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2. The new Scorecard uses a new caregiver survey, instead of the one used in the 2011 *Scorecard*; however, the state rankings are very different. For instance, Oregon ranked #1 in 2011, falling to #41 in 2014. How do you reconcile these results?

Background:

1. What are “long-term services and supports”?

Long-term services and supports (LTSS), also called long-term care services, consist of a range of services and supports for people who need assistance with routine activities of daily life (such as bathing, eating, preparing meals, and shopping for necessities) because of a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time. LTSS consist mainly of assistance from another person with these routine activities. Supports also include assistive equipment such as wheelchairs and environment modifications such as ramps. Individuals may receive LTSS in their home, or a nursing home, assisted living facility, or other setting.

The *Scorecard* examines the performance of state LTSS systems for older people and adults with physical disabilities. People whose need for LTSS arises from intellectual disabilities or chronic mental illness are not included in the *Scorecard*'s assessment of state performance. The LTSS needs for these populations are substantively different than the LTSS needs of older people and adults with physical disabilities.

2. Why does the *Scorecard* focus on individual states rather than the nation as a whole?

Policies at the state level play a huge role in shaping the LTSS system. State Medicaid programs pay for a substantial share of LTSS and have a major effect on the availability of LTSS for people with low incomes, and middle-income people who exhaust their financial resources paying for medical care and LTSS. Medicaid programs vary in eligibility rules and in the types of LTSS covered. (For a brief description of Medicaid, see text box in the “Dimension 1” section of the report.)

Other state policies, in addition to Medicaid policies, are also important in shaping the types and quality of services available in the state (such as policies determining non-Medicaid public financing for LTSS and the licensing and regulation of providers). State policies also affect the availability of good information and support systems to help people find and access LTSS, the extent to which family caregivers receive needed support, and other characteristics of the LTSS system.

Some of the indicators that measure state performance may be directly changed by the actions of public policy-makers in the state. For other indicators, state policy has an important but less direct effect -- these indicators are determined by the actions of multiple private-sector actors, including providers and consumers, who are responsive to public policy.

Data & Methodology

1. What is the method for determining each state's ranking?

The *Scorecard* first ranks states, from highest performance to lowest, on each of the 26 indicators. Next, the *Scorecard* ranks states on each of the five dimensions, based on states' average ranking for the indicators in the dimension. Finally, each state's overall ranking is determined by computing each state's average ranking across dimensions. Thus, each dimension has an equal weight in determining the overall ranking. The method is described in more detail in the text box in the Introduction section of the report called "A Note on Methodology."

This approach was chosen for its ease of understanding and straightforward interpretation. It is also consistent with the method used in the *State Scorecard on Health System Performance* developed by The Commonwealth Fund.

2. Are there national data for these indicators? If so, does the *Scorecard* show how states perform relative to a national average?

The method used in the *Scorecard* is to determine each indicator at the state level and to compare states with each other to determine the rankings. For each indicator, dimension, and overall, the states are ranked from highest performance (rank equals 1) to lowest. The *Scorecard* does not use national averages for the indicators. However, the *Scorecard* does report the "all state median" for each indicator, which is the value of the indicator for the middle state after they have been ranked. About half of the states (25) are above the all-state median for each indicator, and about half (25) are below.

After the states are ranked, they are divided into four approximately evenly-sized groups (quartiles). The states in the two highest quartiles are at or above the median (or middle value) among all states; the states in the bottom two quartiles are below the median.

3. What data sources and time frame are used for the *Scorecard*?

The *Scorecard* uses data from numerous sources, including several national surveys. For each indicator, the most recently available data as of January 2014 are used. The years of the data range from 2009-2013, with most indicators relying on data for 2011, 2012, or 2013. The specific data sources used for each indicator are listed in Appendix B.2 and B.3.

We strive to use the most current data available. However, in some instances, the most current data available was from 2009. In the Effective Transitions dimension, we used three indicators from the Chronic Conditions Warehouse Timeline file, currently available for 2009, because it tracks individuals across settings, allowing us to measure their transition behavior.

The Medicaid indicators from 2009 are based on the Medicaid Analytic eXtract File. The 2009 file is the most current edition that covers all 50 states and the District of Columbia.

4. How can I compare my state's performance on this *Scorecard* with its performance in the 2011 *Scorecard*?

One goal of the *Scorecard* is to measure change in performance (improvement or decline) over time. For 19 of the 26 indicators in the *Scorecard*, prior year data (typically 2-3 years earlier than the "most current" data) are available to measure change.

We recommend making comparisons based on the actual level of performance on each indicator, and not the change in rank.

At the dimension and overall level, only rank scores are available. Because of changes in the indicator set, it is **not legitimate** to make dimension or overall rank comparisons between the 2011 and 2014 *Scorecards*.

However, we know that some readers will insist on comparing dimension or overall ranks. For this reason, we provide an exhibit in Appendix A1 that contains a valid baseline for comparison. It is not identical to the 2011 *Scorecard*, because of the following factors:

- Some indicators have been eliminated or added between the two *Scorecards*.
- Some indicators are repeated, but with methodological changes that make direct comparison impossible.
- Some indicators are repeated, but moved to a different dimension, changing the computation of dimension and overall ranks.

The exhibit in Appendix A1 illustrates overall rank and quartile of performance by dimension for the 2014 *Scorecard*, and a comparable baseline.

The baseline overall rank may be different from the 2011 *Scorecard* overall rank because of the factors listed above.

5. Are there significant data gaps?

Gaps in available data limited to some extent what the *Scorecard* could measure. Some aspects of a high performing LTSS system could not be assessed because adequate data, consistent across all states, are not currently available. Despite the data limitations, the *Scorecard* represents a good starting point for measuring the performance of state LTSS systems and a solid baseline for tracking progress over time.

Quality of care and quality of life data have significant gaps. Quality of care measures are only available for nursing homes services, but not for home and community-based services. Ideally, consistent data would measure consumer experience and satisfaction with the full range of home and community-based services, including adequacy of care plans, timely delivery of services, and other indicators of quality. In addition, quality of life measures are limited to people with disabilities in the community, but are not available for residents of nursing homes or other residential care settings.

Another data gap is information on the availability of respite care for family caregivers. Having that information would strengthen the Scorecard's dimension on support for family caregivers.

6. How were the indicators in the *Scorecard* chosen?

Criteria used in selecting indicators required that the measures be clearly-understood, unambiguous, important, and meaningful. Selection of an indicator also required that state level data be available and be consistently-defined across states for comparability.

In developing the dimensions and indicators, the *Scorecard* team received extensive input and guidance from the Scorecard National Advisory Panel, as well as numerous other experts in LTSS populations, services, financing, data, and state & national policy. Our expert advisors suggested new avenues of research which led to the development of several new indicators, including the use of anti-psychotic drugs in nursing homes, nursing home transitions to the community, the rate of end-of-life burdensome transitions, and others. Conversely, some proposed new indicators were ruled out because of problems with the quality or completeness of the data available for them. The members of the advisory panels are listed in Appendix B.1.

7. Because your methodology only ranks the states against each other, how can one determine if a poor performing state is substantially worse than higher-ranked states?

Wide variation exists within all dimensions and on most indicators, with low-performing states being markedly different from those that score high. For example:

- a. The percent of low income adults with disabilities receiving Medicaid LTSS ranges from 16% to 85%
- b. The percent of Medicaid LTSS spending on HCBS ranges from less than 15% to 65%
- c. The number of people self-directing their services per 1,000 adults with disabilities ranges from .03 to 127
- d. The percent of nursing home residents with low care needs ranged from 26.7% to 1.1%.

- e. The health maintenance tasks that nurses can delegate, from a list of 16 tasks range from 0 to all 16

8. How does the second Scorecard calculate change in performance over time?

A threshold of 10 percent was used to identify states with a meaningful change in performance for most indicators.

For count or ratio data, usually indicators of the form (number of things)/(population subgroup) - a threshold of 10 percent change in the ratio was used. For example, if a state had 20 assisted living units per 1,000 people age 65+, a ratio of 18 or lower in 2012/13 would be classified as a decline and a ratio of 22 or higher would be classified as an improvement. A ratio of 19, 20, or 21 would be classified as “little or no change” so as not to highlight small changes in the data that may not reflect meaningful change.

For percentage data, a threshold of 10 percent change in the odds was used instead, in order for meaningful change to be possible for any starting value, and for the indication of change to be the same whether the indicator is expressed in a positive or negative way.

For more information, including a complete explanation of the change in the odds ratio, see Appendix B.5 “Measuring Change over Time”.

Policy Considerations:

1. What are the leading federal policy considerations?

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.

Federal policies that provide states with incentives and financial assistance to improve their LTSS systems can help guide meaningful positive nationwide change in LTSS system performance. We need a rational approach, at the federal level, to guide the states and to establish standards below which no state should fall. When the first *Scorecard* was published in 2011, there was hope that a new comprehensive public insurance program, the CLASS Act, would move the nation forward. Its repeal was a setback. The 2013 federal Commission on Long-Term Care began a discussion of the steps necessary to support family caregivers, improve quality, and establish mechanisms for financing LTSS. But we remain without political consensus on the best way to reform LTSS financing. Until this stumbling block is overcome, middle-income families will continue to struggle with how to pay for LTSS, often impoverishing themselves – at great personal and family distress – to get the services they need.

Some federal incentives have helped guide improved state performance. For example, states receive federal matching funds for implementing either the Community First Choice or Balancing Incentives programs, which help states expand Medicaid HCBS. Federal efforts to reduce unnecessary hospitalizations provide an incentive for states to ensure that providers improve the quality of care they provide in all settings and take steps that make transitions among settings less disruptive.

There also is a role for the federal government to play in improving data collection. A key finding of the Scorecard is that better data are needed to assess state performance. For example, uniform measures do not exist to measure HCBS quality across the states and data on states' effectiveness in coordinating the delivery of primary, chronic, acute, and long-term services are scarce. Even in Medicaid, the largest source of public payment for LTSS, no federal agency requires that states report on consumer and family experience with services received, adequacy of care plans, timely delivery of services, coordination of HCBS with housing, transportation, and health services, or the cultural competency of service providers.

2. What can low-performing states do to improve?

One goal of the *Scorecard* is to shed light on high-performing states so other states can learn from their successes. An area of substantial change between the 2011 *Scorecard* and this report was in the legal and system supports for family caregivers. Several jurisdictions enacted laws requiring employers to provide paid sick days – an important protection for working caregivers who need to use sick leave to take family members to medical appointments, or to maintain their own health. Jersey City, New Jersey, New York City, Portland, Oregon, and Seattle, Washington all enacted such laws.

Connecticut enacted major legislation to support family caregivers, statewide. The state now requires employers to provide paid sick days, and its employment antidiscrimination provisions prohibit employers from asking workers about their familial responsibilities.¹ In addition to these changes, Connecticut expanded the number of health maintenance tasks that nurses may delegate. Of note, however, Connecticut's law allows sick days to be used for the worker's own illness, or to care for a child or spouse. It does not cover workers who care for a parent or other relative. Rhode Island enacted legislation that requires employers to provide paid family and medical leave, an enormous benefit to family caregivers.

States that take action to change laws such as these benefit a broad scope of people who are affected by the LTSS system, not just people with limited incomes who turn to the Medicaid program for help. Legislation to help family caregivers, including the many caregivers who also hold down paid employment is an important area of state policy action. Such legislation places some of the responsibility on the private sector to treat family caregivers fairly. Caregivers remain the backbone of our nation's LTSS system and even those who have adequate incomes need help and support to sustain their important roles.

But given the high cost of LTSS, many people continue to rely on Medicaid as the program of last resort. The *Scorecard* shows that the top states generally scored very high on measures of Medicaid performance. For example, looking at the four indicators of Medicaid performance, the top 12 states scored in the top quartile on these measures more than three-quarters of the time.

California and Oregon, both strong performers on measures of Medicaid balancing, were the first two states approved for the Community First Choice option – a federal initiative that helps move states toward leveling the playing field between institutional services and HCBS. Arizona and Maryland have submitted applications to implement this program, and several other states (Arkansas, Minnesota, Montana, and New York) have indicated their intention to do so.ⁱⁱ

Mississippi has been a low performer on many *Scorecard* indicators. However, it showed substantial improvement in serving new Medicaid LTSS users first in HCBS settings, going from 32.5 percent in the first *Scorecard* to 48.1 percent in the current report: the largest rate of improvement in any state on this measure. While still ranked 24 on the indicator, it shows that the state is making efforts to improve its historically low level of Medicaid balancing.

Although many quality measures reflect actions of the private sector providers of services, states can play an important oversight role. For example, Colorado instituted a “pay for performance” (P4P) program that provides higher Medicaid reimbursement to nursing facilities that achieve designated benchmark measures.ⁱⁱⁱ Demonstrating its commitment to quality, it added a measure on use of antipsychotic medications in nursing homes to its P4P program,^{iv} a measure reflected in this *Scorecard*.

Other Questions:

1. Will the Scorecard continue to be updated, and when?

The goal is to update the Scorecard in approximately two to three years.

2. The new Scorecard uses a new caregiver survey, instead of the one used in the 2011 Scorecard; however, the state rankings are very different. For instance, Oregon ranked #1 in 2011, falling to #41 in 2014. How do you reconcile these results?

Our substitution was involuntary; the Behavioral Risk Factor Surveillance System survey moved the question identifying caregivers to an optional module not completed by any states. Moreover, it should be noted the survey results are not comparable for several reasons.

First, from a technical standpoint, the surveys were conducted by different polling companies with different methodologies a few years apart. Indeed, the U.S. average is 61.3% in one survey, and 76.6% in another.

Second, the surveys are asking different questions, getting at different aspects of caregiver emotional health. The BRFSS question in 2011 asked if caregivers were usually or always getting needed support. In contrast, the Gallup-Healthways Well-Being Index asked of caregivers whether they experienced a lot of worry, a lot of stress, whether they felt well rested, and whether they felt they had enough time.

Third, these survey questions were selected for their strong year to year reliability. A correlational analysis shows no relationship between the two indicators, but that is well in line with our expectations.

ⁱ Joan C. Williams, Robin Devaux, Patricija Petrac, and Lynn Feinberg, “Protecting Family Caregivers from Employment Discrimination” (Washington, DC: AARP Public Policy Institute, August 2012).

ⁱⁱ Kaiser Family Foundation, “State Health Facts.” Accessed on the Web at <http://kff.org/medicaid/state-indicator/section-1915k-community-first-choice-state-plan-option/>

ⁱⁱⁱ National Conference of State Legislatures, “Health Cost Containment and Efficiencies in Colorado.” (April 2010) Accessed on the Web at http://www.ncsl.org/portals/1/documents/health/CO_PERFORMANCE_PAY.pdf

^{iv} “State of Colorado Department of Health Care Policy and Financing: 2013 Nursing Facilities Pay for Performance Review” (June 28, 2013) Accessed on the Web at <http://www.colorado.gov/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1251871445594&ssbinary=true>