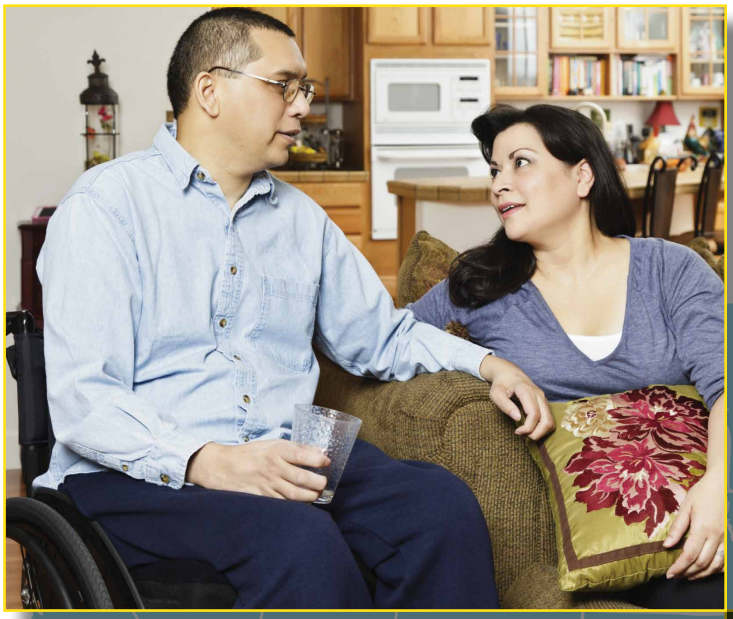
EXECUTIVE SUMMARY

RAISING EXPECTATIONS 2014

SECOND EDITION

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

Susan C. Reinhard, Enid Kassner, Ari Houser, Kathleen Ujvari, Robert Mollica, and Leslie Hendrickson



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We seek opportunities for change that are bold, catalytic, and transformational to better connect health care and supportive services. These innovations put people first by helping them stay in their homes and communities whenever possible in order to advance aging with dignity, choice, and independence.

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ABSTRACT

This *State Long-Term Services and Supports (LTSS) Scorecard* is a multidimensional approach to measure state-level performance of LTSS systems that assist older people, adults with disabilities, and their family caregivers. This second edition of the *State LTSS Scorecard* measures LTSS system performance across five key dimensions: (1) affordability and access, (2) choice of setting and provider, (3) quality of life and quality of care, (4) support for family caregivers, and (5) effective transitions.

Performance varies tremendously across the states, with LTSS systems in leading states having markedly different characteristics than those in lagging states. LTSS performance is gradually improving, both nationally and in most states. Progress is notable in many areas where public policy has a direct impact, including performance of the Medicaid safety net and legal and system supports for family caregivers. But the pace of improvement must accelerate as the Baby Boom Generation moves toward advanced ages.

Preface

The AARP Foundation, The Commonwealth Fund, and The SCAN Foundation are pleased to sponsor this second edition of the *State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers.* We hope it will build on the success of the first *Scorecard* by offering policymakers, stakeholders, and advocates a way to analyze state long-term services and supports (LTSS) systems and target areas for improvement.

Long-term services and supports help older people and adults with disabilities perform activities of daily living that would be difficult or impossible for them to perform on their own. Services and supports are delivered in a variety of settings, but nearly everyone prefers to remain at home. Family caregivers often provide the support to help their loved ones remain at home and the oversight to ensure that the care they receive in nursing homes, assisted living, or hospitals is appropriate and addressing their needs. But family caregivers also need services and supports to avoid burnout.

Most Americans will eventually rely on the LTSS system, either as consumers or as caregivers providing support to family and friends. An aging population, changing demographics, the rising cost of LTSS, and tight federal and state budgets are driving a growing national concern about LTSS for both consumers and policymakers.

Comprehensive information about state and national LTSS systems is hard to find. Public financing of LTSS programs allows people with low or modest incomes access to services that would otherwise be unaffordable. But too many Americans deplete their life savings and end up paying out of pocket for services.

States play an important role in increasing the choices available to consumers, ensuring those choices meet high-quality standards, and increasing access to LTSS for those who would otherwise be left behind. While the federal Commission on Long-Term Care released a report last year with goals for LTSS reform, individual states remain the centers of innovation and progress.

State and national leaders must build on the incremental gains observed so far. We hope it will build on the success of the first Scorecard by offering policymakers, stakeholders, and advocates a way to analyze state LTSS systems and target areas for improvement.

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On the Scorecard National Advisory Panel, we would like to thank Lisa Alecxih of The Lewin Group; Robert Applebaum of Miami University of Ohio; Shawn Bloom of the National PACE Association; Jennifer Burnett of the Centers for Medicare & Medicaid Services; Brian Burwell of Truven Health Analytics; Penny Feldman of the Visiting Nurse Service of New York; Mike Fogarty of the Oklahoma Health Care Authority; Charlene Harrington of the University of California, San Francisco; Lauren Harris-Kojetin of the National Center for Health Statistics; Bob Hornyak of the U.S. Administration on Aging; Carol Irvin of Mathematica Policy Research; Rosalie Kane of the University of Minnesota; Ruth Katz of the U.S. Department of Health and Human Services; Kathleen Kelly of the National Center on Caregiving, Family Caregiver Alliance; Mary B. Kennedy of the Association for Community Affiliated Plans; Alice Lind of the Washington State Health Care Authority; Kevin Mahoney of Boston College; Vince Mor of Brown University; Lee Page of Paralyzed Veterans of America; Pamela Parker of the State of Minnesota Department of Human Services; D.E.B. Potter of the Agency for Healthcare Research and Quality; Martha Roherty of the National Association of States United for Aging and Disabilities; Elaine Ryan from AARP State Advocacy & Strategy Integration; Paul Saucier of Truven Health Analytics; William Scanlon of the National Health Policy Forum; Mark Sciegaj of Penn State University; James Toews of the U.S. Department of Health and Human Services, Administration for Community Living; and Jed Ziegenhagen of the Colorado Department of Health Care Policy and Financing.

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We would like to thank the members of the 2010 National Advisory Panel, who developed a working definition of long-term services and supports (LTSS) and a vision of what would constitute a high-performing LTSS system, as well as the members of the 2010 Technical Advisory Panel, who helped develop a list of indicators to include in the ***Scorecard***. A full list of those panel members can be found in Appendix B1.

We would also like to thank the following individuals who provided expert consultation during the development of the report: Carrie Blakeway of The Lewin Group; Alice Bonner of the Centers for Medicare & Medicaid Services; Katherine Brown of the MIT AgeLab; Joy Cameron of the National PACE Association; Eric Carlson of the National Senior Citizens Law Center; Joseph F. Coughlin of the MIT AgeLab; Cheryl L. Fletcher of APS Asset Preservation Strategies; Steve Eiken of Truven Health Analytics; Dana Ellis of the MIT AgeLab; Ilene Henshaw of AARP State Advocacy & Strategy Integration; Alice Hogan of the Centers for Medicare & Medicaid Services; Gail Hunt of the National Alliance for Caregiving; Gavin Kennedy of the U.S. Department of Health and Human Services; Anne Montgomery of the U.S. Senate Special Committee on Aging; Ed Mortimore of the Centers for Medicare & Medicaid Services; Terence Ng of the University of California, San Francisco; Mary Beth Ribar of the Centers for Medicare & Medicaid Services; Robert Rosati of the Visiting Nurse Service of New York; Diana Scully, formerly of the National Association of States United for Aging and Disabilities; Manisha Sengupta of the National Center for Health Statistics; and Anita Yuskauskas of the Centers for Medicare & Medicaid Services.

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EXECUTIVE SUMMARY

Our nation faces an unprecedented public policy challenge: how to transform our system of long-term services and supports (LTSS) to promote independence among older adults and people with disabilities, and provide support for the family members who help them. In just 12 years, the leading edge of the Baby Boom Generation will enter its 80s, placing new demands on the LTSS system. This generation, and those that follow, will have far fewer potential family caregivers to provide unpaid help. Despite this looming care gap, we lack a national solution to providing LTSS. That job still falls mainly to the states. Where you live really matters because there are very large differences across the states in how well they do this job. While many policymakers and advocates are working hard to improve their state LTSS systems and making important incremental changes, the pace of change is slow. A few states stand out for leading the way. We need to learn from these states, bring more national solutions to the table, and pick up the pace of change.

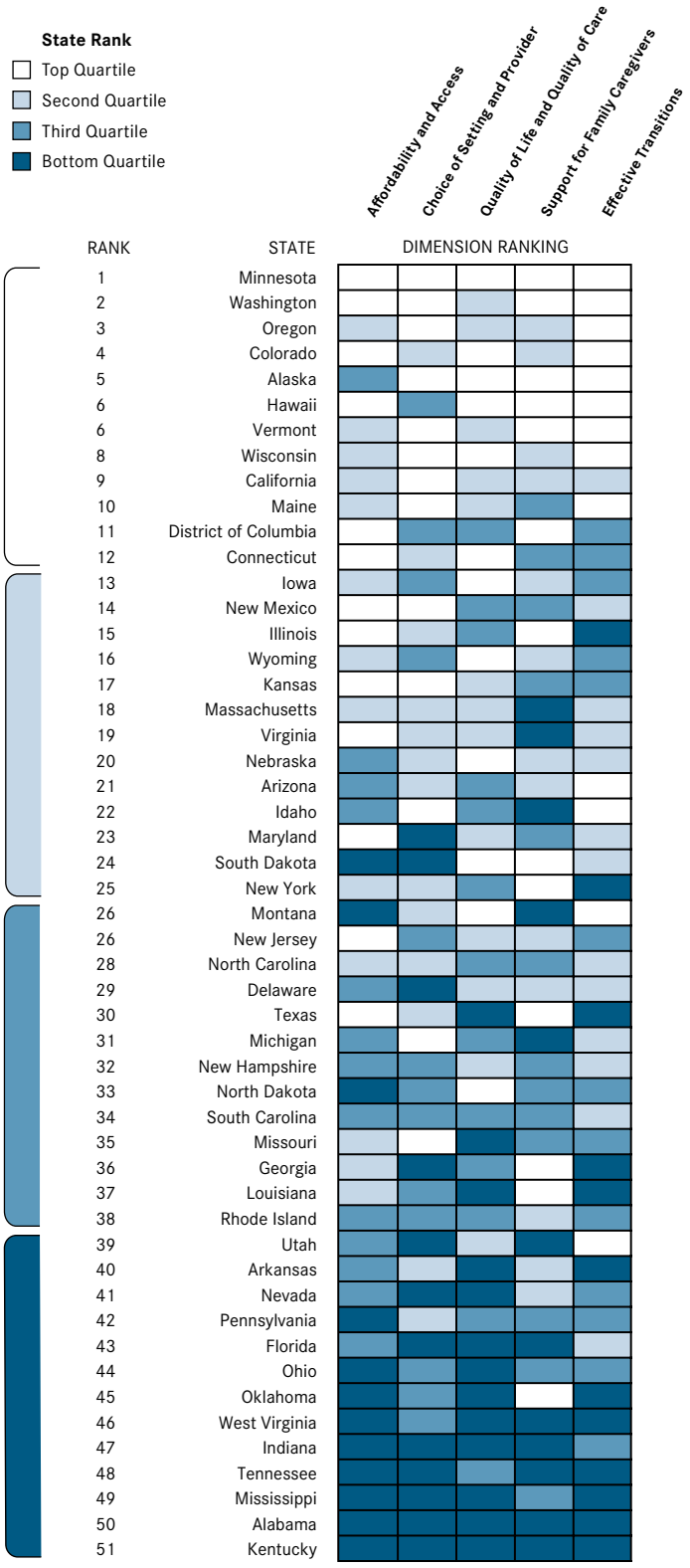
One way to accelerate progress is to articulate a vision of a high-performing LTSS system, operationalize that vision in a way that can be measured, develop a baseline of indicators, track changes over time, and use this information to focus on policies and other strategies to advance further and faster toward that vision. This second *State LTSS Scorecard* aims to do just that by building on the vision and starting set of indicators published in the 2011 edition. It measures state LTSS system performance across five dimensions: (1) affordability and access, (2) choice of setting and provider, (3) quality of life and quality of care, (4) support for family caregivers, and (5) effective transitions.

Exhibit 1 shows each state's rankings as well as its quartile of performance in each of the five dimensions. Within the five dimensions, the *Scorecard* includes 26 indicators. Exhibit 2 lists the indicators that compose each dimension, giving previous (or "baseline") data and the most recent performance, including the range of performance and the median. Thus, this *Scorecard* not only takes the pulse of the nation for how well we are doing on providing services and supports to people who use the LTSS system, but it also assesses change on the 19 indicators for which comparable data are available to show trends.

Many aspects of performance measured by the 26 indicators are related. When costs are high for people who pay privately and do not have long-term care insurance, they will more quickly deplete their life savings and turn to the public safety net. If that safety net is inadequate, people may rely so heavily on family caregivers that those caregivers damage their own health and well-being. States that have not built an infrastructure of services and care settings that offer residential alternatives will strain their own resources by paying more for costly nursing homes. The *Scorecard* shows that states that rely heavily on nursing homes for LTSS also demonstrate less effective transitions across care settings. This means that people with complex needs getting care at home or in nursing homes are more likely to experience inappropriate and costly hospitalizations and inadequate support in moving from a nursing home back into the community. And poor quality of care, in all settings, leads to worse health outcomes that contribute to higher costs for both the medical and LTSS systems.

EXECUTIVE SUMMARY Exhibit 1

State Scorecard Summary of LTSS System Performance Across Dimensions



Note: Rankings are not entirely comparable to the 2011 Scorecard rankings in Exhibit A2. Changes in rank may not reflect changes in performance, and should not be interpreted as such.
Source: State Long-Term Services and Supports Scorecard, 2014.

Major Findings

Minnesota, Washington, Oregon, Colorado, Alaska, Hawaii, Vermont, and Wisconsin, in this order, ranked the highest across all five dimensions of LTSS system performance. These eight states clearly established a level of performance at a higher tier than other states—even other states in the top quartile. But even these top states have ample room to improve.

The cost of LTSS continues to outpace affordability for middle-income families, and private long-term care insurance is not filling the gap.

A major finding of the 2011 *Scorecard* is that the cost of LTSS was unaffordable for middle-income families in all states, even for those in the top states. Nationally, this situation did not improve; in three states, nursing home costs became even less affordable.

- On average, nursing home costs would consume 246 percent of the median 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 382 percent of income.
- Home care generally is more affordable than nursing home care, allowing consumers to stretch their dollars further. But at an average of 84 percent of median income, the typical older family cannot sustain these costs for long periods.

This finding has profound implications for the entire LTSS system. States have limited ability to control the costs of care for those who pay privately. However, when the cost of such care far exceeds families' ability to pay it, more people will face spending down their life savings and ultimately qualify for Medicaid, which is funded through state and federal dollars. Despite national campaigns to encourage people to purchase private long-term care insurance, very few people do, usually citing its high cost. Only 10 percent of Americans aged 50 and older have these policies.[1] With instability in this insurance industry, coverage is not increasing. People are on their own, with a state's Medicaid program providing the only safety net.

Public policy makes a difference.

The private sector can do much to help achieve the vision of a high-performing LTSS system, such as developing more affordable care options, employing more people with disabilities, and promoting more effective transitions between care settings. But public policy directly influences many key indicators that have a clear road map toward improved performance. These include measures of several Medicaid policies, resource centers to help people of all incomes access information, supports for family caregivers (especially those who are employed), and laws that permit nurses to delegate tasks to direct care workers to help maintain consumers' health.

Several of these measures appear to drive overall LTSS state system performance, particularly two that had the strongest relationship to overall performance. The first is the states' efforts to provide LTSS to low- and moderate-income adults with disabilities through their Medicaid or other state-funded programs. The second is balancing spending on LTSS, shifting funds away from an overreliance

Exhibit 2

List of 26 Indicators in State Scorecard on Long-Term Services and Supports

Indicator	Most Recent Data				Baseline Data			
	Data Year	Median Value	Bottom Value	Top Value	Data Year	Median Value	Bottom Value	Top Value
Affordability and Access								
Median annual nursing home private pay cost as a percentage of median household income age 65+	2013	234%	456%	168%	2010	224%	444%	166%
Median annual home care private pay cost as a percentage of median household income age 65+	2013	84%	111%	47%	2010	89%	125%	55%
Private long-term care insurance policies in effect per 1,000 population age 40+	2011	44	26	130	2009	41	28	300
Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance	2011-12	51.4%	42.3%	78.1%	2008-09	49.9%	38.7%	63.6%
Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community	2009	42.3	16.3	85.2	2007	36.6	15.9	74.6
Aging and Disability Resource Center functions (composite indicator, scale 0-70)	2012	54	14	67	2010	***	***	***
Choice of Setting and Provider								
Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities	2011	31.4%	14.5%	65.4%	2009	29.8%	10.7%	64.6%
Percent of new Medicaid aged/disabled LTSS users first receiving services in the community	2009	50.7%	21.6%	81.9%	2007	49.8%	21.8%	83.3%
Number of people participant-directing services per 1,000 adults age 18+ with disabilities	2013	8.8	0.03	127.3	*	*	*	*
Home health and personal care aides per 1,000 population age 65+	2010-12	33	13	76	2007-09	29	16	80
Assisted living and residential care units per 1,000 population age 65+	2012-13	27	11	125	2010	28	7	78
Quality of Life and Quality of Care								
Percent of adults age 18+ with disabilities in the community usually or always getting needed support	2010	71.8%	66.6%	79.1%	2009	68.5%	61.3%	78.2%
Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life	2010	86.7%	82.5%	92.1%	2009	85.0%	80.2%	92.4%
Rate of employment for adults with ADL disability ages 18–64 relative to rate of employment for adults without ADL disability ages 18–64	2011-12	23.4%	13.8%	37.2%	2009-10	24.2%	16.7%	44.4%
Percent of high-risk nursing home residents with pressure sores	2013	5.9%	9.0%	3.0%	*	*	*	*
Nursing home staffing turnover: ratio of employee terminations to the average number of active employees	2010	38.1%	72.0%	15.4%	2008	46.9%	76.9%	18.7%
Percent of long-stay nursing home residents who are receiving an antipsychotic medication	2013	20.2%	27.6%	11.9%	**	**	**	**
Support for Family Caregivers								
Legal and system supports for family caregivers (composite indicator, scale 0-14.5)	2012-13	3.00	0.50	8.00	2008-10	***	***	***
Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks)	2013	9.5	0	16	2011	7.5	0	16
Family caregivers without much worry or stress, with enough time, well-rested	2011-12	61.6%	54.3%	72.8%	2010	60.8%	53.3%	66.6%
Effective Transitions								
Percent of nursing home residents with low care needs	2010	11.7%	26.7%	1.1%	2007	11.9%	25.1%	1.3%
Percent of home health patients with a hospital admission	2012	25.5%	32.3%	18.9%	*	*	*	*
Percent of long-stay nursing home residents hospitalized within a six-month period	2010	18.9%	31.1%	7.3%	2008	18.9%	32.5%	8.3%
Percent of nursing home residents with moderate to severe dementia with one or more potentially burdensome transitions at end of life	2009	20.3%	39.5%	7.1%	**	**	**	**
Percent of new nursing home stays lasting 100 days or more	2009	19.8%	35.0%	10.3%	**	**	**	**
Percent of people with 90+ day nursing home stays successfully transitioning back to the community	2009	7.9%	4.8%	15.8%	**	**	**	**

* Baseline data not comparable to current data.
** Baseline data not available.
*** Change over time data for these composite indicators are based on a partial baseline (data not shown); see Exhibits A6 and A14 in Appendix A for additional detail.
Source: State Long-Term Services and Supports Scorecard, 2014.

on nursing homes to support more funding of home- and community-based services (HCBS). Both are key indicators of performance, with dramatic variation as discussed below.

The *Scorecard* emphasizes several key findings related to public policy:

- Tremendous variation exists in the adequacy of the states' Medicaid LTSS safety nets.

  The *Scorecard* finds substantial variation in the reach of the Medicaid LTSS safety net to people with low and moderate incomes and a disability. The average rate of coverage in the top five states (68 per 100 adults) was more than three times the average in the bottom five states (22 per 100 adults). As highlighted above, this basic measure of program access is the indicator most strongly associated with overall LTSS state system performance.

- Once people access Medicaid, shifting service delivery toward home- and community-based services is critical.

  Regardless of age or type of disability, the desire to remain in one's home is nearly universal. Balancing Medicaid LTSS by shifting more resources from institutions to care in homes and other community-based settings has been the centerpiece of advocacy efforts for decades. The range of state variation is enormous. The top five states allocated an average of 62.5 percent of LTSS dollars for older people and adults with physical disabilities for HCBS, nearly four times the proportion in the bottom five states, which allocated an average of just 16.7 percent. The national average was 39.3 percent.

  Another measure of balancing Medicaid looks at where a person who is newly approved by the state to receive LTSS services under Medicaid initially receives those services—in an institution or in their home or other community setting. States that are committed to serving people in their own homes (or a homelike option) develop policies and procedures to make that possible. When that infrastructure is not in place, people have no choice but to enter an institution because they cannot wait weeks or months for services to be approved and delivered. In the top five states, 77.6 percent of new LTSS users were served in HCBS settings—more than three times the performance of the bottom five states, in which only 25.6 percent of new LTSS users were served in HCBS.

- Few HCBS consumers have the choice to direct their own services.

  Hiring the people who will help you bathe, dress, eat, use the toilet, and move from one place to another is fundamental to having more personal control over what happens to you on a daily basis. Many consumers who need LTSS want that basic control over their lives; yet in most states, few consumers have this option. By far, California leads the nation in the proportion of people with disabilities that self-direct their services (127 people per 1,000 adults with a disability in the state) compared to the lowest states, in which less than 1 person per 1,000 has this option.

- Greater efforts are needed to increase the employment of adults with disabilities.

Across the nation, adults with disabilities are far less likely to be employed than are those without a disability. But the relative rate of employment of adults with disabilities in the top five performing states was double that found in the bottom five states: 32 percent compared to 16 percent. In addition to the obvious benefit of income gained through employment, workforce participation enhances social connection, identity, and sense of purpose.

- States play a key role in minimizing the inappropriate use of antipsychotic medications in nursing homes.

  As states have dramatically reduced the use of physical restraints in nursing homes, some appear to have substituted the inappropriate use of sedating antipsychotic medications. There is a substantial range of performance in this area, and all states must work to eliminate inappropriate prescribing for vulnerable nursing home residents.

- More states or jurisdictions are enacting laws that support family caregivers.

  Given the critical role that caregivers play in support for people with LTSS needs, support for family caregivers is an area of great public policy interest. The range of performance was substantial, and new provisions sometimes extended only to select jurisdictions within a state. Among the components measured in this indicator are the extent to which the state exceeds federal requirements under the Family and Medical Leave Act, the state's paid family leave and mandatory paid sick day provisions, and its policies to prevent discrimination toward working caregivers. Many of these policies to support family caregivers extend to actions in the private sector. Because most family caregivers are employed, ensuring access to leave and protection from discrimination is critical to helping them avoid burnout and keep working—factors that can help caregivers maintain their own health and financial security.

- Allowing nurses to delegate health maintenance tasks to direct care workers in home settings helps family caregivers and is more cost-effective for public programs.

  Many LTSS consumers need help with such health maintenance tasks as taking medications, giving tube feedings, or managing bowel and bladder care (for example, giving enemas or changing catheters). For many people with disabilities, performing these tasks is as routine as other activities of daily living, like bathing and dressing. In all states, nurses can teach family caregivers to perform these health maintenance tasks. But in many states nurses are not allowed to delegate such tasks to a paid direct care worker assisting a consumer at home with other activities of daily living. In those states, the family caregiver often becomes the only person who can do this work. Looking at 16 specific tasks, the *Scorecard* found that some states allow nurses to delegate all 16, whereas other states do not permit any delegation. Changing nurse practice laws can help family caregivers and potentially save public dollars by broadening the type of workers who can capably perform these tasks.

States with more effective transitions have lower use of nursing homes and generally score better on both choice and quality.

The addition of the effective transitions dimension in this *Scorecard* is important. Changes between such care settings as home, hospital, and nursing home involve transitions that can be critical points in maintaining the continuity of care. We find that the top-ranking states in overall system performance generally ranked in the top quartile of performance on this new dimension. High-performing states tend to minimize disruptive transitions among care settings and make efforts to return nursing home residents to home- and community-based settings that most people prefer.

- As nursing home alternatives have flourished, individuals who can remain in less restrictive environments generally prefer to do so. Therefore, states in which a relatively high proportion of nursing home residents have low care needs may not be taking appropriate steps to transition these individuals to HCBS settings. In the top five states, just 4.6 percent of nursing home residents had low care needs, compared to the bottom five states, in which 23 percent of residents had such needs—a level five times higher.
- Excessive transitions between nursing homes and hospitals are disruptive to patients and their families and costly to the system. States can minimize these transitions by providing better care in nursing homes, addressing residents' needs before acute conditions develop, or treating them in the nursing home rather than sending them to a hospital. In the top five states, 10.3 percent of nursing home residents were hospitalized, almost a third the level in the bottom five states, which averaged 27.9 percent.
- Vulnerable nursing home residents at the end of life should not be subjected to excessive hospitalizations or other unnecessary transfers, referred to here as "burdensome transitions." In the top five states, an average of 9.3 percent of nursing home residents with moderate to severe dementia experienced a potentially burdensome transition at end of life, while the bottom five states averaged 34.8 percent, almost four times as high.
- People who enter nursing homes and remain for 100 or more days are far less likely to return to the community than are those who have shorter stays. In the top five states, 12.9 percent of nursing home residents remained for 100 or more days, less than half the average (27.9 percent) in the bottom five states.
- A measure of high performance is the states' continuing efforts to help nursing home residents who would prefer to reside in the community make this transition. On average, the top five states transitioned 13.1 percent of long-stay nursing home residents to HCBS settings, compared to only 5.3 percent in the bottom five states.

Some states have made progress on important indicators, but there are persistent differences in state performance.

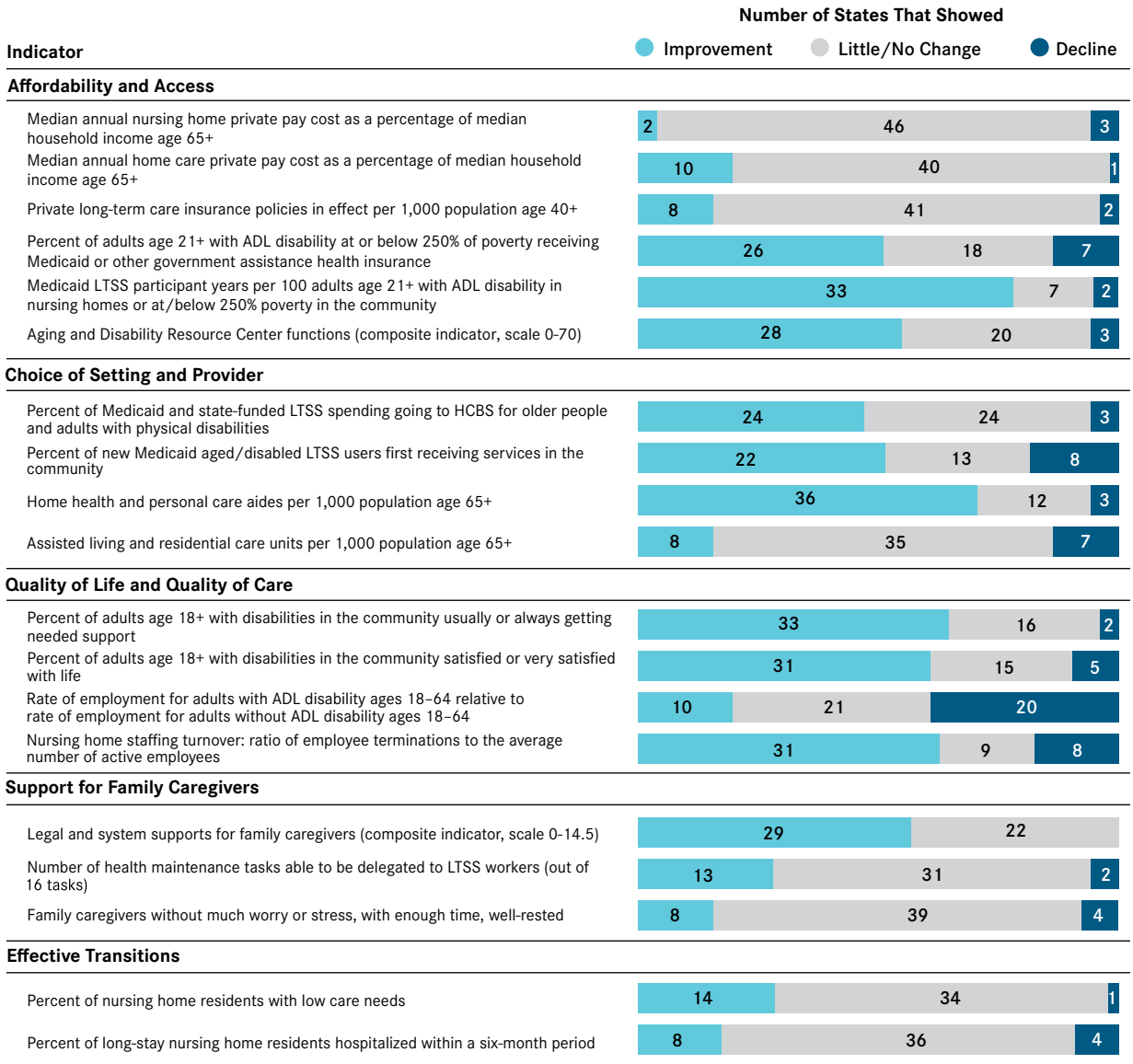
On many indicators, there was little to no change in most states. But when states did show substantial change (more than 10 percent), they more often improved than declined (see

Exhibit 3). Although most improvements were modest, some are noteworthy, especially during the difficult budget years following the Great Recession. Two noteworthy accomplishments:

- More than half of the states (26) improved their Medicaid safety net for low-income people with disabilities, many of whom had already spent all they had saved in their lifetimes to pay for services before they applied to Medicaid for help.
- More than half of the states (28) improved the functioning of Aging and Disability Resource Centers that help people of all

EXECUTIVE SUMMARY Exhibit 3

Change in State Performance by Indicator



Notes: Improvement or decline refers to a change between the baseline and current time periods of at least 10 percent or equivalent (see Appendix B5 for detail). Showing trend for the 19 of 26 total indicators–trend data are not available for all indicators.
Source: State Long-Term Services and Supports Scorecard, 2014.

incomes find the services they need. The Federal Administration for Community Living and the Centers for Medicare & Medicaid Services have invested both funding and technical assistance to stimulate this infrastructure development, which takes considerable collaboration across state departments to create.

Despite these improvements, where you live is still the best predictor of the services you will receive when and where you need them. (See Appendix A3 for a breakdown of state performance on all indicators by quartile.) The variation between states remained tremendous on most indicators. High-performing states had indicator scores that doubled or tripled (or more) the rates attained by lower-performing states. While improvement of 10 percent (the threshold used to show meaningful change) is a notable achievement, it is not enough to cross the gap between low- and high-performing states, where differences routinely exceed 200 percent. (See Exhibit 2 for the range of performance on each indicator and Appendix A4 for the count of indicators improving, declining, and staying about the same for every state.)

Impact of Improved Performance

What would significant improvement in a state's performance look like? What would it mean to older people, adults with physical disabilities, and family caregivers? One way to capture the potential impact of improved performance is to benchmark the top-performing state in a specific indicator and measure what would happen if the rest of the states could match that performance. For example:

- People cannot have the option of remaining at home if there aren't enough workers to provide services. If all states rose to Minnesota's level of performance, 1.5 million more personal care, home care, and home health aides would be available to provide LTSS in communities nationwide.
- States that effectively serve new LTSS users in their homes or other community settings honor consumer preferences and save the costly public expense of unnecessary nursing home use. If all states rose to Alaska's level of performance on this measure, approximately 200,000 more people per year would first receive services in the community instead of in a nursing home.
- Some states continue to have people with low care needs receive services in nursing homes. If all states achieved the rate found in Maine, over 150,000 more people per year would be served in home and community settings.
- States vary in the extent to which nursing home residents are able to make a transition back to the community. If all states achieved the level found in Utah, more than 100,000 individuals per year would be able to leave a nursing home for a more homelike setting.

The Need for Action

The *Scorecard* clearly shows that where one lives has a tremendous impact on the experience that people and their families are likely to have when the need for LTSS arises. (See Exhibit 4.) Positive trends exist, but enormous variation among the states continues to affect the millions of people

who encounter the LTSS system. We still have very far to go.

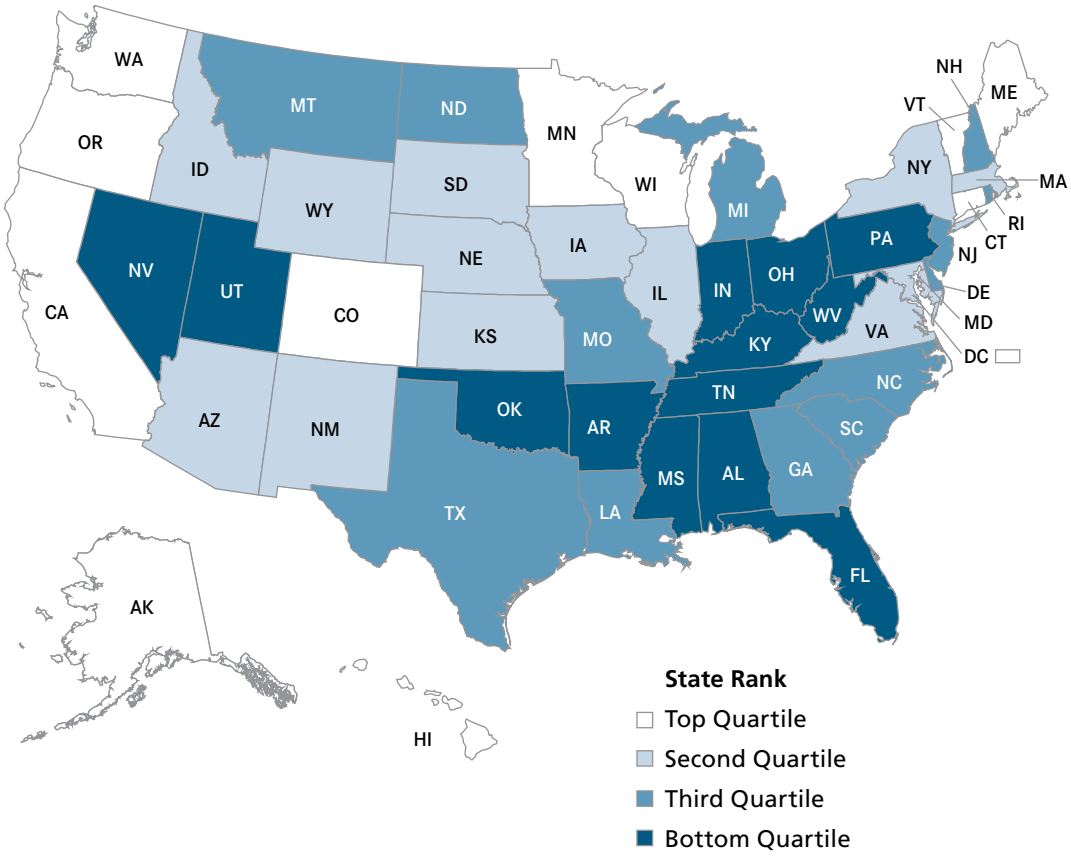
Despite decades of effort, the private insurance market for long-term care reaches very few people, even in leading states. For most middle-income families, care is unaffordable. As a result, families are on their own, often spending down to Medicaid eligibility or placing unrealistic and unsustainable demands on family caregivers to manage all of their complex needs.

Two things are clear. First, *we need a rational approach at the federal level to guide the states and to establish standards for LTSS system performance below which no state should fall*. The 2013 federal Commission on Long-Term Care began a discussion of the steps necessary to support family caregivers, improve quality of services, and establish mechanisms for financing LTSS. Until our nation improves, middle-income families will continue struggling to pay for LTSS, often impoverishing themselves—at great personal and family distress—to get the services they need.

Second, despite the lack of strong federal solutions, *state leadership and vision make a difference*. Willingness to experiment, innovate, and challenge the status quo are the hallmarks of successful states. Leading states combine these characteristics with a commitment to the rights of people with disabilities and older people to live with dignity in the setting of their

Exhibit 4

State Ranking on Overall LTSS System Performance



Source: State Long-Term Services and Supports Scorecard, 2014.

choice, supported by the services they and their family caregivers need to maximize their independence. They build Medicaid programs that serve as a safety net.

Slow and steady progress has started the nation's move toward better LTSS system performance. But this gradual rate of progress will not be adequate to meet the needs of aging baby boomers. While large numbers of boomers are not likely to need LTSS for 20 or so years, major system changes cannot be accomplished overnight. It's time to pick up the pace.

Our hope is that this *Scorecard* will help provide targets for improvement and motivate state action in a more positive direction. With concerted work across the multiple dimensions, it should be possible to accelerate the pace of change. Success depends on states taking initiative and making a commitment to do better. In partnership with federal initiatives and private-sector actions, states have the capacity to improve the delivery of LTSS, thereby improving the lives of older adults, people with disabilities, and their family caregivers. In the future, where you live should matter less than it does today when it comes to having choices and receiving high-quality, well-coordinated care.