

Long-Term Care and Supports: A Tool for Targeting State Improvement

By Enid Kassner

A high-performing system of long-term care services and supports must address four critical dimensions: affordability/access; choice of setting/provider; quality of life and care; and support for family caregivers. A recent scorecard assessed the states on 25 indicators within these dimensions and found marked differences in performance. States can use these findings to target system improvements.

Introduction

The Cook County Almshouse ... was the only public institution at any jurisdictional level specifically established to provide long-term refuge for the most extremely destitute people in the Chicago area. These were people with chronic physical illnesses or disabilities, mental illness or retardation, [or] elderly people. ... [T]he almshouse was regarded as a refuge of last resort. The number of residents peak[ed] ... [at] ... about 4,300 in January 1932. ...

Encyclopedia of Chicago¹

Throughout most of the 20th century, caring for older family members and people with disabilities was not a major public policy concern. In 1900, life expectancy at birth in the United States was just 49.2 years, compared to 77.5 years in 2003.² Most women did not work outside the home and older relatives often lived with their children when they could no longer care for themselves. Older people who had no one to care for them ended up in publicly run “almshouses” or private “old age homes”³ as a last resort. But over the course of the 20th century, the population age 65 and older increased 11-fold and the share of the older population increased from 1-in-25 to 1-in-8 Americans.⁴

In the early 20th century, people with physical disabilities were less likely to be accepted as part of the American mainstream than they are today, often lacking full access to public education and career opportunities. For example, although Franklin D. Roosevelt was stricken with polio as an adult and was unable to walk without assistance, he was almost never photographed in his wheelchair. Through the 1930s, someone disabled at a young age or born to a family with few economic resources may well have had a future in an almshouse.

When Medicare and Medicaid were enacted in 1965, they were designed to address, respectively, the health care needs of the elderly and the poor. Nursing home coverage was added, almost as an afterthought, to the Medicaid program with no anticipation as to how the cost of this coverage would soar in the following decades. Although much has changed in the years since Medicaid’s enactment—in terms of demographics, societal expectations and the health care delivery system—the nation’s system of services and supports for older people and adults with physical disabilities bears the imprint of policies enacted for a society that is now obsolete.

Today, older people and working-age adults with physical disabilities prefer to remain in their own home or in small-group settings that have a homelike feel. Some states have made enormous strides in reducing public spending for long-term care services and supports for nursing homes, which is a costly and undesirable option for most. Although steady progress has occurred throughout the nation, change has been hampered at times by resistance among institutional providers who derive revenue from publicly provided services, and by Medicaid rules themselves, which continue to favor institutional care as the first-line service for people who need assistance.

The AARP Public Policy Institute, with support from The Commonwealth Fund and The SCAN Foundation, set out to develop a method for evaluating states’ systems of long-term care support and services for the elderly, adults with physical disabilities and family caregivers by articulating a vision of how a high-performing system would look. Then came the painstaking task of determining what data were available to measure performance in a way that would be meaningful, unambiguous,

available for all states and replicable. The goal was to take a multidimensional look at the long-term care support and services system from the perspective of consumers and their families.

Vision of a High-Performing System

The project, referred to as the *Scorecard*, first defined the characteristics of a high-performing system for older people, adults with physical disabilities and family caregivers. It then measured and ranked the states on four critical dimensions:

Affordability and Access—*In a high performing long-term support and services system, consumers can easily find and afford the services they need and a safety net is in place for those who cannot afford services.*⁵ Measures of affordability and access include the affordability of nursing home and home care services for private pay patients, the reach of private long-term care insurance, the breadth of the state's Medicaid program, and an assessment of the state's access and navigation system. These navigation systems are variously referred to as "single entry point," "no wrong door," or "Aging and Disability Resource Center."

Choice of Setting and Provider—*A person- and family-centered approach to long-term services and supports places high value on allowing consumers to exercise choice and control over where they receive services and who provides them.*⁶ Measures of choice included the extent to which the state has balanced its expenditures for long-term care toward home and community-based services, as opposed to nursing homes; the ability of participants in public programs to direct their services and choose their provider; the availability of home care workers and alternative residential settings in the state; and the percentage of nursing home residents with comparatively low care needs.

Quality of Life and Quality of Care—*Services maximize positive outcomes and consumers are treated with respect. Personal preferences are honored when possible.*⁷ Quality of life was measured by looking at survey data regarding life satisfaction among people with disabilities and the relative percentage of working-age adults with disabilities who are employed. Quality of care in nursing homes and home health care also was measured.

Support for Family Caregivers—*The needs of family caregivers are assessed and addressed so they can continue in their caregiving role without being overburdened.*⁸ Because family caregivers play such a substantial role in providing long-term care and support, this component was considered

of equal importance to the other elements of a high-performing system. Measures included legal and system supports for family caregivers, state laws on the ability of nurses to delegate certain health maintenance tasks to home care workers, and the extent to which caregivers believe they receive the support they need.

Every state was ranked on each of the 25 indicators (except for a handful of instances in which missing data prevented a state ranking) and on each of the four dimensions. The states also were ranked for overall system performance.

Scorecard Purpose

The *Scorecard* was designed to help state policymakers and private sector service providers evaluate the strengths and weaknesses of their state's long-term care system. The goal of the project was to enable policymakers and other stakeholders to target improvement efforts on low-performance areas and learn from the actions taken in higher-ranking states.

States were ranked relative to each other. Even the top-performing state falls short of the overall vision of high performance. Moreover, the highest rank on any indicator illustrates the best that any state performed at the time the data were collected—not the best a state could possibly perform. While the most recently available data were used for every indicator, state performance may have changed in the intervening years.

The *Scorecard* illustrates meaningful differences among the states on a broad range of performance measures. In many cases, a four- or six-fold difference separated top and bottom states. In some areas, the range was even broader.

Because the *Scorecard* looked at the long-term care system from a wide range of needs that consumers experience, its indicators span areas that are subject to varying degrees of state control. For example, the private pay cost of services is important to system users, but is an area that is difficult for states to directly control. Measures of life satisfaction are influenced by myriad factors, some of which have nothing to do with state policy or even the individual's needs as a person with a disability. Other areas are influenced by a combination of factors. For example, quality of care is determined largely by private providers, but public oversight, monitoring and regulation can affect it. Yet there are numerous areas of performance that are directly controlled by state laws and policies. States have a major role in determining

who is eligible to receive services, what services are provided, and how family caregivers will be supported.

The *Scorecard* measured the reach of both the state’s overall Medicaid, as well as its Medicaid long-term care services and support programs for people with disabilities who have low incomes; the functions performed by the state’s Aging and Disability Resource Center or single entry point system; the balancing of each state’s Medicaid system toward home and community-based services; the proportion of consumers who are able to direct their own services; the state’s tools and policies to facilitate choice (such as programs to divert or transition long-term care users from nursing homes into the community-based settings they choose); legal and system supports for family caregivers (such as laws that extend family and medical leave to working caregivers or prevent employment discrimination); and the number of health maintenance tasks (from a list of 16) that nurses may delegate to home care workers.

Major Findings

States that ranked in the top quartile of performance tended to rank high across all dimensions, as illustrated in Figure A.⁹ Conversely, states in the bottom quartile generally ranked low across all dimensions. Even so, no state ranked in the top quartile across all 25 indicators and every state in the bottom quartile ranked in the top on at least one indicator. Thus, every state has areas of both strength and weakness.

However, across *all* states, the private pay cost of long-term care and support was determined to be unaffordable for middle-income people. This emphasizes the importance of the public safety net. Many families in the United States rely on family caregivers for the majority of the services they receive, and then exhaust their life savings paying for care when they need more help than their families can provide. Only after they have impoverished themselves, they may turn to the public safety net as a last resort.

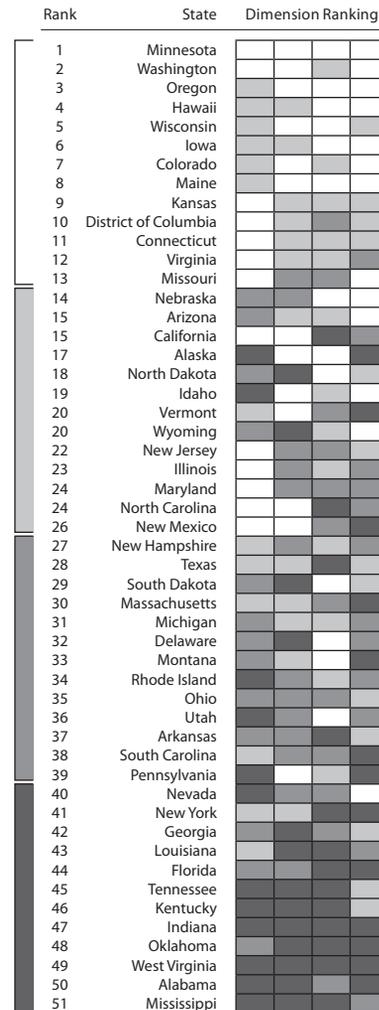
The *Scorecard* found that Medicaid was a leading indicator for state performance. States that ranked high on the performance of their Medicaid systems for providing both access to and choice in services tended to rank well overall. This finding is not surprising, as Medicaid is the primary source of payment for long-term care and support. States that have improved their Medicaid systems generally have embraced a philosophy that supports choice

Figure A: State Scorecard Summary of LTSS System Performance across Dimensions

State Rank

- Top Quartile
- Second Quartile
- Third Quartile
- Bottom Quartile

Affordability and Access
 Choice of Setting and Provider
 Quality of Life and Quality of Care
 Support for Family Caregivers



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

and control among people with disabilities. States that have adopted person- and family-centered policies designed to enhance choice and control among people who need assistance with daily activities look different than those states that have let outdated policies languish.

Also of note was the finding that states that ranked well on providing support for family caregivers, in general, ranked high overall. Family caregivers are the backbone of the nation's long-term care system. The economic value of their contributions equaled some \$450 billion in 2009, an amount that exceeded Medicaid spending on long-term care and support by a factor of four.¹⁰

Gaps in data prevented the research team from developing measures in critical areas. Areas that could be included in future versions of the *Scorecard* include home and community-based services quality, state spending for respite services, measures of coordination and integration among health care and long-term care, and the availability of housing and transportation options for people with disabilities.

Steps to Improve State Performance

The U.S. has come a long way from the days when people with physical or cognitive disabilities were segregated from public life. With the tremendous growth of the aging population, both public and private sectors have made strides in developing the infrastructure necessary to support the ability of people to age in their homes and communities. But as the *Scorecard* reveals, progress is uneven across the states and across the various dimensions of a complex long-term care and support system.

For the foreseeable future, Medicaid will continue to be the default public system for long-term care. Because it consumes such a large share of state budgets, generally second only to public education, policymakers often are concerned that it is growing out of control. Although the cost of long-term care is high, analysis of Medicaid spending trends reveals that the costs associated with it are not the driver in rising Medicaid budgets. Between 1997 and 2007, Medicaid spending on long-term care increased 80 percent, whereas non-long-term care spending increased 102 percent.¹¹ In particular, use of nursing homes declined substantially and disability rates among residents increased. Had nursing home use remained constant between 1994 and 2004, there would have been nearly three-quarters of a million more nursing home residents by 2004.¹²

The good news is that states that make the effort to move away from institutionally based long-term care systems toward the home and community-based systems that consumers prefer will, over time, see slower growth in public spending compared to states that continue to rely on nursing homes.¹³ In general, states can serve three people in home and community-based settings for the cost of maintaining one person in a nursing home.¹⁴

With the passage of the Patient Protection and Affordable Care Act, states were offered a host of new tools to improve their long-term care systems through Medicaid. Several provisions specifically address system balancing, including:

Community First Choice offers states a 6 percentage point increase in federal matching funds if they offer person-centered home and community-based care, including attendant services. States may not impose waiting lists and must offer services statewide. Depending on the income eligibility used, states have the option to provide services to individuals with disability levels lower than those required for institutional care, provided beneficiaries' incomes do not exceed 150 percent of the federal poverty level.

Balancing Incentives Payment Program directs the greatest financial incentives to states that have the least balanced systems. These five-year grants provide either a two or five percentage point increase in federal matching funds to qualifying states. In return, states must implement certain structural changes. These include developing a single entry point system, adopting conflict-free case management services and implementing a uniform method for determining eligibility. States also must increase the percentage of their Medicaid long-term care dollars that go toward home and community-based services by the end of the grant period. It is notable that the structural reforms, such as single entry point systems and standardized assessments, are factors measured by the LTSS *Scorecard*.

Other federal funding for system improvement approved through the Affordable Care Act included new "Money Follows the Person" grants designed to move people from nursing homes into home and community-based settings, as well as expanded grants to establish or expand Aging and Disability Resource Centers. The Affordable Care Act included provisions for states to establish "health homes"—a team of professionals that provide person-centered, integrated health care. These could be used to improve coordination of

services for people with both long-term care needs and chronic health conditions. It also established the Federal Coordinated Health Care Office, which is charged with improving the integration of benefits.

Conclusion

The flexibility states have to craft their own long-term care systems results in both challenges and opportunities. States that endeavor to improve their systems can learn from the creative approaches demonstrated by states that scored high on the *Scorecard* and that were highlighted in that report for their promising practices. Yet this same flexibility results in glaring disparities in the support available to frail older people, low-income people with disabilities and family caregivers. What the *Scorecard* demonstrated was that all states have some areas of strength on which to build, but also challenges to overcome.

The highest-ranked state, Minnesota, scored in the top quartile in 15 of 25 indicators and was ranked in the top five states on 11 indicators. Yet it had several low scores in the area of home health care services. Rather than resting on their laurels, state officials in Minnesota have taken a keen interest in improving their performance on home health measures.

In a different situation, Tennessee ranked in the fourth quartile on three of four dimensions, with 13 of 25 indicators in the bottom tier. Yet despite these challenges, the state is dedicated to improving the balance of its long-term care toward home and community-based services. After being ranked dead last in Medicaid balancing in a 2008 AARP report,¹⁵ Tennessee implemented a Medicaid managed long-term care program. The *Scorecard* found the state's share of public long-term care dollars going toward home and community-based services had increased to 26 percent, bringing it into the third quartile. While still below the national average of 37 percent, it represents progress and a commitment to change that is commendable.

A key factor in state success is the philosophy that guides its public policy decisions. States that embrace the importance of older people and people with disabilities having dignity, choice, autonomy and control will have a head start on crafting programs and policies that facilitate these features. While the almshouses of the 18th and 19th centuries no longer exist, our nation still has a long way to go to achieve the vision of a high-performing long-term care system as articulated in

the *Scorecard*. But the *Scorecard* can be used as an effective tool for states to target low-performing areas for improvement. Our intent is to repeat the *Scorecard* approximately every three years so that we can measure progress over time: state by state, and as a nation overall.

Notes

¹Encyclopedia of Chicago, Accessed on the Web at <http://encyclopedia.chicagohistory.org/pages/1735.html>.

²Laura B. Shrestha, *Life Expectancy in the United States*, CRS Report for Congress, Washington, D.C. August 16, 2006. Accessed on the Web at <http://aging.senate.gov/crs/aging1.pdf>.

³Accessed on the Web at Pegasus.cc.ucsf.edu/~oetjen/HLTC.ppt.

⁴U.S. Department of Commerce, *Sixty Five Plus in the United States*, May 1995. Accessed on the Web at <http://www.census.gov/population/socdemo/statbriefs/agebrief.html>.

⁵Susan C. Reinhard, Enid Kassner, Ari Houser, and Robert Mollica. *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, AARP, The Commonwealth Fund, and The SCAN Foundation, September 2011.

⁶Ibid.

⁷Ibid.

⁸Ibid.

⁹Ibid.

¹⁰Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula. *Valuing the Invaluable: 2011 Update*, AARP, June 2011.

¹¹Robert L. Mollica, Enid Kassner, Lina Walker, and Ari Houser. *Taking the Long View: Investing in Medicaid Home and Community-Based Services is Cost-Effective*, AARP, March 2009.

¹²Donald L. Redfoot and Ari Houser. *More Older People with Disabilities Living in the Community: Trends From the National Long-Term Care Survey 1984–2004*, AARP, September 2010.

¹³Stephen H. Kaye, Mitchell P. LaPlante, and Charlene Harrington. "Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?," *Health Affairs*, January/February 2009: 262–272.

¹⁴Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, and Jean Accius. *A Balancing Act: State Long-Term Care Reform*, AARP, July 2008.

¹⁵Ibid.

About the Author

Enid Kassner, MSW, is director of Independent Living/ Long-Term Services and Supports for the AARP Public Policy Institute. She has nearly 30 years of experience in the field of aging as a policy analyst, researcher, author, lobbyist and speaker on a broad range of issues, including long-term services and supports, Medicaid and long-term care insurance.

Medicaid Managed Care. Improvement Initiatives. Performance Measurement. Releases & Announcements. CMS developed a number of technical assistance tools for states, and other stakeholders to enhance the availability and quality of MLTSS. These tools include: Documents outlining CMS' expectations for MLTSS programs operating under section 1115 or 1915(b) authorities. Webinar Slides: Quality Measures of Long Term Services and Supports (LTSS) Rebalancing and Utilization for State Medicaid Agencies and Managed LTSS Plans (PDF, 526.92 KB). . (Recording) CMS presented a webinar on May 22, 2019, to provide additional information about the following measures: LTSS Admission to an Institution from the Community (includes FFS version). Quality assurance and improvement Using real-time service-monitoring tools, such as electronic visit verification systems, to monitor home care delivery; analyzing encounter data and other information to create a comprehensive set of quality indicators; and posting up-to-date information on MCO quality indicators on state websites. Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports. coding system used by all payers and providers). As more states develop integrated care programs for people who are eligible for Medicaid and Medicare, consumer groups are calling for more comprehensive coordinated oversight systems between states and the federal government, in collaboration with consumers and key stakeholders.7. long-term care, ambulatory care, and pediatric settings Education and Travel Support Monthly newsletter (News and Views) Promotion of IP related education events in community Providing IP representatives for HAI policy groups (e.g., Minnesota HAI Prevention Advisory Group, CHAIN, Emerging Infections Group, MRSA Recommendations Advisory Group).