About this Paper

*High Performance Revisited* is meant to inform the LTSS State Scorecard framework in the development of the 2023 edition. The LTSS State Scorecard is a project from AARP Foundation and AARP, funded by The SCAN Foundation, The Commonwealth Fund, and The John A. Hartford Foundation.

High-Performance Revisited: Examining Long-Term Services and Supports System Performance

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Introduction

AARP Public Policy Institute (PPI) published the inaugural *Long-Term Services and Supports (LTSS) State Scorecard* (the *Scorecard*) in 2011. This first-of-its-kind project measured state LTSS system performance and ranked states in comparison to one another. Building on the work of previous scorecard projects focused on health care (e.g., the Commonwealth Fund’s State Scorecard on Health System Performance), this *Scorecard* sought to raise the profile of LTSS and drive action both federally and within states. Since then, the *Scorecard* has helped both drive and spotlight change in state LTSS systems as well as improve services and supports that older adults and people with physical disabilities receive.

Each edition of the *Scorecard* measured state performance against an objective, data-driven set of metrics, or indicators, that collectively tell a story of how states were doing with their LTSS systems at a given time. This paper is meant to discuss our approach to the 2023 edition of the *Scorecard*, reflect on what has changed since the *Scorecard* was first published, and consider how future editions of the *Scorecard* may best meet the needs of where we are today.

Definitions to Meet Today’s Needs

LTSS may involve, but are distinct from, short-term and/or medical care for older people and adults with disabilities.
Definitions of the term vary; we adopted this definition from formative research that led up to the 2011 Scorecard, including an extensive literature review, key expert interviews, and discussion with our National Advisory Panel (NAP).¹

To that end, we define LTSS as follows:

Assistance with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and complex care tasks provided to older people and other adults with disabilities who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more.

LTSS include human assistance, supervision, cueing and standby assistance, assistive technologies/devices and environmental modifications, health maintenance tasks (e.g., medication management), information, and care and service coordination for people who live in their own home, a residential setting, or a nursing facility. LTSS also include supports provided to family members and other unpaid caregivers.

A high-performing LTSS system provides services and supports in a manner that is equitable across groups, particularly by race and ethnicity. A system that delivers “good” care for some and “lesser” care for others does not serve all and cannot be considered high-performing while leaving individuals, families and communities behind.

Individuals with LTSS needs may also have chronic conditions that require health care services.

LTSS must be coordinated with housing, transportation, and health care services, especially during periods of transition among acute, post-acute, and other settings.

For the purpose of this project, we do not include services for people whose need for LTSS arises from intellectual disabilities, developmental disabilities, or behavioral health diagnoses in the Scorecard. Further, the Scorecard does not include LTSS for children.

The Scorecard Conceptual Framework

Since the Scorecard was first published in 2011, five key dimensions have framed it: affordability and access, choice of setting and provider, quality of life and quality of care, effective transitions, and support for family caregivers. As discussed in our article in Health Affairs,² these dimensions not only have framed the Scorecard since its inception but also collectively measure state system performance.

While the Scorecard framework has remained constant since 2011, each subsequent edition has brought about some indicators that were revised from the prior version as well as new indicators entirely. Depending on data availability and level of relevance, some indicators over time have been removed from the framework or replaced by other indicators. In 2011, for example, we included effective transitions as a dimension, although no data were available to populate indicators for this area, so it was not calculating in scoring for the 2011 publication. In later Scorecards, we introduced new and revised indicators to the effective transitions dimension. Exhibit 1 shows the dimensions and their respective number of indicators across each of the four Scorecards. Appendix B contains the framework for the 2011 Scorecard.


In a high-performing LTSS system...

1. **Affordability and Access** Consumers can easily find and afford services, with meaningfully available safety net for those who cannot afford services. Safety net LTSS does not create disparities by income, by race/ethnicity, or by geography.

2. **Choice of Setting and Provider** A person- and family-centered approach allows for consumer choice and control of services (including self-directed models). A well-trained and adequately paid workforce is available to provide LTSS. Home and community-based services (HCBS) are widely available. Provider choice fosters equity, and consumers across communities have access to a range of culturally competent services and supports.

3. **Quality and Safety** Consumers are treated with respect and preferences are honored when possible, with services maximizing positive outcomes- including during and after care transitions. Residential facilities and HCBS settings are adequately staffed and are prepared for emergencies. Policy-, system-, and practice-level efforts reduce and/or prevent disparities in quality and outcomes.

4. **Support for Family Caregivers** Family caregivers’ needs are assessed and addressed, so they can receive the support they need to continue their essential roles. A robust LTSS workforce limits over-reliance on family caregivers. Family caregiver supports are culturally appropriate and accessible to all communities.

5. **Community and Integration** Consumers have access to a range of services and supports that facilitate LTSS, including safe and affordable housing. Communities are age-friendly, supported by state master plans for aging. Policy and programming that facilitates livable communities also drive equitable communities.

While the dictionary definition of LTSS has not changed significantly in recent years, it is clear based on all we know has occurred over the last decade that we must revisit how we define a high-performing LTSS system and how we measure success. In 2023, we intend to update the Scorecard framework to both retain many of the key characteristics from past editions but will also adapt to current times and make needed changes to reflect our current understanding of what drives a high-performing LTSS system. To that end, in consultation with our NAP, we intend to adopt a revised approach to defining a high-performing LTSS system.

As detailed below and visualized in exhibit 2, we outline our vision for a high-performing LTSS system for the 2023 Scorecard.
This vision of a high-performing LTSS system that centers on equity will, in consultation with our stakeholders, drive the 2023 *Scorecard*.

We recognize that even a strong “average” or “median” LTSS experience may not be available to all communities—and that no LTSS system can really deliver strong results unless it can do so for people across populations, including all races and ethnicities, genders, incomes, and geographies. We intend to measure this by incorporating measures of LTSS equity throughout the framework and across multiple dimensions of LTSS system performance.

Virtually every stakeholder with whom we have engaged in recent years has cited the workforce as a critical challenge touching LTSS across all populations and services. Our next *Scorecard* will include new indicators that measure LTSS workforce size, strength, and stability.

The dimensions of quality of life and quality of care and effective transitions will merge to become a new dimension: **quality and safety**. We will keep many of the existing indicators from the two previous dimensions and intend also to incorporate new indicators that measure emergency preparedness, infection control procedures, and/or evacuation planning. The COVID-19 pandemic along with a slate of natural disasters impacting LTSS have made clear that each of these domains is essential to a strong LTSS system and must be included in the next edition of the *Scorecard*.

A fifth dimension—**community and integration**—will include long-standing indicators such as access to affordable housing. We recognize that LTSS does not take place in a vacuum. People need access to a broad range of supports that facilitate and/or allow LTSS to meaningfully occur, and the new dimension is designed to assess state performance in this area through the development of new and/or refined indicators, including those focused on housing, transportation, and key aspects of community engagement like broadband access. For example, a new indicator will measure state Master Plans for Aging (or lack thereof). We also intend to assess the presence of age-friendly communities.

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We plan to retain the critical dimensions of **affordability and access, choice of setting and provider,** and **support for family caregivers** and adjust the indicators we use for each area to reflect needed measurements both in the workforce and in LTSS equity.

In the sections that follow, we present additional context that informed our understanding of a high-performing LTSS system, including the implications of the COVID-19 pandemic for LTSS systems and demographic and policy changes over the last decade that we must consider as we proceed with the 2023 *Scorecard*.

**A Growing and Shifting Population**

In the years since the first *Scorecard* was published, there have been stark transformations both within LTSS systems and in our country more broadly that impact how people receive the services and supports they need.

First, the older adult population has itself changed. In 2010, there were about 40 million Americans over the age of 65. By 2019, more than 55 million Americans reached that age level—**a 35 percent increase**. The U.S. population grew by just 6 percent over that same period. Our country is aging, and as the Boomer generation continues to grow older, this trend is only going to escalate. By 2035, the Census Bureau forecasts that adults over age 65 will outnumber children under 18—a phenomenon that has not yet occurred in our country. We must have strong LTSS systems to meet the needs of the older population over time.

Older Americans are also becoming more diverse. The percentage of older adults who are non-Hispanic white decreased by 4 points from 2010 (80 percent) to 2019 (76 percent). Over that same time, the older Black, Hispanic, Native, and Asian populations grew faster than did the older non-Hispanic white population (see exhibit 3) and drove about 35 percent of the 65+ population’s growth since 2010.

![Exhibit 3: Growth of 65+ Population, by Race/Ethnicity, 2010-2019](image-url)

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**EXHIBIT 3: GROWTH OF 65+ POPULATION, BY RACE/ETHNICITY, 2010-2019**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2010</th>
<th>2019</th>
<th>Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>76%</td>
<td>67%</td>
<td>76%</td>
</tr>
<tr>
<td>Hispanic or Latino (of any race)</td>
<td>67%</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>American Indian and Alaska Native</td>
<td>60%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Black or African American</td>
<td>48%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander</td>
<td>34%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>34%</td>
<td>34%</td>
<td>34%</td>
</tr>
<tr>
<td>White alone, not Hispanic or Latino</td>
<td>27%</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

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4 AARP Public Policy Institute analysis of U.S. Census Bureau data


6 AARP Public Policy Institute analysis of U.S. Census Bureau data
Notably, Black, Hispanic, Native American, and Asian American adults also made up a larger share of the 55- to 64-year-old population in 2019, compared with the 65+ population, which shows that over the next decade, we will see even more diversity among older adults. As the older population continues to expand and further diversify, it will be critical for LTSS systems to have equitable services and supports in place to serve all older adults.

The last decade also saw a rise in the population of adults who need assistance to complete activities of daily living (ADLs). From 2010 to 2019, this population grew from almost 6.9 million to more than 7.4 million, a 13 percent increase. For reference, the adult population regardless of disability status grew by 9 percent over the same period.

**Demand for and Use of Home and Community-Based Services Continues to Grow**

As the population grows older, there is a greater need for LTSS and more demand for those services and supports to be delivered in a manner that people want. Over the last decade, that has meant more home and community-based services relative to institutional settings, which historically have been the primary settings for LTSS.

Public opinion polling research consistently demonstrates a public preference among older adults and/or adults of all ages to receive care in the home and community, and specifically not in nursing facilities. A 2018 AARP Research study showed that more than 3 in 4 adults 50+ want to stay in their homes and communities for as long as possible, and studies from other organizations have returned similar findings. Particularly after the peak of COVID-19, people want LTSS options outside of nursing facilities, and this longstanding consumer sentiment has informed both supply of services as well as policy to facilitate more HCBS.

As the largest public payer for LTSS, Medicaid plays a significant role in not only financing LTSS but also driving where LTSS takes place. Each fiscal year (FY) since the late 1990s has witnessed a larger percentage of Medicaid LTSS dollars going to care in home and community settings—and this figure reached 60 percent in FY 2020 across all populations. Shifting Medicaid LTSS dollars more toward HCBS has become known as “LTSS balancing,” or, in other words, leveling the playing field between institutions and the home and community. **LTSS balancing specifically for older adults and people with physical disabilities has historically lagged balancing across all populations but is similarly trending towards a larger share of dollars going to HCBS.**

Paired with increased Medicaid spending on HCBS is more people receiving Medicaid-funded services. From FY 2012 to FY 2020, state 1915(c) waiver enrollment among older adults and people with

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3 The John A. Hartford Foundation. Age-Friendly Insights: Poll Reveals How Older Adults Feel About Nursing Homes.


disabilities increased by 28 percent, from about 807,000 people to 1.03 million people.\textsuperscript{12} Enrollment in state plan personal care services, which are available across populations, similarly grew from 944,000 in FY 2012 to more than 1.2 million in FY 2020- a 27 percent increase.\textsuperscript{13} While less easily comparable with previous years, enrollment in 1115 waivers for HCBS exceeded 1.2 million in FY 2020. Enrollment in other HCBS options has also grown. More areas of the country have access to Programs for All-Inclusive Care for the Elderly (PACE) as new and existing PACE organizations expand. From 2012 to 2022, PACE enrollment has more than doubled to more than 60,000 older adults served.\textsuperscript{14}

Not all Medicaid HCBS experiences are equal, though, and literature consistently identifies disparities by race and ethnicity. For example, one study found that among Medicaid recipients of HCBS, per-person spending for white recipients exceeded spending for Black and Hispanic participants. Other studies have shown disparities in quality of services and access to services. LTSS systems must act to not only identify but also substantively reduce these disparities in order to be a considered strong systems, and our \textit{Scorecard} must contribute to measuring success in this area. At the same time, research has also found that Black and Hispanic communities are more likely to use certain HCBS and often delay nursing home entry as a result. When these populations do enter nursing homes, they often do so with higher acuities and greater care needs relative to their white counterparts.

While it is difficult to quantify how many people pay for HCBS out-of-pocket, or privately, we know that of the 52 percent of older adults who are likely to need paid LTSS some point after turning 65, more than half are projected to pay out of pocket and/or with long-term care insurance.\textsuperscript{15} Assessing the services this population pays for in a given year is important to determining a state LTSS system's overall performance.

Even noninstitutional residential settings have expanded. Assisted living facilities and other residential care communities have grown markedly in recent years. From 2012 to 2018, for example, more than 330,000 new units in residential care communities entered the market- close to a 40 percent increase from 2012. According to the data, occupancy did not declined over that time.\textsuperscript{16}

Steadily increasing enrollment in HCBS underscores how important these services are to a high-performing LTSS system. More than ever, a robust network of HCBS that provides real choices, high-quality care, and equitable access is paramount to any state having a strong LTSS system.

State policy decisions can play a significant role in whether and how much HCBS are available both to people enrolled in Medicaid and to the public at large, and the \textit{Scorecard} has and will continue to assess and rank state LTSS performance using a holistic set of measures and data. Those data and measures, however, necessarily need to change to reflect the current time and what factors do and do not matter to how well a state is doing with respect to LTSS.

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\textsuperscript{12} AARP Public Policy Institute analysis of KFF home and community-based services enrollment data, 2012-2020. See \url{https://www.kff.org/tag/homecommunity-services/}.

\textsuperscript{13} Ibid.

\textsuperscript{14} AARP Public Policy Institute analysis of National PACE Association PACE enrollment data.

\textsuperscript{15} Faverault, M. and Dey, J. Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation.

\textsuperscript{16} Centers for Disease Control. National Post-acute and Long-term Care Study. \url{https://www.cdc.gov/nchs/npals/index.htm}
More recently, the COVID-19 pandemic has altered our lives in as many ways as imaginable. LTSS is no exception. Because COVID-19 posed such an acute threat to the lives and well-being of older people and people with disabilities, how states and society adapted to the pandemic is of particular importance to LTSS system performance.

**The Impact of COVID-19 on Nursing Homes and Other LTSS**

The COVID-19 pandemic swept across the United States starting in March 2020, and quickly began impacting nursing homes and other residential LTSS settings. According to the AARP Nursing Home COVID-19 Dashboard, more than 150,000 nursing home residents and more than 2,000 nursing home staff died of COVID-19 as of May 2022.17

The pandemic exposed long-standing, structural problems facing LTSS and nursing homes in particular. These include inconsistent staffing, lack of sufficient oversight, and a low paid workforce not always equipped with the training it needs. It also showed the danger inherent in congregate settings; nursing homes that housed residents in shared rooms saw more COVID-19 spread. Disparities quickly emerged, with the early months of 2020 resulting in more deaths in nursing homes with larger Black and Hispanic populations than in other facilities.

Critically, nursing homes were caught by surprise. While no setting or individual could have anticipated the COVID-19 pandemic, the lack of emergency planning specifically in nursing homes left residents and staff vulnerable. Moving forward, it will be important for strong LTSS systems to have plans in place to ensure participant safety and continuity of care in the event of emergencies, be it a global pandemic, flu outbreak, natural disaster, or other event.

During the COVID-19 pandemic, nursing home occupancy plummeted. Residents were dying of COVID-19, and people who might otherwise have lived in a nursing home did not move into these facilities. In some states, occupancy fell to below 50 percent by mid-2020. Nursing home residency has not recovered even now, more than two years after the pandemic began. As of April 2022, the occupancy rate is at 71 percent, down from 82 percent just before the pandemic began in March 2020.18

In 2022, the National Academies of Science, Engineering and Medicine (NASEM) issued a report focused on nursing home safety, focused in part on the COVID-19 pandemic, and made several recommendations for future action. The report found that “[t]he way in which the United States finances, delivers, and regulates care in nursing home settings is ineffective, inefficient, fragmented, and unsustainable.” The NASEM report resulted in sweeping recommendations across almost every area of nursing home policy, from workforce improvements and increases, minimum staffing policies for facilities, improving cultural competency in facilities, and changing how we finance LTSS.19

Policymakers are considering their next steps following the NASEM report, and the *Scorecard* could play a role in assessing how states are positioned to act with these recommendations in hand.

COVID-19 also had a marked impact on home and community-based services and the people who relied on this support. Many providers suspended in-person services, and people who otherwise received

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18 AARP Public Policy Institute analysis of CMS Care Compare data.

support from a personal care aide or at an adult day center no longer had access to that support. This placed further strain on family caregivers who were themselves also dealing with the pandemic and led to increased acuity among many that went without HCBS. The federal policy response to COVID-19 did not prioritize HCBS, and while some states filled the gap, many did not. States did eventually receive dedicated funding for Medicaid HCBS as part of the American Rescue Plan Act, and how states choose to use these dollars could impact the strength of their LTSS systems.

Even Before COVID-19, Long-Standing Problems Existed in Nursing Homes

The COVID-19 pandemic accelerated the ongoing shift in LTSS financing and delivery from nursing homes to home and community-based options. Over the last several years, as spending on Medicaid HCBS has increased, the portion of Medicaid LTSS dollars directed to nursing homes and other institutional settings has been on a steady decline. The continued shift of both resources and consumer interest in home and community-based options has paired with a decline in nursing home usage and supply.

Reduced spending on nursing home care pairs with less utilization of these institutions. Even before the drop in occupancy following the onset of the COVID-19 pandemic, there has been a steady decline in both the number of beds available to prospective residents and the number of people who are actually living in these facilities. The reduction in residents has outpaced the reduction in beds, and the nursing home occupancy rate has fallen over the last several years.

While nursing homes struggle with occupancy, this is not the only policy challenge they present. The Centers for Medicare & Medicaid Services (CMS) regulates nursing homes and has for several decades issued regulations for these facilities. They have not, however, required that these facilities have any specific minimum staffing ratio. Rulemaking in 2016 required that nursing staff levels be “sufficient,” but did not quantify what constitutes sufficiency. Some states have taken action to set minimum ratios for facilities under their jurisdiction. Nursing home staffing is tied to patient outcomes, with literature consistently showing that facilities with adequate staffing and specifically adequate registered nurse staffing leading to better outcomes. As of 2020, adequate staffing also was proven to reduce the impact of COVID-19 in facilities.

Further rulemaking in 2017 revised the penalty process for nursing homes in violation of federal rules from a per-day basis to a per-instance basis, thereby significantly lowering the cost to facilities for noncompliance across domains. The 2017 policy was reversed in 2021, but for the years leading up to COVID-19, nursing homes were less incentivized to comply with federal regulation.

Nursing homes have also historically both mirrored and worsened disparities in health care and LTSS systems. Compared with other health care settings, these facilities are more segregated, and studies have shown that Black and Hispanic residents, compared with other nursing home residents, more often receive low-quality care and experience disparities in specific areas (e.g., pressure ulcers).

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Flinn, B. Nursing Home Closures and Trends.

Li, Y. et al. COVID-19 Infections and Deaths among Connecticut Nursing Home Residents: Facility Correlates.

Some financial issues are at play here, with a larger share of Black and Hispanic residents enrolled in Medicaid, which does not adequately cover nursing home care costs. Although nursing facilities should always provide high-quality care across populations, the financing needs to be there for every patient to receive high-quality care. Notably, limited data exist to quantify experiences of Asian, Native American, and other populations of nursing home residents.

Next Steps

This paper’s revised framework for high-performing LTSS systems will serve as the basis for the next Scorecard, due to publish in the fall of 2023. We envision a Scorecard that centers LTSS equity and fully incorporates each of our five dimensions to provide a realistic and actionable picture of LTSS system performance in a post-COVID-19 world.
Appendix A: LTSS Definition from the 2011 Scorecard

Long-term services and supports (LTSS) may involve, but are distinct from, medical care for older people and adults with disabilities. Definitions of the term vary, so we must articulate what is meant. In this report, we define LTSS as follows:

Assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided to older people and other adults with disabilities who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more.

LTSS include human assistance, supervision, cueing and standby assistance, assistive technologies/devices and environmental modifications, health maintenance tasks (e.g., medication management), information, and care and service coordination for people who live in their own home, a residential setting, or a nursing facility. LTSS also include supports provided to family members and other unpaid caregivers.

Individuals with LTSS needs may also have chronic conditions that require health/medical services. In a high-performing system, LTSS are coordinated with housing, transportation, and health/medical services, especially during periods of transition among acute, post-acute, and other settings.

For the purpose of this project, people whose need for LTSS arises from intellectual disabilities (ID) or chronic mental illness (CMI) are not included in our assessment of state performance. The LTSS needs of these populations are substantively different than the LTSS needs of older people and adults with physical disabilities. Including services specific to the ID and CMI populations would have required substantial additional data collection, which was beyond the scope of this project. This LTSS definition was developed with input from a National Advisory Panel and a Technical Assistance Panel (referred to as the Scorecard Advisors).

Appendix B: 2011 Scorecard Framework

FRAMEWORK FOR ASSESSING LTSS SYSTEM PERFORMANCE

High-Performing LTSS System

is composed of five characteristics

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

that are approximated in the Scorecard, where data are available, by dimensions along which LTSS performance can be measured, each of which is constructed from individual indicators that are interpretable and show variation across states


About the Author

Brendan Flinn is a senior policy advisor at the AARP Public Policy Institute, where he works on long-term services and supports issues, including policy affecting home and community-based services and nursing homes.

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