dollars for older people and adults with physical disabilities on HCBS, followed closely by New Mexico, Alaska, and Oregon. Ten states spent 50 percent of their Medicaid and state funding on HCBS. Alabama had the least-balanced Medicaid LTSS system, spending 13.6 percent on HCBS. The top five states allocated on average 63.8 percent of LTSS dollars for HCBS, compared with an average of just 16.8 percent in the bottom five states—about one-fourth the level. The national average was 41.2 percent.

Exhibit 5 **State Variation: Measures of Medicaid LTSS Balance**



Top Five States

1	Minnesota	1	Minnesota
2	Washington	2	Alaska
3	New Mexico	3	New Mexico
4	Alaska	4	District of Columbia
5	Oregon	5	Illinois

Data: LTSS Spending - AARP Public Policy Institute analysis of Truven Health Analytics, Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014: Managed LTSS reached 15 Percent of LTSS Spending (2016); AARP Public Policy Institute Survey (2016); New Medicaid Users - AARP Public Policy Institute analysis of Mathematica Policy Research, Pathways to Indepencence: Transitioning Adults under Age 65 from Nursing Home to Community Living, Table 5 (2012); Truven Health Analytics, Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014, Table AS; Truven Health Analytics, Medicaid Expendiitures for Long Term Services and Supports (FY 2011).

Source: State Long-Term Services and Supports Scorecard, 2017.

Percentage of New Medicaid LTSS Users First Receiving Services in the Community

Nearly 90 percent of people ages 65 and older want to remain in their own homes as long as possible.[12] Meanwhile, those who enter a nursing home may find it difficult to return home. In order to honor the choice of older people and adults with physical disabilities to receive services in the community, it is important that they begin receiving LTSS in the community. With such factors in mind, this indicator measures the proportion of new users of Medicaid LTSS who first received services in the community.

The *Scorecard* finds that 29 states showed significant improvement in the percentage of new Medicaid LTSS users first receiving services in the community. The 8 states with the greatest improvement—Montana, Pennsylvania, Maryland, Iowa, Delaware, Louisiana, Vermont, and Nebraska—all showed increases of more than 10 percentage points between 2009 and 2012. In the top 5 states, 79.8 percent of new Medicaid LTSS users received services in HCBS settings, almost three times the performance of the bottom 5 states, which averaged 29.5 percent.

Participant Direction

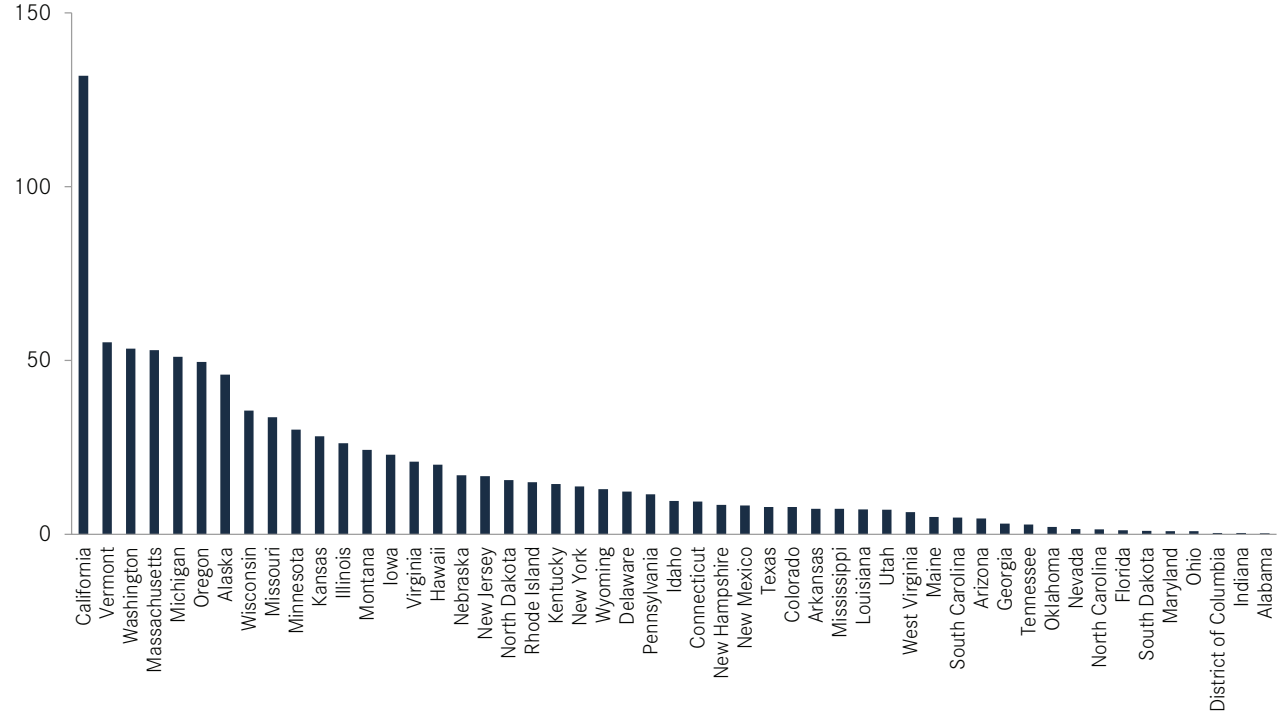
In a high-performing system, consumers should have the right to decide how and where those services are delivered, and who provides them. Consumer direction, self-direction, or participant direction are used interchangeably to describe a model that allows individuals to hire and fire service providers, set their hours, and, in some cases, determine their rate of pay. Nationally, the number of participant-directed LTSS programs remains relatively stable, with 253 programs reported in 2016 compared with 261 in 2013.

However, program enrollment has grown considerably from 739,711 in 2011 to 1,058,899 in 2016 (an increase of 143 percent). The majority of consumer-directed programs (75 percent) are being offered statewide compared with only 44 percent in 2013. The *Scorecard* finds that California continues to lead the nation by the proportion of people with disabilities who self-direct their services, followed by Vermont, Washington, Massachusetts, and Michigan. In the top five states, 69 per 1,000 people with disabilities self-direct their services, compared with less than 1 per 1,000 in the bottom five states.

The range of performance is illustrated in exhibit 6.

Exhibit 6 **State Rates of Participant-Directed Services for People with Disabilities**

Number of People Participant-Directing Services per 1,000 People with Disabilities



Data: National Inventory of Self-Directed Programs in the United States survey, 2016 (unpublished); 2015 American Community Survey.
Source: State Long-Term Services and Supports Scorecard, 2017.

Home Health and Personal Care Aides

A large majority of older adults and individuals with physical disabilities would prefer to receive services and supports in their homes and communities. Without an adequate workforce, consumers may find it difficult—regardless of their payment source—to remain in their homes and communities. As a result of the aging population, the Bureau of Labor Statistics projects demand for personal care and home health aides to increase by 64 percent by 2024, much faster than the average for all occupations.[13]

The *Scorecard* finds that 24 states significantly improved on this measure. The leading state was New York, followed by Minnesota, New Mexico, Idaho, and Vermont.

Assisted Living and Residential Care

Assisted living and other residential settings represent a critical component of the LTSS system for older adults and individuals with physical disabilities. When living in their own home is no longer a viable option, and they do not require or seek skilled care provided by nursing homes, these settings offer a good option. The availability of these residential alternatives is reported as the number of assisted living and residential care units per 1,000 people ages 75 and older. Nationally, 83 percent of assisted living/residential care residents are ages 75 and older.[14] Although most assisted living residents pay for services out of pocket, some Medicaid and state-funded programs pay for services in these settings.

The *Scorecard* finds no significant change in performance for most states. There was significant improvement of 10 percent or more in seven states (Wisconsin, Ohio, Rhode Island, Oklahoma, Arkansas, New York, and Wyoming). However, seven states also declined by 10 percent or more. In the top five states,

there were on average 102 units per 1,000 people ages 75 and older, compared with the bottom five states, which averaged just 24 units. The national average was 52.

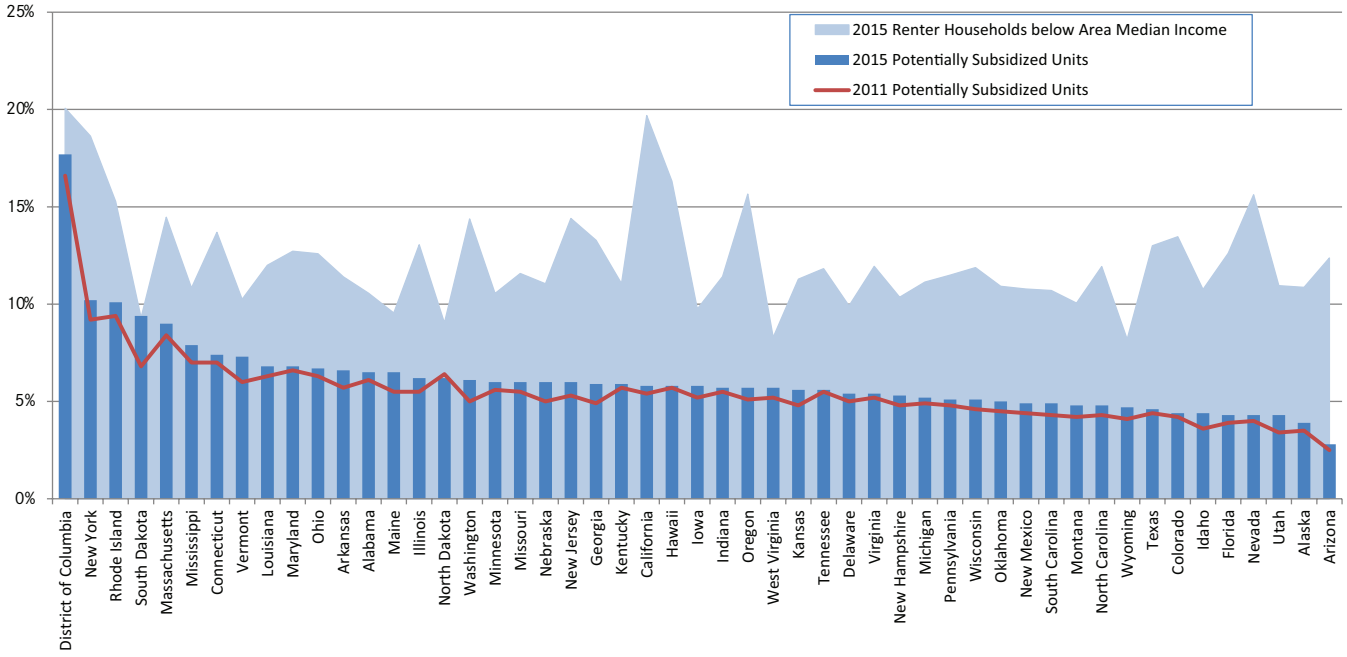
Subsidized Housing Opportunities

Affordable housing is essential to shifting the delivery of LTSS from an institutional model toward home- and community-based care. However, a major barrier to transitioning people out of institutions and back into their communities is the lack of affordable and accessible housing options. For the first time in the *Scorecard*, we are able to include a housing measure that captures a broad spectrum of housing subsidies that can create or support affordable housing. Federal programs such as sections 8, 202, and 236 used to create new affordable housing that was available to those with low incomes. Since the federal government stopped funding new construction, fewer affordable apartments are available under these programs. This has contributed to the affordable housing crisis in the United States.

This new housing measure captures the total amount of subsidized housing opportunities divided by the total number of housing units in a state. Not all opportunities are realized, as many place-based subsidized units are vacant and vouchers go unused.

The top performers were the District of Columbia, New York, Rhode Island, South Dakota, and Massachusetts. Despite a significant increase in 28 states, there is still an affordable housing crisis in our country. Nationally, there are more than 18 million renters at or below area median income (most of whom are cost burdened by housing) and fewer than 8 million potentially subsidized units.

Exhibit 7 **Subsidized Housing Opportunities and Demand, as a Percentage of All Housing Units, by State**



Data: AARP Public Policy Institute analysis of National Housing Preservation Database (2012, 2016); AARP Public Policy Institute analysis of Center on Budget and Policy Priorities, Housing Vouchers (2011, 2015); AARP Public Policy Institute analysis of U.S. Census Bureau, American Community Survey, Table B25001 (2011, 2015).

Source: State Long-Term Services and Supports Scorecard, 2017.

Due to slow growth of the overall housing market and the increased use of vouchers, tax credits, and other financing mechanisms, the total percentage of subsidized housing opportunities has risen despite the freeze in sections 8, 202, and 236 units, but still falls far short of current and future needs. Simply having a relatively high number of affordable units is not enough—states and local partners still need to make sure that those units are available for people who need them and that their design and locations serve those in need, including those with LTSS needs and their families. In particular, those with very low incomes find that some program subsidies are not deep enough to make housing affordable for them. States and local partners can fund, design, and locate housing to ensure that it meets needs.

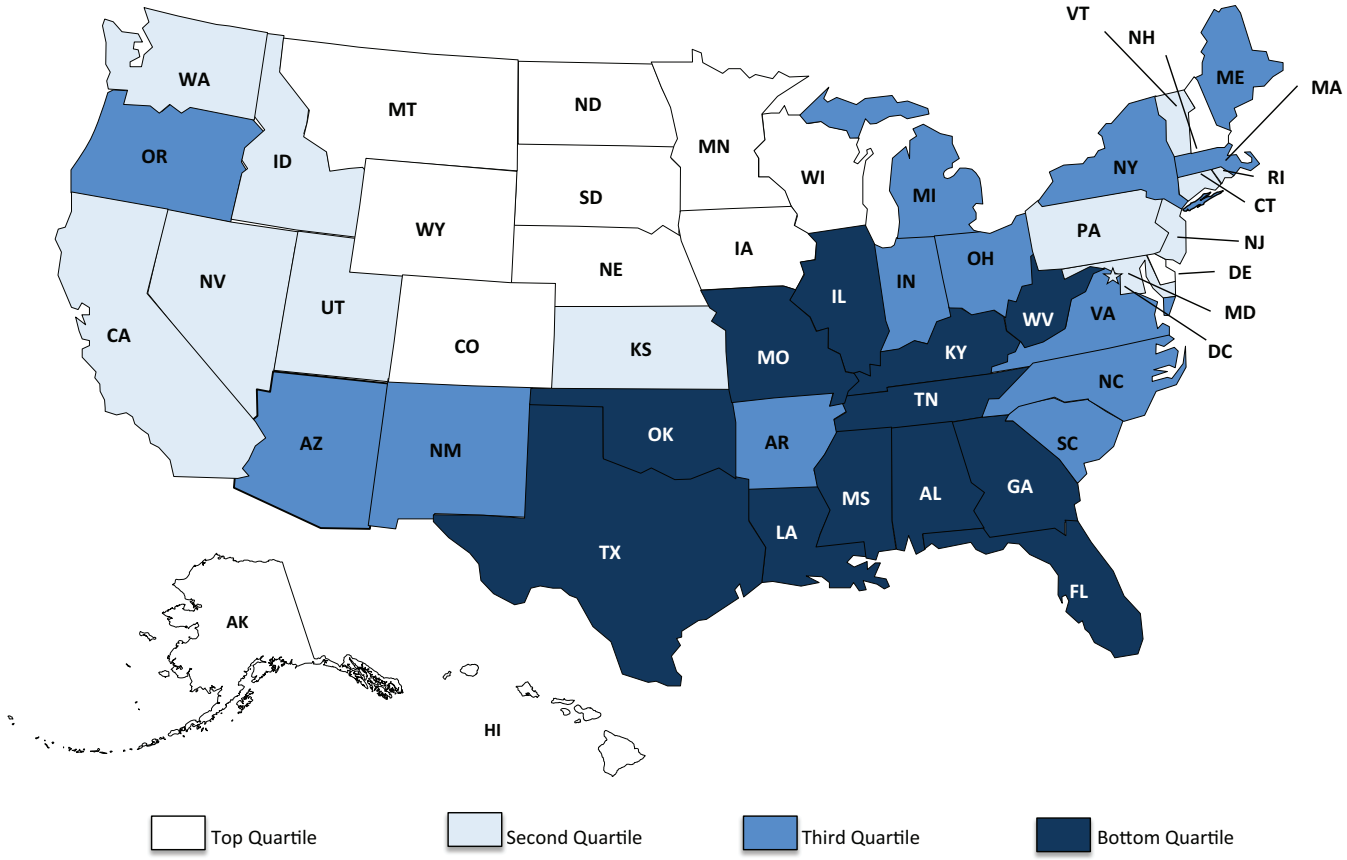
DIMENSION 3 Quality of Life and Quality of Care

A high-performing system focuses on outcomes and ensures that the delivery of high-quality LTSS emphasizes consumer preference, independence, choice, control, dignity, and privacy. Over the past 30 years, the delivery of LTSS has evolved toward a greater reliance on home- and community-based services as a meaningful alternative to institutional care. Despite numerous efforts to identify, propose, and develop consistent quality measures, the lack of a uniform, consistent, and reliable source of data across all states for HCBS continues to be a challenge.

The quality of HCBS, therefore, was an area we were not able to measure in the 2011, 2014, and current *Scorecard*. In addition, one-half of the quality measures in the 2014 State LTSS *Scorecard* had to be dropped from this *Scorecard* due to discontinuation or unreliability of the data and a lack of any adequate alternative measures. The Quality of Life and Quality of Care dimension contains only three measures (compared with six for the other indicator-based dimensions), and has substantive gaps in the areas of HCBS quality, quality of life for people with disabilities, and staffing turnover.

Because of these gaps, the Quality of Life and Quality of Care dimension received only one-half of the weight of the other four dimensions in determining states' overall ranks on LTSS system performance. For 2017, this dimension includes one measure of quality of life and two measures of quality of care in nursing homes.

Exhibit 8 **State Ranking of Quality of Life and Quality of Care Dimension**



Source: State Long-Term Services and Supports Scorecard, 2017.

Rate of Employment

Adults with disabilities are much less likely to be employed than are people without a disability. This is a major issue for person with disabilities and their families not only because jobs bring income, but also because being able to work is part of an adult's identity and ability to connect with others. The *Scorecard* finds that the relative rate of employment for adults with disabilities remains a significant challenge. While there was a positive trend in 5 states (Nevada, Rhode Island, Wyoming, West Virginia, and Oregon), 21 states saw a significant decline in the relative rate of employment for adults with disabilities since 2011. The top performers were Nevada, Minnesota, Wyoming, Montana, and Iowa, where the relative rate of employment among people with disabilities was 33.4 percent. By contrast, in the bottom 5 states, employment averaged just half this level: 16.3 percent.

Nursing Home Residents with Pressure Sores

Pressure sores—areas of damaged skin that result from staying in one position too long—are a key measure of nursing home quality. They are preventable with good care, but once they develop, they can lead to serious medical complications, including life-threatening infections. Thus, nursing homes that have low rates of pressure sores among their residents are generally providing higher-quality care. The *Scorecard* finds that there has been a slight drop in the incidence of pressure sores among long-stay residents in nursing homes since 2013. However, more work needs to be done nationally to pick up the pace of change. While there was no significant change in performance in 35 states, 14 states improved in this measure by

significantly reducing the incidence of pressure sores, and the rate of pressure sores increased in 2 states (Hawaii and Montana).

The range in performance on this indicator is significant. The top-performing state (Idaho) reported 3.4 percent of nursing home residents with pressure sores, compared with the lowest-ranked state (District of Columbia) which reported 8.6 percent. While these percentages may sound low, they translate to tens of thousands of people who suffer from a dangerous and preventable condition. Other top states were New Hampshire, Alaska, Delaware, Hawaii, and Nebraska. In the top five states, the incidence of pressure sores was 3.7 percent, less than half the average in the bottom five states (7.6 percent).

Use of Antipsychotic Medications

Concern over excessive and inappropriate use of antipsychotic medications in nursing homes has become an area of focus in recent years. Studies by CMS and independent researchers report that off-label use of these drugs is high among nursing facility residents with dementia. In many cases, these medications are used despite a specific warning on the label against administering these drugs to older adults for dementia-related conditions. In 2012, CMS launched the National Partnership to promote good health and quality of life in nursing facilitates. One of the main goals was to "protect residents from being prescribed antipsychotic medications unless there is a valid, clinical indication and a systematic process to evaluate each individual."[15]

Data that became available for the first time a few years ago from Medicare's Nursing Home Compare website enabled us to report on this measure for the first time in the second *Scorecard*, and so we are now able to measure change over time. Nursing home residents with a diagnosis of bipolar disorder, schizophrenia, Tourette's syndrome, and Huntington's disease were excluded from the sample. Since 2013, potentially inappropriate use of antipsychotic medications in nursing homes has declined by 4 percentage points, with the national average slightly over 17 percent. Forty-eight states showed significant improvement in reducing inappropriate use of antipsychotic medications among long-stay nursing home residents. Hawaii, Wyoming, New Jersey, Wisconsin, and California had the lowest use of inappropriate antipsychotic medications (averaging 12 percent), far below the level of the five bottom-ranked states, which averaged 21 percent use.

DIMENSION 4 Support for Family Caregivers

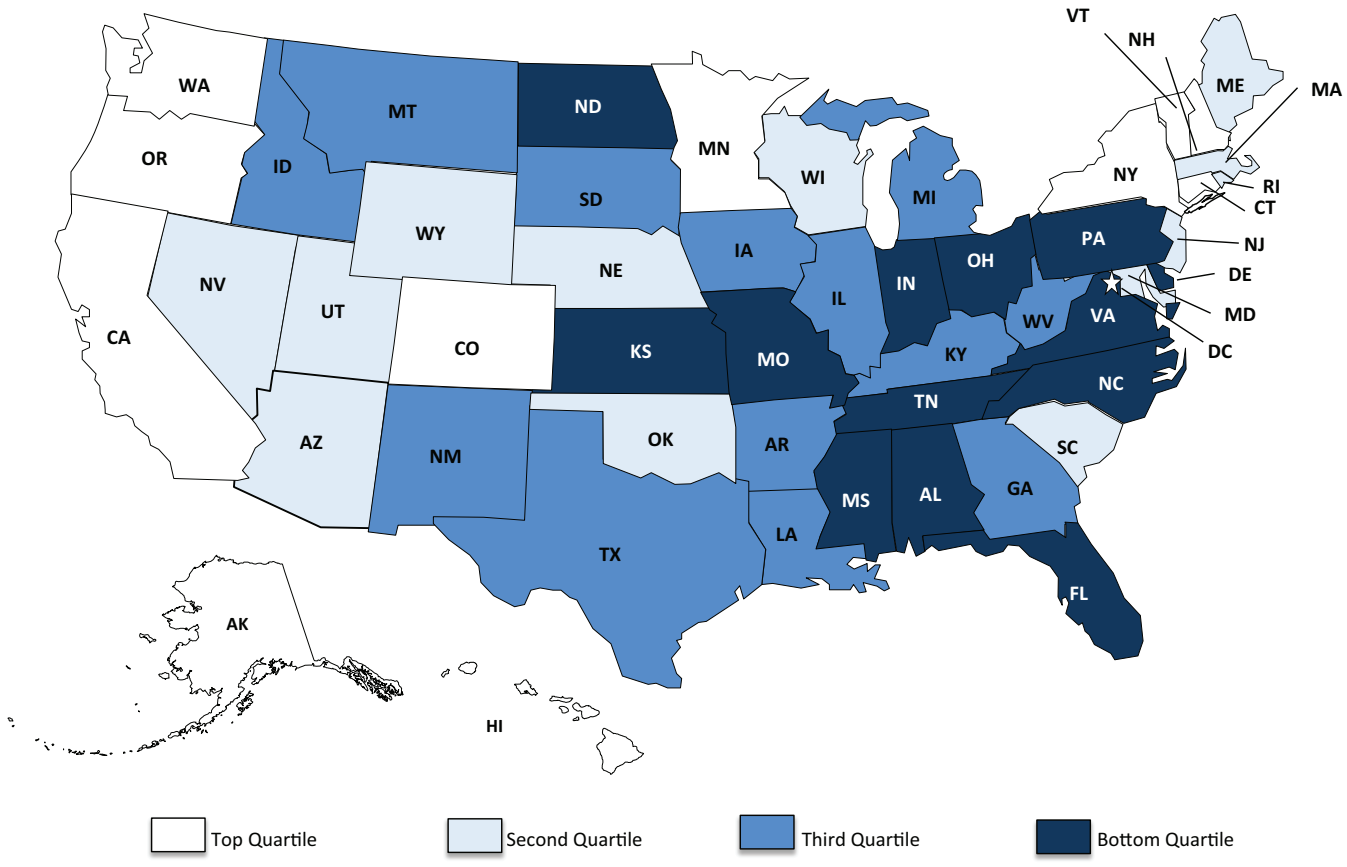
Most people rely on unpaid family members and friends for the bulk of their LTSS needs. The *Scorecard* defines "family caregiver" broadly as any relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance for an older person or other adult with a chronic or disabling condition. In 2013, about 40 million family caregivers in the US provided care to an adult with limitations in daily activities at any given point in time.[16] While a caregiver's role can provide meaning and purpose to their own lives, many experience significant physical, psychological, and financial stresses in association with that role.

A recent study finds that more than three in four family caregivers (78 percent) report incurring out-of-pocket costs as a result of caregiving. On average, in 2016 family caregivers of adults spent nearly $7,000 on out-of-pocket costs related to caregiving, amounting to 20 percent of their total income, on average.[17] At $470 billion annually, the total economic value of these caregivers' contributions is more than the total amount spent on formal LTSS.[18]

But family caregivers cannot do it all and, moreover, the supply of family caregivers is unlikely to keep pace with future demand. Demographic and cultural trends including rapidly increasing numbers of people in advanced old age, coupled with shrinking families to provide support to them, will demand new solutions to the financing and delivery of LTSS. The past suggests that families will continue as the backbone of support for older relatives or close friends, but the future suggests that family caregivers will themselves require more supportive services to meet the increased stress and burdens that are certain to occur.[19]

We live in a time when care has become more complex, as have family structures and people's everyday lives. If our nation expects family caregivers to continue providing this critical assistance, it must provide help and support to prevent caregiver burnout or the need to quit jobs, jeopardizing the health and economic security of caregivers themselves. One step is to provide instruction and guidance to family caregivers to help them perform complex medical/nursing and daily living tasks, such as assistance with bathing, dressing, and toileting. Another is to permit direct care workers to help with these tasks. In a high-performing LTSS system, caregivers' needs are assessed and addressed. Their strengths are valued, and supports are tailored to their individual values and preferences. In fact, the 2016 National Academies of Sciences, Engineering, and Medicine report on family caregiving calls for a transformation in policies and practices affecting the role of families in the support and care of older adults with health and functional needs.[20]

Exhibit 9 **State Ranking on Support for Family Caregivers Dimension**



Source: State Long-Term Services and Supports Scorecard, 2017.

Support for Working Family Caregivers

Caregiving, of course, can be hard by itself. Balancing caregiving duties, work, and other responsibilities can be a major challenge for all family caregivers. Today, most family caregivers (60 percent) work at a paying job.[21] Caregiving responsibilities often require family caregivers to make workplace accommodations that might include taking scheduled or unscheduled time off from work or, in some cases, leaving the workforce altogether, which could have serious negative economic impacts. The stresses on working caregivers are compounded when they lack the supports and protections that could help them manage their dual responsibilities. These include the ability to take family medical leave and paid sick days, have access to temporary financial assistance through state unemployment insurance programs, and be protected from discrimination on the basis of their caregiver status.

The *Scorecard* finds that states are making improvements in supporting working family caregivers, but more work needs to be done. The most progress has been made with paid sick days to employees. Since 2014, 4 states (California, Massachusetts, Oregon, and Vermont) passed statewide legislation and 2 states (Maryland and Pennsylvania) passed legislation at the local level for paid sick days. In total, 11 states currently have enacted either statewide or local legislation mandating paid sick days. Two additional states (Delaware and Minnesota) enacted laws that include family responsibility as a protected classification from discrimination, bringing the total number of states to 4. Twelve states exceeded the Family and Medical Leave Act requirement to provide up to 12 weeks of unpaid leave for certain employees. Twenty-five states provided temporary financial assistance to family caregivers through the state unemployment insurance program if there was "good cause" to stop working to care for an ill family member.

The top performers on this indicator were the District of Columbia, Connecticut, California, Oregon, and Rhode Island.

Person- and Family-Centered Care

The needs of family caregivers deserve greater attention and support. Family caregivers are on the front lines assisting individuals with a chronic, disabling, or serious health condition. They identify, arrange, and coordinate services and supports; provide emotional support; accompany their family member or friend to health provider visits; perform medical/nursing tasks; administer medications; assist with personal care (such as bathing and dressing); pay bills and deal with health insurance; and perform other vital activities to help individuals remain in their homes and communities for as long as possible. Family members also provide vital emotional support and other assistance to older relatives/close friends residing in nursing homes.

It is critical to recognize and assess the needs of family caregivers. It is important that family caregivers are directly asked about their own health and well-being, level of stress, feelings of being overwhelmed, needs for training in knowledge/skills for assisting the care recipients, and any desire for additional services and supports. The person- and family-centered measure includes whether states adopted spousal impoverishment provisions in Medicaid HCBS; the Caregiver Advise, Record, Enable (CARE) Act; and an assessment of family caregiver needs for some of their HCBS and caregiving programs—that is, asking questions of the family member about his or her own health and well-being, and any services or support he or she may need to be better prepared for the caregiving role.[22]

The *Scorecard* finds significant improvement in all three areas for this measure. Forty-two states improved since 2012–13 in at least one of these areas.

Most of the progress has been around the CARE Act and caregiver assessments. At the time of writing, 35 states and territories had passed the CARE Act.[23] Since 2013, 15 additional states are conducting assessment of family caregiver needs, bringing the total to 33 states.

Finally, seven states permit the spouse who lives in the community to keep the maximum Medicaid amount of income and assets per month that is allowable under federal guidelines.

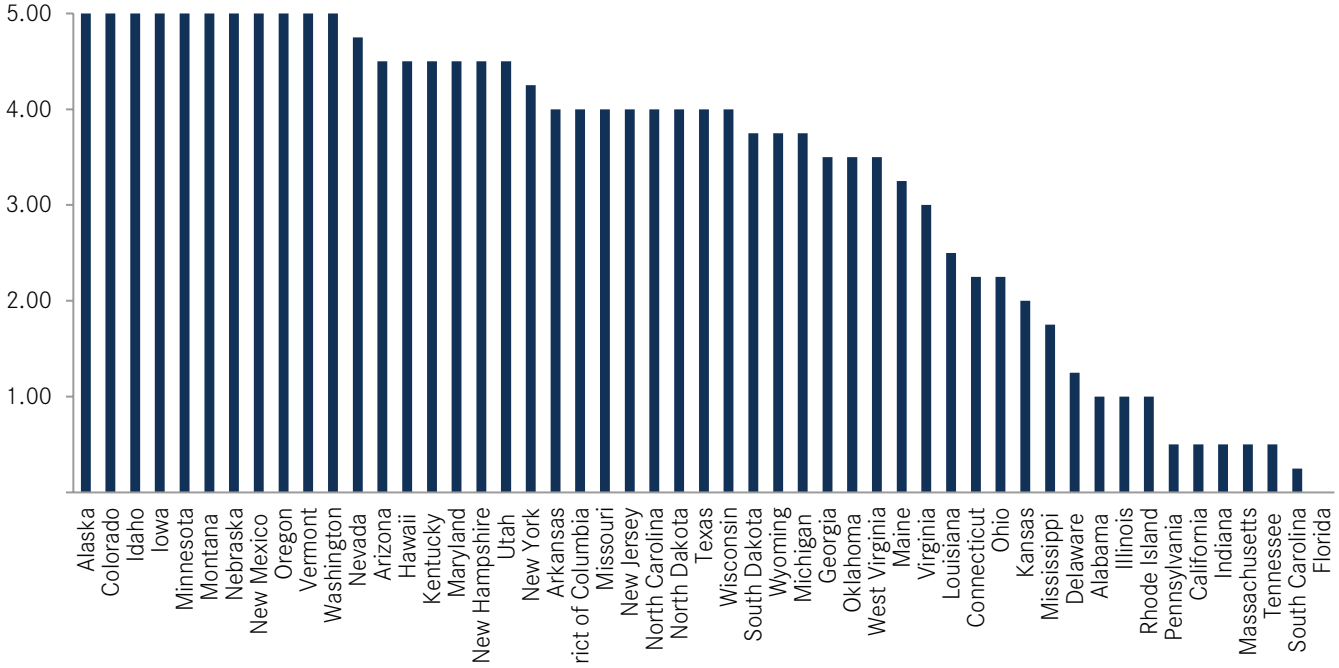
Overall, the top-performing states were Illinois, Wyoming, Hawaii, Mississippi, Georgia, and Louisiana.

Nurse Delegation and Scope of Practice

State Nurse Practice Acts generally determine the extent to which direct care workers can provide assistance with a broad range of health maintenance tasks—a practice known as "nurse delegation." Nurses are allowed to train a family member to perform these tasks, but in many states they cannot be delegated to a paid direct care worker assisting in home settings. Because many family caregivers are employed, they often hire a paid caregiver to help while they are at work. If the aide cannot perform these health maintenance tasks, the family caregiver may have to leave work during the day to administer a medication, perform a tube feeding, or even administer eye or ear drops. The caregiver's alternative would be to hire a nurse to perform these routine tasks, at significantly higher costs.

Exhibit 10 **State Policies on Delegation of 16 Health Maintenance Tasks and State Licensure Laws on Nurse Practitioner Scope of Practice**

Composite score up to a maximum of 5.0 points (0.25 points for each of 16 health maintenance tasks 0.5 points for reduced scope of practice , and 1.0 point for full scope of practice.).



Note: 2014 nurse delegation data repeated for South Carolina. No health maintenance tasks are allowed to be delegated in Florida, Indiana, Pennsylvania, and Rhode Island. Nurse practitioner scope of practice is restricted in California, Florida, Georgia, Massachusetts, Missouri, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, and Virginia.

Data: Nurse delegation data from AARP Public Policy Institute, Survey on Nurse Delegation in Home Settings, 2016; AARP interpretation of state board of nursing regulations; nurse practitioner scope of practice data from American Association of Nurse Practitioners, Nurse Practitioner State Practice Environment, accessed January 2017.

Source: State Long-Term Services and Supports Scorecard, 2017.

Twenty-four states improved on this indicator, and we now have 16 states (an increase from 9 in 2013) that permit registered nurses to delegate the full sample set of 16 health maintenance tasks. These 16 tasks are examples of what consumers with complex care needs may require. This is not an exhaustive list and should not be considered a "laundry list" of tasks. The *Scorecard* found that states are also adding 1 or more health maintenance tasks to the sample list of tasks that can be delegated to direct care workers. Thirty-two states and the District of Columbia now permit delegation of at least 12 or more of their health maintenance tasks to direct care workers.

Nurse practitioner scope of practice is a new component in the nurse delegation composite indicator. States are scored based on the regulatory authority that allows nurse practitioners (NPs) the ability to practice to the full, reduced, or restricted scope of their education and clinical training. Twenty states and the District of Columbia grant NPs full-practice authority, which is up from 17 in 2013. The *Scorecard* also found a positive relationship between nurse delegation and greater scope of practice. Eleven states (Alaska, Colorado, Idaho, Iowa, Minnesota, Montana, Nebraska, New Mexico, Oregon, Vermont, and Washington) delegate the full sample set of nursing tasks and permit full scope of practice.

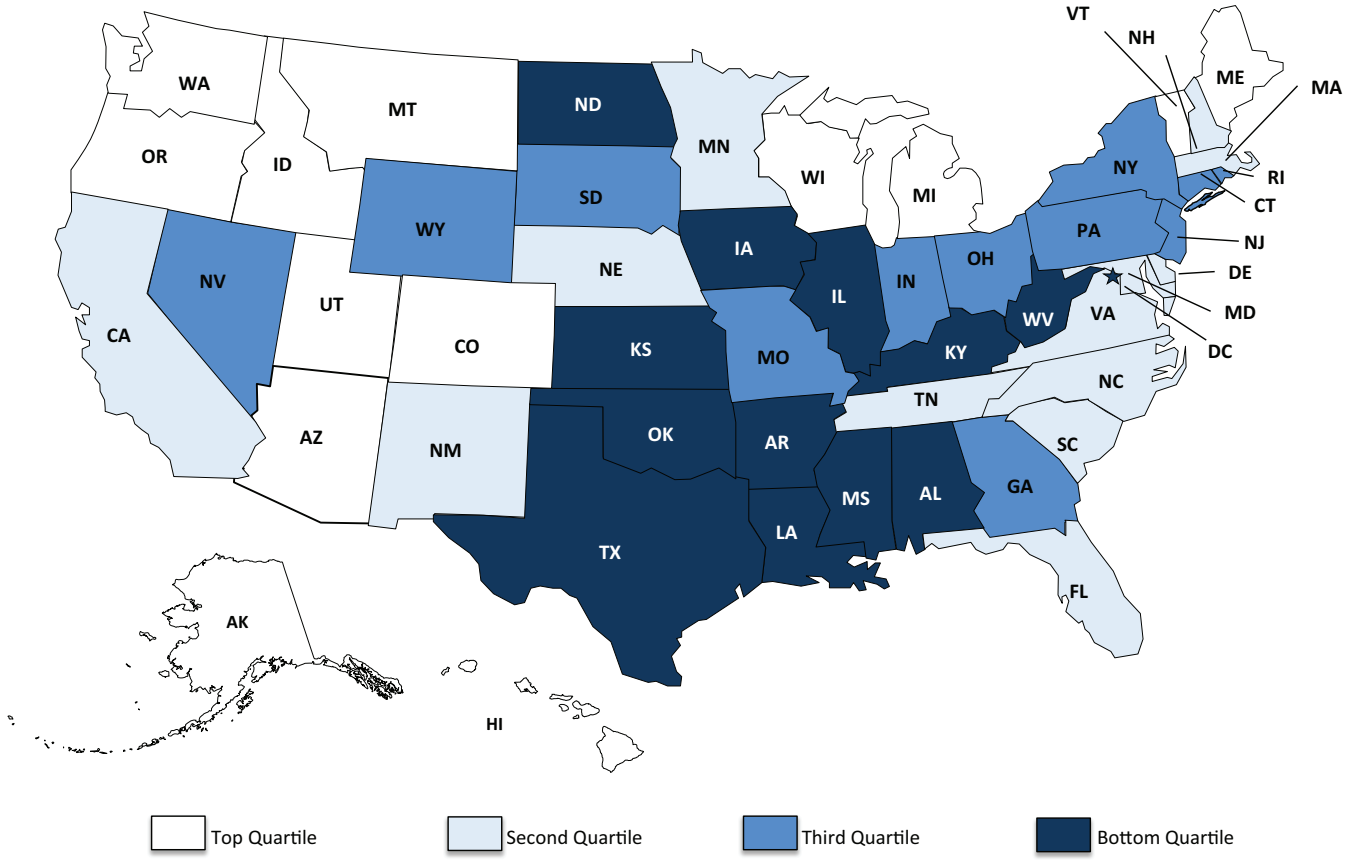
Transportation Policies

In a high-performing system, LTSS are coordinated with transportation, especially during periods of transition among acute, post-acute, and other settings. Transportation is the vital link that connects older adults to social activity, economic opportunity, and community services. The ability to age in one's home and community is compromised without it. Having access to transportation services ensures that older adults and individuals with disabilities are able to deal with life's day-to-day demands such as getting to medical appointments, shopping for food or other necessities, and being integrated with community resources and social activities. In addition to other tasks, family caregivers provide transportation for a range of activities that help members remain independent for as long as possible.[24] State policy related to human services– and volunteer-provided transportation helps individuals and family caregivers navigate their communities and get access to vital services.

Many states have established committees to coordinate service among myriad human services and public transportation providers with the aim of reducing fragmentation and improving service. In addition, many older adults and individuals with disabilities depend on volunteer driver programs to help them get to the grocery store, doctor's office, and other critical destinations. These programs not only help them remain in their homes and communities for as long as possible but also provide economic benefits to families and society by reducing the need for family caregivers to leave work early or make other adjustments to get their relatives where they need to be. Only six states provide protection from unreasonable or unfair increases in liability or insurance rates, eight states exempt volunteer drivers from taxi "livery" laws, and five states facilitate private investment in volunteer driver programs. Eighteen states have councils that coordinate specialized transportation planning and service delivery across all agencies that fund transportation. Twenty-five states established councils, but seven state councils were either repealed in recent years or are now defunct or inactive.

The top-performing states are Colorado, South Carolina, California, Massachusetts, and Washington.

Exhibit 11 **State Ranking on Effective Transitions Dimension**



Source: State Long-Term Services and Supports Scorecard, 2017.

DIMENSION 5 Effective Transitions

People who need LTSS often also have complex chronic health conditions and functional limitations. Yet fragmentation in the health and social service systems means most people must navigate two separate programs in order to receive basic health care and LTSS. These programmatic silos can lead to a service delivery system that is plagued with administrative inefficiencies, rising costs, and poor quality.

Improving care transitions when people move between one care setting or provider and another is critically important for achieving better population health and better care at a lower per capita cost. Services should be organized to avoid unnecessary transitions among care settings and promote effective transitions between levels and types of care when they are necessary. Smooth care transitions are at the core of person- and family-centered care. Better care transitions can prevent costly hospital admissions and readmissions, particularly for people who are at high risk and often have multiple chronic conditions.

Nursing Home Low Care Needs

States that have a relatively high proportion of nursing home residents who have low care needs may not be taking appropriate steps to transition these residents to more desirable alternatives. The *Scorecard* finds that the percentage of nursing home residents with low care needs dropped slightly (12.1 percent in 2012 to 11.5 percent in 2014) and more needs to be done nationally to pick up the pace of change. While there

was no significant change in performance for a majority of the states, four states (Illinois, Rhode Island, Tennessee, and Utah) improved by more than 20 percent since 2012. The top states were Maine, Hawaii, Utah, South Carolina, and Tennessee, which averaged 5 percent of nursing home residents with low care needs, compared with the bottom five states, in which 21 percent of residents had low care needs—or four times as many.

Home Health Hospitalization

Nationwide, hospitalizations among people receiving home health services declined by 6.6 percent since 2012. Most states improved on this measure but only 10 states improved by 10 percent or more since 2012. The top-performing states (Utah, Montana, Delaware, Idaho, Maine, and Washington) averaged 21.1 percent of patients with hospitalizations, compared with the bottom 5 states, which averaged 28.4 percent.

Nursing Home Hospitalization

The percentage of long-stay nursing home residents with a hospital admission declined by 7 percent, on average, from 2012 to 2014. However, roughly one in six long-stay nursing home residents were still hospitalized within a six-month period. The *Scorecard* finds that 20 states showed a reduction in hospitalization of 10 percent or more between 2012 and 2014. Delaware and Wyoming reduced nursing home hospitalizations by more than 20 percent during this period.

The top-performing states (Hawaii, Minnesota, Arizona, Colorado, and Rhode Island) averaged 7.5 percent of long-stay nursing home residents hospitalized within a six-month period, compared with the bottom five states, which averaged 24.8 percent—or three times as many.

Burdensome Transitions

End-of-life care and care for people with advanced and serious illnesses are part of the overall LTSS system. People at the end of life should not be subjected to excessive hospitalizations. They should retain choice and control over where they die. This indicator measures state performance in minimizing burdensome hospital transitions by looking at the transitions experienced by people who die in a nursing home.

The *Scorecard* finds significant change in performance for this measure. Nationally, the odds of nursing home residents having one or more potentially burdensome transitions at the end of life dropped by 16.6 percent between 2011 and 2013. Twenty-nine states improved in their performance by 10 percent or more. The biggest change in performance was Louisiana, which saw a 14 percent reduction in burdensome transitions.

The top-performing states were Alaska, Idaho, Vermont, Wyoming, and Hawaii.

Long Nursing Home Stays

Many people may enter a nursing home for a short period of time, often to receive post-acute or rehabilitative care. However, individuals who enter a nursing home and remain there for 100 or more days are far less likely to return to the community. This indicator was first included in the second *Scorecard* to analyze state variation in the proportion of nursing home residents who appear to be unlikely to leave that setting.

The *Scorecard* finds significant change in performance for this measure. Thirty-five states improved on this measure between 2009 and 2012, reducing the odds of a nursing home stay lasting 100 days or longer by 10 percent or more. There was great variation in performance on this indicator. In the top five states, 11.2 percent of nursing home residents remained for 100 or more days, less than half the average in the bottom five states (26.6 percent). Similar to the past *Scorecard*, people entering a nursing home in Louisiana were

nearly four times as likely (35 percent) to stay for 100 or more days than were residents in the top state (Arizona, at 8.9 percent). The top states on this indicator were Arizona, Oregon, Utah, Idaho, and Maine.

Transitions Back to Community

This indicator represents the percentage of people with 90-day or longer nursing home stays who transitioned back into the community. About 1.5 million Americans currently live in a nursing facility. Many of these individuals do not want to reside in these institutions permanently and would prefer to return to their homes and communities. In fact, many nursing home residents can return to the community. But in order for that to happen, the right policies and practices need to be in place. This population includes both long-stay residents as well as extended rehab patients, who are at high risk of not being able to return home after such a long time in the nursing facility.

A high-performing LTSS system can prevent excessive use of institutional settings and facilitate in helping nursing home residents who would prefer to reside in the community to make this transition. The *Scorecard* finds that there was a significant decline in performance for this measure in 21 states between 2009 and 2012.

The top states were Utah, Oregon, Washington, Arizona, and Idaho. On average, these states transitioned 12.3 percent of long-stay nursing home residents to community settings. By contrast, the rate of transitions was just 4.8 percent in the bottom five states.

1 Melissa Favreault and Judith Dey, *Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief* (Washington, DC: US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2015), https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief.

2 Jennifer Benz et al., The Associated Press-National Opinion Research Center (NORC), *Long-Term Care in America: Expectations and Preferences for Care and Caregiving* (Boston, MA: The Associated Press-NORC, 2016), http://www.longtermcarepoll.org/PDFs/LTC%202016/AP-NORC%20Long%20Term%20Care_2016.pdf.

3 Jean Accius, *The $92,378 Question: How High Can the Cost of Long-Term Services and Supports Go?* (Washington, DC: AARP Public Policy Institute, 2016), http://blog.aarp.org/2016/05/27/the-92378-question-how-high-can-long-term-service-supports-go/.

4 Richard Frank, MarcCohen, and Neale Mahoney, *Making Progress: Expanding Risk Protection for Long-Term Services and Supports through Private Long-Term Care Insurance* (Long Beach, CA: The SCAN Foundation, 2013), http://www.thescanfoundation.org/sites/default/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf.

5 Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2014* (Bethesda, MD: Truven Health Analytics, April 2016), https://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-2014.pdf.

6 Wendy Fox-Grage, *Medicaid: A Last Resort for People Needing Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, 2017), http://www.aarp.org/ppi/info-2017/medicaid-a-last-resort-for-people-needing-long-term-services-and-supports.html.

7 Joshua Wiener et al., *Medicaid Spend Down: New Estimates and Implications for Long-Term Services and Supports Financing Reform* (Washington, DC: RTI International, March 21, 2013), http://www.rti.org/sites/default/files/resources/tsf_ltc-financing_medicaid-spend-down-implications_wiener-tumlinson_3-20-13_0.pdf.

8 Elizabeth Cornachione, MaryBeth Musumeci, and Molly O'Malley Watts., *Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015* (Washington, DC: Kaiser Family Foundation, 2016), http://kff.org/medicaid/report/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015/.

9 For information on the Americans with Disabilities Act, see http://www.ada.gov/pubs/adastatute08.htm#12101.

10 For information about the Supreme Court's Olmstead decision, see http://www.ada.gov/olmstead/olmstead_about.htm.

11 Steve Eiken et al., *Medicaid Expenditures*.

12 Nicholas Farber et al., *Aging in Place: A State Survey of Livability Policies and Practices* (Washington, DC: AARP Public Policy Institute, 2011), http://www.aarp.org/home-garden/livable-communities/info-11-2011/Aging-In-Place.html.

13 Bureau of Labor Statistics, *Home Health Aides and Personal Care Aides* (Washington, DC: US Department of Labor, Bureau of Labor Statistics, 2015), http://www.bls.gov/ooh/healthcare/home-health-aides.htm and http://www.bls.gov/ooh/personal-care-and-service/personal-care-aides.htm.

14 Christine Caffrey et al., *Characteristics of Residents Living in Residential Care Communities, by Community Bed Size: United States, 2012* (Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, 2014), https://www.cdc.gov/nchs/data/databriefs/db171.pdf.

15 Centers for Medicare & Medicaid Services, *National Partnership to Improve Dementia Care in Nursing Homes* (Baltimore, MD: Centers for Medicare & Medicaid Services, 2016), https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html.

16 National Alliance for Caregiving (NAC) and AARP Public Policy Institute, *Caregiving in the U.S. 2015* (Bethesda, MD: NAC; Washington, DC: AARP, June 2015), http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf.

17 Chuck Rainville, Laura Skufca, and Laura Mehegan, *Family Caregiving and Out-of-Pocket Cost: 2016 Report* (Washington, DC: AARP Research, November 2016), http://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-cost-survey-res-ltc.pdf.

18 Susan Reinhard et al., "Valuing the Invaluable: Undeniable Progress, but Big Gaps Remain," (Washington, DC: AARP Public Policy Institute, July 2015), http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-undeniable-progress.pdf.

19 Donald Redfoot, Lynn Feinberg, and Ari Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2013), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf.

20 National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016), http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx.

21 Lynn Feinberg, *The Dual Pressures of Family Caregiving and Employment* (Washington, DC: AARP Public Policy Institute, May 2016), http://www.aarp.org/ppi/info-2016/the-dual-pressures-of-family-caregiving-and-employment.html.

22 Kathleen Kelly et al., *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home-and Community-Based Service Waivers* (Washington, DC: AARP Public Policy Institute, December 2013), http://www.aarp.org/home-family/caregiving/info-11-2013/including-family-caregiver-assessment-in-medicaid-hcbs-waive-programs-AARP-ppi-ltc.html.

23 In addition to the 32 states and Washington, DC (see exhibit A17), that have passed the CARE Act as of February 28, 2017, it has also been enacted in Puerto Rico and the Virgin Islands.

24 National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*.