FAQs

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. What is the purpose of the *Scorecard*?

The purpose of the *State LTSS Scorecard* is to inform efforts to improve state LTSS systems so people in all states are able to obtain affordable, high-quality, well-coordinated services, and family caregivers receive the support they need. The *Scorecard* is a resource that state policymakers, national leaders, and others can use to identify areas where improvement is needed, provide a baseline against which to measure efforts to improve performance, uncover gaps within the system, and highlight the need for better information across a broader range of services.

3. What are the characteristics of a "high-performing LTSS system?"

The ultimate goal of a high-performing (excellent) LTSS system is to enhance the well-being of people who need LTSS and the family members and others who assist them. A high performing LTSS system has the following characteristics:

- **Affordability and access**: Consumers should be able to easily find and afford the services they need.

- **Choice of setting and provider**: A person-centered approach to LTSS places high value on allowing consumers to exercise choice and control over where they receive services and who provides them.

- **Quality of life and quality of care**: Services should maximize positive outcomes and consumers should be treated with respect. Personal preferences should be honored when possible.

- **Support for family caregivers**: The needs of family caregivers are assessed and addressed so that they can continue in their caregiving role without being overburdened.

- **Effective transitions and organization of care**: LTSS are effectively coordinated or integrated with health-related services, as well as with social supports.

These characteristics are aims—goals to strive for when considering public policies and private sector actions that affect the organization, delivery, and financing of LTSS.

4. What does the *Scorecard* measure?

The Scorecard measures LTSS system performance in all states and the District of Columbia using 25 specific indicators. The indicators are grouped into four key dimensions that are essential to a high-performing LTSS system:

- **Affordability and access** includes indicators of the affordability of privately-paid home care and nursing home services, the proportion of people with private long-term care insurance to help pay for LTSS, the reach of the state's Medicaid program for people with disabilities and low incomes, and availability of supports that help consumers navigate the LTSS system.

- **Choice of setting and provider** includes indicators of the availability to consumers of choices in LTSS, including alternatives to nursing home care. These include indicators of the balance between institutional services and home and community-based care; the extent of "consumer-directed services" – an approach to home-based care that allows individuals to hire and direct their care providers, in contrast to receiving services from agency-employed workers; and the supply and availability of alternatives to nursing home care.

- **Quality of life and quality of care** includes indicators of the quality of life of people with disabilities -- including whether adequate support is received, satisfaction with life, and employment among people of working age with disabilities -- and the quality of care experienced by nursing home residents and by home health care recipients.

- **Support for family caregivers** includes indicators of the extent to which caregivers receive needed support, and of state legal and regulatory supports that assist caregivers**.** It also includes state practices regarding nurse delegation of health maintenance tasks.

The states are ranked (from highest performance to lowest) on each indicator, on each of the four dimensions, and overall. The highest-performing states indicate what has already been achieved and, therefore, set a standard by which other states can evaluate their current performance. These achievements do not indicate an upper limit, because even high-performing states can aspire to continued improvement.

The 25 specific indicators that constitute the four dimensions are listed and defined in **Appendix B.2.**

5. 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 available 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.

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

The *Scorecard* first ranks states, from highest performance to lowest, on each of the 25 indicators. Next, the Scorecard ranks states on each of the four 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.

7. 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.

8. 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 June 2011 are used. The years of the data range from 2007 to 2011, with most indicators relying data for 2008, 2009, or 2010. The specific data sources used for each indicator are listed in Appendix B.2 and B.3.

9. 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 and home health, but not for other community-based home and community 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.

In addition, because of data limitations, the *Scorecard* could not include an assessment of a fifth characteristic of a high-performing LTSS system, the extent to which LTSS are effectively coordinated or integrated with health-related services and other social services. Ideally, adequate information would be available to include effective coordination of care across medical, LTSS, and other services as a dimension in the Scorecard.

10. 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 two advisory panels and numerous other people with a range of expertise in LTSS populations, services, financing, data, and state and national policy. Although the activities of the two advisory panels overlapped, the National Advisory Panel focused primarily on issues of defining the key characteristics of a high-performing state LTSS system, developing the dimensions for the Scorecard, and considering appropriate indicators to use for each dimension. The Technical Advisory Panel focused more on data-oriented questions, such as determining which potential indicators could be measured well using available data. Some potential indicators were ruled out, for example, 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.

11. Will the Scorecard be updated and when?

The goal is to update the Scorecard in approximately two to three years. In addition to updating the rankings, future *Scorecards* will examine progress in states' LTSS systems over time.

Findings:

1. What are the major findings of the *Scorecard*?

Leading states do well in multiple dimensions -- but all states have opportunities to improve performance. The leading states generally score in the top half of states across all dimensions. However, no state scored in the top quartile across all 25 indicators, demonstrating that every state LTSS system has some areas in which it trails the top states. States can target their efforts to areas where they lag, following paths to higher performance demonstrated in other states.

Poverty and high rates of disability present challenges. Among the states in the bottom quartile overall, many have some of the lowest median incomes and highest rates of both poverty and disability in the nation. This pattern largely holds across all dimensions, but there are exceptions. Some states with median incomes below the national average rank in the top quartile in the *Scorecard*, and other states with median incomes above the national average, rank in the lower half of states in the Scorecard.

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. 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. This is an area over which states have direct control and some states have led the way to improve access and choice in Medicaid.

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. The most

meaningful support for caregivers may be a better overall system that performs well on the other dimensions – that is, that makes LTSS more affordable, accessible, and higher quality with more choices. 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.

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.

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.

2. Which states performed best? What are the high performing states doing particularly well?

The states that ranked in the top one-fourth of states overall are (starting with highest ranking): Minnesota, Washington, Oregon, Hawaii, Wisconsin, Iowa, Colorado, Maine, Kansas, District of Columbia, Connecticut, Virginia, and Missouri. In general, these states performed well in all four dimensions.

These leading states generally score in the top half of states across all dimensions. Some of the top results are determined directly by state policy choices, such as expanding availability of home and community-services in Medicaid and developing a system to help consumers learn about LTSS options and how to get the services they need (referred to as "single entry point/no wrong door organizations or Aging and Disability Resource Centers, or ADRCs). Other aspects of high performance are largely affected by actions by providers, and by economic and other factors over which state governments have less direct control, such as the affordability of home care and nursing home care. Each state's performance is unique and it is important to look at the entire array of indicators to understand where each state ranked high and where its performance lagged.

3. Which states need the most improvement? What are the key reasons for their low performance?

The states in the lowest quartile for overall performance are: Mississippi, Alabama, West Virginia, Oklahoma, Indiana, Kentucky, Tennessee, Florida, Louisiana, Georgia, New York, and Nevada. Low performing states vary in which specific indicators are weakest. However, the lowest-performing states are almost always in the bottom half of states in all four dimensions.

4. Is performance related to economic conditions in individual states?

Economic factors do appear to have some relationship to state performance, but there are many exceptions. Among the states in the bottom quartile overall, many are among the states with the lowest median incomes and highest rates of poverty in the nation. However, some states with median incomes below the national average rank in the top quartile in the *Scorecard*. And other states with median incomes above the national average rank in the lower half of states in the *Scorecard*.

5. **What is the impact of state Medicaid policy on performance?**

Medicaid, which is the primary source of public funding for LTSS, plays a major role in determining what types of LTSS are available to consumers with low and modest incomes -- in particular, whether individuals can obtain services in home and community-based settings as an alternative to nursing home care. 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 indicators that measure the proportion of Medicaid LTSS spending that states devote to home and community based services and states' success in directing people who newly become eligible for Medicaid LTSS to home and community services, as opposed to nursing homes.

The dimensions most directly affected by Medicaid policy are Affordability and Access; and Choice of Setting and Provider. Medicaid policies directly affect 2 indicators (of 6) in the affordability and access dimension -- the reach of the state's Medicaid program for people with disabilities who have low incomes; and the reach of the state's Medicaid LTSS for people with disabilities who have low incomes. They directly affect 4 indicators (of 7) in the Choice of Setting and Provider dimension: the proportion of Medicaid and state LTSS funds that support HCBS; the proportion of new Medicaid LTSS beneficiaries who use HCBS; the proportion of participants in publicly funded LTSS programs who direct their own services; and the effectiveness of the state's tools to facilitate choice (such as programs to divert or transition LTSS users from nursing homes and into the community-based settings they choose).

In addition, because Medicaid is the major source of funding for nursing homes, it has a significant effect on the industry and the quality of services. Thus, Medicaid payment and other policies have an important, though indirect, affect on the indicators of nursing home quality. Further, because Medicaid affects access, affordability, choice, and quality of care, Medicaid policies also indirectly affect the quality of life of people with disabilities and their caregivers.

6. What are some key state policy actions that states can take to improve performance?

Medicaid safety net

State policymakers have substantial control over Medicaid policies that determine the types of LTSS services offered and the settings in which they are provided. States have substantial control over establishing financial eligibility standards for Medicaid coverage as well as the level of disability needed to qualify for services. These decisions can either encourage or discourage access to HCBS. States that take advantage of options to expand eligibility increase both access and choice for older people and adults with disabilities. States can take advantage of new opportunities offered by the Affordable Care Act to improve their LTSS systems.

LTSS "balancing"

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 non-institutional 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 Affordable Care Act to improve the balance of their LTSS systems.

Maximizing consumer choice of LTSS options

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.

Fully functioning ADRC or single entry point systems play a critical role in helping people of all incomes and types of disability to access LTSS information and services. States with more effective systems will expand access to HCBS services.

Consumer direction

States have great flexibility to give consumers 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

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

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 has the ability to 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

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 policy directly determines what health related tasks can be delegated. This difference will have a major impact on family caregivers. 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.

7. 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 – such as some promising new incentives for states in the Affordable Care Act -- can help move us toward the goal of achieving access the goal of a nation in which people with

disabilities have meaningful choices, access to affordable services, a high quality of life and care, and support for their family caregivers in all states.

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.

Other Questions:

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

The following policy actions could help states raise their level of performance:

- 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.
- Balancing Medicaid LTSS spending toward HCBS 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 non-institutional 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 Affordable Care Act to improve the balance of their LTSS systems.
- 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.
- States have great flexibility to give consumers 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.
- 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.
- 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 has the ability to

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.

- 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.
- 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.

2. 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:

- The percent of low income adults with disabilities receiving Medicaid LTSS ranges from 16% to 75%
- The percent of Medicaid LTSS spending on HCBS ranges from less than 11% to 64%
- The number of people self-directing their services per 1,000 adults with disabilities ranges from .02 to 143
- The percent of high risk nursing home residents with pressure sores ranges from 17% to less than 7%
- The health maintenance tasks that nurses can delegate, from a list of 16 tasks range from 0 to all 16