Raising Expectations: EXECUTIVE SUMMARY

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

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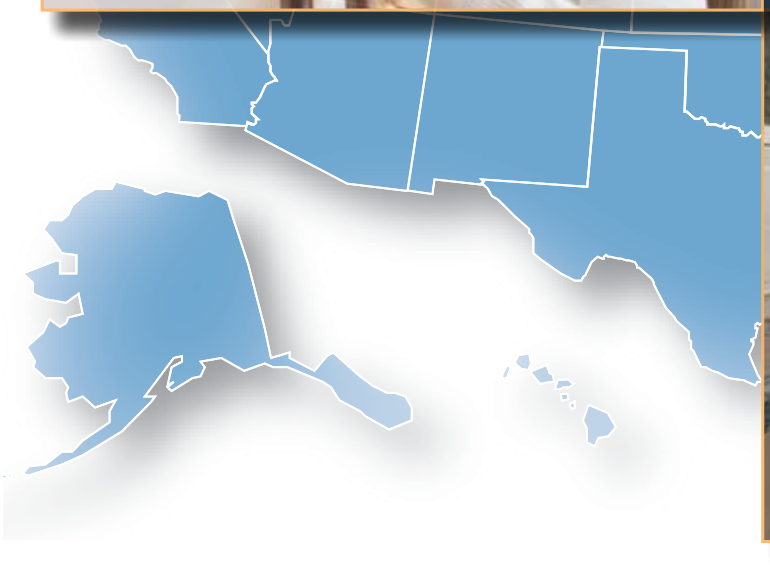

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EXECUTIVE SUMMARY

This *State Long-Term Services and Supports Scorecard* is the first of its kind: a multidimensional approach to measure state-level performance of long-term services and supports (LTSS) systems that provide assistance to older people and adults with disabilities. Analysis of the "starter set" of indicators included in this report finds that performance varies tremendously across the states with LTSS systems in leading states having markedly different characteristics than those in lagging states. Yet even the top-performing states have some opportunities for improvement. In general, the states at the very highest levels of performance have enacted public policies designed to:

- improve access to needed services and choice in their delivery by transforming their Medicaid programs to cover more of the population in need and offer the alternatives to nursing homes that most people prefer;
- facilitate access to information and services by developing effective "single point of entry" systems so that people who need services can find help easily; and
- address the needs of family caregivers by offering legal protections as well as the support and services that can help prevent burnout.

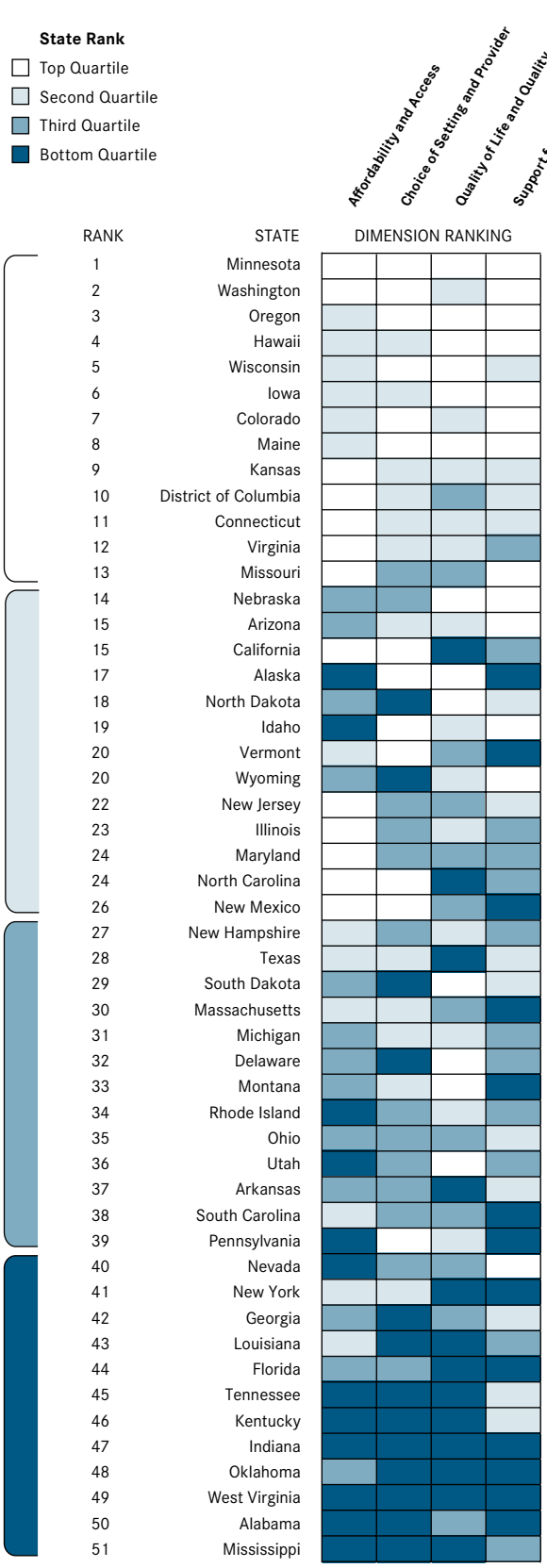
Public policy plays an important role in LTSS systems by establishing who is eligible for assistance, what services are provided, how quality is monitored, and the ways in which family caregivers are supported. Its role is especially critical because the cost of services exceeds the ability to pay for most middle-income families. Even in the most "affordable" states, the cost of nursing home care exceeds median income for the older population. Thus, states need to take action to ensure that alternatives to nursing homes are available, an effective safety net helps people who are not able to pay for care, and family caregivers, who provide the largest share of help, receive the support they need. States also have a leading role to play in ensuring that the LTSS delivered in all settings are of high quality. But public policy is not the only factor affecting state LTSS performance: actions of providers and other private sector forces affect state performance either independently, or in conjunction with the public sector.

The *Scorecard* is designed to help states improve the performance of their LTSS systems so that older people and adults with disabilities in *all* states can exercise choice and control over their lives, thereby maximizing their independence and well-being. Our intention is that this *Scorecard* will begin a dialogue among key stakeholders so that lagging states can learn from top performers and all states can target improvements where they are most needed. Furthermore, we hope that the *Scorecard* will underscore the need for states to develop better measures of performance over a much broader range of services and collect data in order to more comprehensively assess the adequacy of their LTSS systems.

The *Scorecard* examines state performance across four key dimensions of LTSS system performance, developed in consultation with a team of expert advisors: (1) affordability and access; (2) choice of setting and provider; (3) quality of life and quality of care; and (4) support for family caregivers. Exhibit 1

Exhibit 1

State Scorecard Summary of LTSS System Performance Across Dimensions



Source: State Long-Term Services and Supports Scorecard, 2011.

illustrates each state's overall ranking as well as its quartile of performance in each of the four dimensions. These four dimensions align with the characteristics of a high-performing LTSS system as recently articulated by the authors in *Health Affairs*.[1] We identified a fifth dimension, coordination of LTSS with medical services, which is also critically important but were unable to create indicators to measure that dimension with currently available data. Indeed as we discuss below, one of the more noteworthy "findings" of our work on the *Scorecard* is how much we are not able to compare because information on quality, experiences, coordination, costs, or outcomes is simply not available. Information is critical to guide and inform improvement. We hope that this *LTSS Scorecard* will spark future federal and state action.

Within the four dimensions, the *Scorecard* includes 25 indicators. Exhibit 2 lists the indicators that compose each dimension and shows the range of performance across the states for each indicator. While some of the indicators rely on data that have been reported elsewhere, many represent new measures. Several indicators are constructed from a range of data in a related area, facilitating the ability to rank states in areas of performance that are difficult to assess. As such, the findings differ from analyses that examine a single aspect of states' LTSS systems, such as the "balance" of public services provided in home- and community-based settings compared to nursing homes. This multidimensional analysis involves a richer exploration of data to assess performance, thereby capturing state performance across a complex range of system characteristics.

Major Findings

The states that ranked at the highest level across all four dimensions of LTSS system performance, in order, are Minnesota, Washington, Oregon, Hawaii, Wisconsin, Iowa, Colorado, and Maine.

Leading states often do well in multiple dimensions—but all have opportunities to improve

The leading states generally score in the top half of states across all dimensions. Public policy decisions made in these states interact with private sector actions, resulting in systems that display higher performance. But no state scored in the top quartile across all 25 indicators, demonstrating that every state LTSS system has at least one indicator on which it trails the standards set by top states. Even within dimensions, there is only one instance in which a state ranked in the top quartile across every indicator in the dimension.

Poverty and high rates of disability present challenges

Lagging states scored in the bottom half of states on most dimensions. Among the states in the bottom quartile overall (Mississippi, Alabama, West Virginia, Oklahoma, Indiana, Kentucky, Tennessee, Florida, Louisiana, Georgia, New York, and Nevada), many are in the South, and have among the lowest median incomes and highest rates of both poverty and disability in the nation. This pattern largely holds across all dimensions. Among southern states, only Virginia and North Carolina rank in the top half overall. See Exhibit 3 for the geographic pattern of overall LTSS system performance.

Exhibit 2

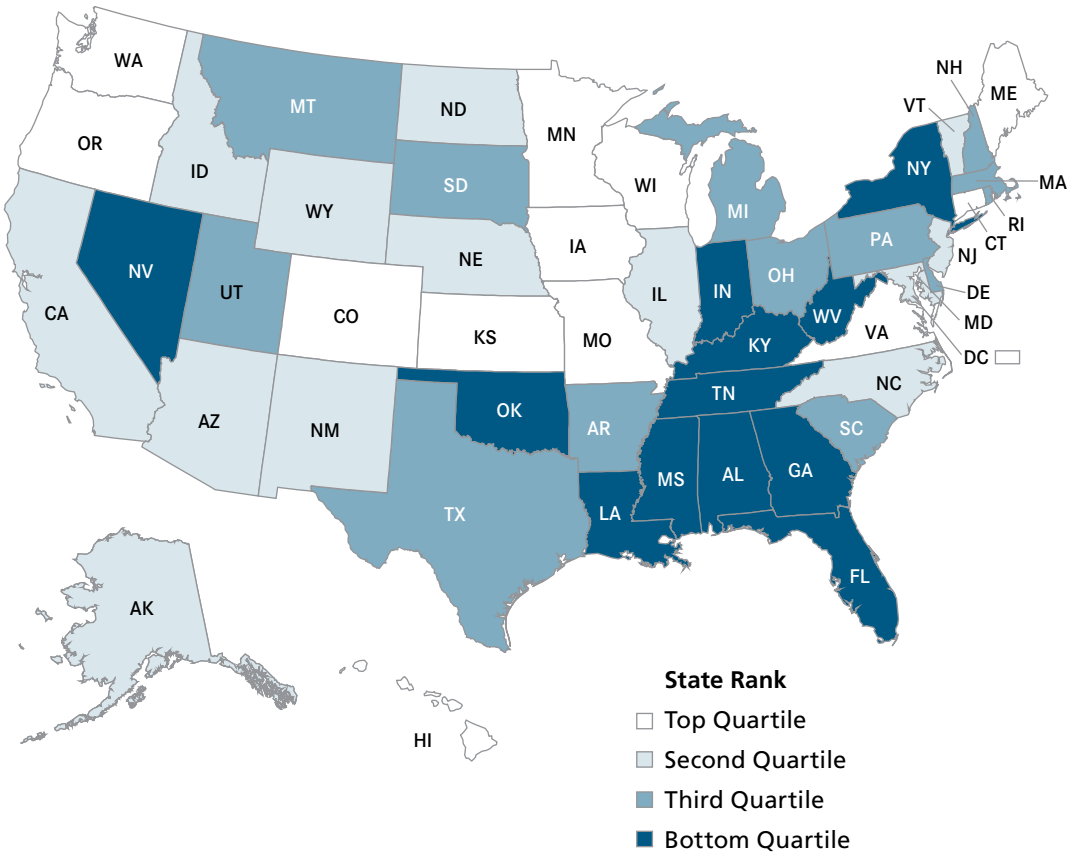
List of 25 Indicators in State Scorecard on Long-Term Services and Supports System Performance

	Dimension and Indicator	Year	All States Median	Range of State Performance (bottom–top)	Top State
	Affordability and Access				
1	Median annual nursing home private pay cost as a percentage of median household income age 65+	2010	224%	444%–166%	DC, UT
2	Median annual home care private pay cost as a percentage of median household income age 65+	2010	89%	125%–55%	DC
3	Private long-term care insurance policies in effect per 1,000 population age 40+	2009	41	28–300	ME
4	Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance	2008–09	49.9%	38.7%–63.6%	ME
5	Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community	2007	36.1	15.9–74.6	MN
6	ADRC/Single Entry Point functionality (composite indicator, scale 0–12)[a]	2010	7.7	1.0–11.0	MN
	Choice of Setting and Provider				
7	Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities	2009	29.7%	10.5%–63.9%	NM
8	Percent of new Medicaid LTSS users first receiving services in the community	2007	49.9%	21.8%–83.3%	MN
9	Number of people consumer-directing services per 1,000 adults age 18+ with disabilities	2010	8.0	0.02–142.7	CA
10	Tools and programs to facilitate consumer choice (composite indicator, scale 0–4)[a]	2010	2.75	0.50–4.00	IL, PA
11	Home health and personal care aides per 1,000 population age 65+	2009	34	13–108	MN
12	Assisted living and residential care units per 1,000 population age 65+	2010	29	7–80	MN
13	Percent of nursing home residents with low care needs	2007	11.9%	25.1%–1.3%	ME
	Quality of Life and Quality of Care				
14	Percent of adults age 18+ with disabilities in the community usually or always getting needed support	2009	68.5%	61.3%–78.2%	AK
15	Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life	2009	85.0%	80.2%–92.4%	SD
16	Rate of employment for adults with ADL disability ages 18–64 relative to rate of employment for adults without ADL disability ages 18–64	2008–09	24.2%	17.6%–56.6%	ND
17	Percent of high-risk nursing home residents with pressure sores	2008	11.1%	17.2%–6.6%	MN
18	Percent of long-stay nursing home residents who were physically restrained	2008	3.3%	7.9%–0.9%	KS
19	Nursing home staffing turnover: ratio of employee terminations to the average number of active employees	2008	46.9%	76.9%–18.7%	CT
20	Percent of long-stay nursing home residents with a hospital admission	2008	18.9%	32.5%–8.3%	MN
21	Percent of home health episodes of care in which interventions to prevent pressure sores were included in the plan of care for at-risk patients	2010	90%	77%–97%	HI
22	Percent of home health patients with a hospital admission	2008	29.0%	40.2%–21.8%	UT
	Support for Family Caregivers				
23	Percent of caregivers usually or always getting needed support	2009	78.2%	71.0%–84.0%	OR
24	Legal and system supports for caregivers (composite indicator, scale 0–12)[a]	2008–10	3.17	0.50–6.43	OR
25	Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks)	2011	7.5	0–16	CO, IA, MO, NE, OR

[a] Composite indicators combine information on multiple policies and programs; see Appendix B2 for detail.
Notes: See Appendix B2 for data year, source and definition of each indicator. ADL = Activities of Daily Living; ADRC = Aging and Disability Resource Center; HCBS = Home and Community-Based Services.
Source: State Long-Term Services and Supports Scorecard, 2011.

Exhibit 3

State Ranking on Overall LTSS System Performance



Source: State Long-Term Services and Supports Scorecard, 2011.

Many states have opportunities to improve

States that ranked in the second quartile (Nebraska, Arizona, California, Alaska, North Dakota, Idaho, Vermont, Wyoming, New Jersey, Illinois, Maryland, North Carolina, and New Mexico) all scored in the top quartile on at least one dimension. With the exception of Alaska (an unusual state because of its unique geography), no state in the second quartile scored in the bottom quartile on more than one dimension. These states all have areas of success, and can also improve to a higher level of performance by targeting their efforts in areas where they lag, and where other states have shown the path to higher performance.

Wide variation exists within dimensions and indicators

Wide variation exists within all dimensions, with low-performing states being markedly different from those that score high. In many cases, low-performing states have not adopted public policies that increase access to services or that enable consumers to exercise choice and control. Substantial variations also are found in the quality of service delivery and in measures of support for family caregivers.

State Medicaid policies dramatically affect consumer choice and affordability

Medicaid is the primary source of public funding for LTSS. It plays a leading role in determining the extent to which low-income older people, people with disabilities, and their families receive support through home- and community-based services (HCBS). It also affects the extent to which people with LTSS needs who want to avoid entering nursing homes are able to do so, by facilitating or hindering the choice of alternative settings, such as assisted living and supportive services in the home.

This is an area over which states have direct control, and some states have led the way to improve access and choice in Medicaid. These policy decisions are reflected in the proportion of Medicaid LTSS spending that states devote to HCBS and their success in supporting new program participants' choice of HCBS, as opposed to nursing homes.

Support for family caregivers goes hand in hand with other dimensions of high performance

The *Scorecard* reports on assistance for family caregivers by assessing whether they are receiving needed support and by examining state laws that can aid caregivers. But the most meaningful support for caregivers is a better overall system that makes LTSS more affordable, accessible, and higher quality, with more choices. Thus, high state scores on access, affordability, and choice may reflect states' recognition that caregivers are essential and policies that aid them include building a strong overall system. Very few states that score highly on support for family caregivers score poorly on other dimensions, and few states that score poorly on the caregiving dimension are ranked in the top quartile overall.

States can improve their performance by exceeding the federal requirements for the Family and Medical Leave Act and mandating paid sick leave to help working family caregivers, as well as preventing impoverishment of the spouses of Medicaid beneficiaries who receive HCBS. States also can implement programs to assess the needs of family caregivers and provide respite care and other services to help support their ongoing efforts.

Better data are needed to assess state LTSS system performance

At this time, limited data make it difficult to fully measure key concerns of the public and of policymakers, including the availability of housing with services, accessible transportation, funding of respite care for family caregivers, and community integration of people with disabilities. Improving consistent, state-level data collection is essential to evaluating state LTSS system performance more comprehensively. Most critically, an important characteristic of a high-performing LTSS system identified by the *Scorecard* team—how well states ensure effective transitions between hospitals, nursing homes, and home care settings and how well LTSS are coordinated with primary care, acute care, and social services—cannot be adequately measured with currently available data.

It is our hope that improved data collection will enable future *Scorecards* to expand upon the strong set of foundational indicators in this initial *State LTSS Scorecard* and provide a more complete and comprehensive analysis of LTSS system performance in the future.

The cost of LTSS is unaffordable for middle-income families

The cost of services, especially in nursing homes, is not "affordable" in any state. The national average cost of nursing home care is 241 percent of the average annual household income of older adults. Even in the five most affordable states, the cost averages 171 percent of income, and in the least affordable states it averages an astonishing 374 percent. When the cost of care exceeds median income to such a great degree, many people with LTSS needs will exhaust their life savings and eventually turn to the public safety net for assistance.

Though less extreme, the cost of home health care services also is unaffordable for the typical user, averaging 88 percent of household income for older adults nationally. People who receive home care services must add these costs to all their other living expenses. If they cannot afford the home care services they need, they may place added burdens on family caregivers who most likely already are providing services.

Impact of Improved Performance

States can improve their LTSS system performance in numerous ways. Improvement to levels achieved by top-performing states would make a difference to the 11 million older people and adults with physical disabilities who have LTSS needs,[2] and their family caregivers, in terms of access, choice, and quality of care. For example:

- If all states' public LTSS safety nets were as effective as that of Maine in covering low-income people with disabilities, an additional 667,171 individuals would receive coverage through Medicaid or other public programs. Such coverage would link people with disabilities and limited incomes to health care as well as long-term services and supports.
- States that effectively inform people with LTSS needs about home and community care options and offer an array of service choices can address the preferences of consumers in a cost-effective manner. If all states rose to Minnesota's level of performance on this measure, 201,531 people could avoid costly and unnecessary nursing home use.
- Many nursing home residents with low care needs can be, and would prefer to be, served in the community. If all states achieved the rate found in Maine, 163,441 nursing home residents with low care needs would instead be able to receive LTSS in the community.
- Excessive transitions between care settings such as nursing homes and hospitals reflect poor coordination of services and are correlated with poor quality of care. If all states matched the performance of Minnesota, 120,602 hospitalizations could be avoided, saving an estimated $1.3 billion in health care costs.

Key Findings on Select Indicators and Public Policy Actions to Improve Performance

The *Scorecard* is a tool to help states improve their LTSS systems. The key findings that follow illustrate areas in which there is a large range in state performance and examples of how public policy action can lead to improvement.

Medicaid safety net

The *Scorecard* finds great variation in the percentage of the low- and moderate-income population with a disability in activities of daily living (ADLs) that is covered by the Medicaid LTSS safety net. In a typical month, the top five states provide Medicaid LTSS to 63 percent of this population. By contrast, in the bottom five states, coverage averages just 20 percent—less than a third of the rate in the top states. The national average is 37 percent.

Policy action: States have substantial control over establishing financial eligibility standards for Medicaid coverage. States also have great flexibility to determine the level of disability needed to qualify for services.

LTSS "balancing"

The five highest performing states on the proportion of Medicaid and state general revenue LTSS spending for older people and adults with physical disabilities going toward HCBS spend, on average, 60 percent of their dollars on HCBS. The average proportion of spending across the United States is 37 percent, and the five lowest performing states devote just 13 percent of Medicaid LTSS spending (for older people and adults with physical disabilities) to HCBS. Relatively few states "balance" spending, that is, spend more than half of their LTSS dollars for HCBS. *The extent of such balancing in the top states is nearly five times as high as in the bottom states.*

Policy action: This is an area over which state governments have tremendous control and, through their public policies, can make considerable strides in ensuring that people who need LTSS can choose noninstitutional options for care. States that have improved the balance of services away from institutions and toward HCBS have taken advantage of Medicaid "optional" services such as HCBS "waivers" and the Personal Care Services option. States also can pursue new opportunities offered by the *Patient Protection and Affordable Care Act* to improve the balance of their LTSS systems.

Maximizing consumer choice of LTSS options

The *Scorecard* finds a threefold difference between the five top- and bottom-performing states in the percentage of new Medicaid beneficiaries who receive HCBS before receiving any nursing home services. This indicator measures the LTSS system's ability to serve people in the community rather than a nursing home when they need support. In the top five states, on average, 77 percent of new Medicaid LTSS beneficiaries receive HCBS. By contrast, in the bottom five states, only 26 percent of new LTSS beneficiaries receive HCBS. The average across all states is 57 percent. Failing to serve new beneficiaries in HCBS settings can have negative impacts for an extended duration: those who enter a nursing home have a more difficult time returning to the community, even if they can and want to live in the community.

Policy action: State policies such as "options counseling" and nursing home diversion programs can help to direct new LTSS users

toward HCBS rather than nursing homes. States also can implement "presumptive eligibility" procedures to quickly establish that a person will be able to qualify for public support for HCBS, thereby preventing unnecessary nursing home admissions.

Consumer direction

The *Scorecard* finds wide variation in the extent to which state systems allow program participants to direct their own services. Variously referred to as consumer direction, participant direction, or self-direction, this model allows the individual to hire and fire a worker he or she chooses, set the hours for service delivery, and, in some cases, determine the wages paid.[3] Over the past several decades, self-direction has proven to be increasingly popular with many participants. The *Scorecard* finds that California was the highest ranking state, reporting 143 people receiving self-directed services per 1,000 adults with disabilities, or about 1 in 7. The average in the next four top-performing states was 51 people per 1,000 adults with disabilities. The national average was 22 people per 1,000 adults with disabilities. In each of the six lowest performing states, fewer than 1 out of every 1,000 adults with disabilities received self-directed services.

Policy action: States have great flexibility to give people who use LTSS the option to direct their own services in publicly funded programs. These programs often allow participants to have greater flexibility as to when services are delivered and who provides them. Such programs also can expand the available workforce, as many participants choose to hire family members who would not otherwise be working in this field.

Nursing home residents with low care needs

The *Scorecard* finds a tremendous range in the percentage of nursing home residents with low care needs. Because the national trend is that people with low care needs receive services in the community, states with a relatively high proportion of nursing home residents with low care needs may be offering an inadequate array of alternatives to nursing homes. In the five top-performing states, only 5 percent of long-stay nursing home residents had low care needs. By contrast, in the bottom five states, the proportion of nursing home residents with low care needs averaged 22 percent; more than four times the rate in the highest performing states.

Policy action: Taking advantage of federal grants such as Money Follows the Person can help states to move nursing home residents who want to return to the community into their own homes or apartments.

Pressure sores among nursing home residents

A key indicator of LTSS quality is the percentage of high-risk nursing home residents who develop pressure sores, a condition that is preventable with good-quality care. The *Scorecard* finds that the bottom five states have more than twice the level of long-stay nursing home residents with pressure sores, compared with the top five states: 16 percent compared with 7 percent.

Policy action: States have the responsibility to establish and enforce high standards for providers and effectively monitor the quality of care nursing homes provide. Every state is funded to operate a nursing home ombudsman program, but each state can determine how frequently the ombudsmen visit each facility, how they respond to complaints, and the

methods they use to monitor quality. State nursing home inspectors have a major role in enforcing federal directives to reduce pressure sores, and states can use quality bonuses to reward providers who demonstrate significant progress.

Preventing hospitalizations

Another indicator of LTSS quality, both in nursing homes and among home health patients, is the rate of hospitalizations. People who are receiving appropriate primary care and whose medical care is well coordinated with other services and supports should have fewer hospitalizations. States that do a better job of monitoring the quality of nursing home and home health care will reduce unnecessary hospital stays and, thus, achieve lower costs. The *Scorecard* finds that the bottom-performing states had, on average, three times the rate of hospitalization of long-stay nursing home residents compared with the top states: 29 percent compared with 10 percent.

Better quality of care can be cost-effective as well. For example, there is a strong correlation between occurrence of pressure sores and hospital admissions among long-stay nursing home residents (see Exhibit 15, p. 48). This finding is important for two reasons. Pressure sores are preventable with high quality of care and can result in serious, life-threatening infections in people who develop them. In addition, transitions between settings (e.g., nursing home to hospital), especially those that are caused by poor quality care, are both costly and often traumatic for LTSS users and their family caregivers. Though the variation is less dramatic, hospitalization rates among home health patients in the bottom five states averaged 37 percent, compared with 23 percent among the top five states.

Policy action: Some states are beginning to develop more coordinated service delivery systems that integrate primary, acute, chronic, and long-term services. Integrated approaches such as the Program of All-Inclusive Care for the Elderly (PACE) have a proven record of improving outcomes and reducing the use of institutions.

Nurse delegation

State Nurse Practice Acts usually determine the extent to which direct care workers can provide assistance with a broad range of health maintenance tasks.[4] For this *Scorecard*, we asked the National Council of State Boards of Nursing about state practices in delegating 16 specific tasks, including administration of various types of medications, ventilator care, and tube feedings. The five top-performing states allowed all 16 tasks to be delegated, whereas the bottom six states allowed none to be delegated. The median number of tasks that states allowed nurses to delegate was 7.5. Lower ranked states can learn from the top performers that delegation of these tasks to direct care workers is possible and supports consumers' choice to live in homelike settings.

Policy action: State policy directly determines what health-related tasks can be delegated. Unlike some policy changes that may cost states money and are therefore more challenging to implement, changing nurse practice laws will, if anything, save money in public programs by broadening the type of workers who can safely perform these tasks.

Conclusion

The *Scorecard* finds wide variation across all dimensions of state LTSS system performance. Part of this variation is attributable to the fact that the United States does not have a single unified approach to the provision of LTSS. The primary public program that funds LTSS is Medicaid: a federal-state partnership that gives states substantial flexibility to determine who is eligible for LTSS, how LTSS are accessed, what services will be provided, what the payment rates will be, and where services will be delivered. This flexibility provides opportunities to learn from creative approaches to delivering services yet results in disparities in the support available to frail older people and low-income people with disabilities. But there is also a need to learn from successful states so that the health and independence of people who need LTSS are not at risk because of their state of residence.

The *Affordable Care Act* offers states promising new incentives for improving their LTSS systems, and the lowest performing states have the most to gain by taking advantage of these new provisions. Reforms offer the opportunity to raise the bar for all states, particularly states that are lagging behind, to achieve the vision stated in legal and public policy goals. The Supreme Court in the 1999 *Olmstead* decision affirmed the right of people with disabilities to live in the least restrictive environment appropriate to their needs.[5] States that provide limited HCBS options through their Medicaid programs, do not provide sufficient information about or facilitate access to HCBS options, do not offer enhanced support to family caregivers, or do not effectively use home care workers to perform health maintenance tasks can learn from leading states that doing so can be cost-effective as well as responsive to the needs and preferences of older adults and people with disabilities.

Geography should not determine whether people who need LTSS have a range of choices for affordable, high-quality services. All Americans should share a unified vision that supports the ability of older people to have choices, and to be able to age in their own homes with dignity and the support they need to maximize their independence. The lives of people with disabilities should be integrated into the community, where they can maintain social connections, engage productively through employment or other meaningful activities, and contribute to the rich diversity of American life.

Building an improved system is possible and must begin now: the successes achieved by leading states have already shown the way. It is time to raise expectations for LTSS performance. We must move to become a nation in which older people and those with disabilities are given meaningful choices, have access to affordable, coordinated services, a high quality of life and care, and support for their family caregivers regardless of the state they live in.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