As the baby boomer generation in the United States continues to age into older adulthood, an unprecedented number of Americans ages 65 years and older with long-term conditions, disabilities, or frailty will need long-term services and supports (LTSS) in their lifetimes to thrive and remain as independent as possible.\(^1,2\) LTSS constitute an array of day-to-day assistance, including complex care or medical/nursing tasks (e.g., medications, wound care) and assistance with activities of daily living (e.g., eating, dressing), household chores (e.g., laundry, shopping), transportation, scheduling health care provider appointments, and other ongoing social services.\(^3\) LTSS may be provided in a range of settings, including assisted living and other supportive house settings.


and nursing facilities. LTSS also includes supportive services (e.g., respite, financial assistance) provided to family caregivers and other unpaid caregivers. Altogether, these services are meant to help older adults to maintain their independence and well-being as they age in their setting of choice as well as give family caregivers the help they need.

Older adults may need LTSS to varying degrees and durations due to age-related functional or cognitive impairments or disabling chronic conditions. Although most older adults prefer to age in place and receive LTSS in noninstitutionalized settings, such as home- and community-based services (HCBS) from family caregivers or paid providers, some may require a higher level of care delivered in a residential setting, such as nursing homes. Medicaid remains the nation’s primary payer for LTSS because the annual cost for LTSS often exceeds what individuals and families can afford to pay out of pocket, long-term care insurance is often not affordable, and comprehensive Medicare LTSS benefits are usually not available beyond a short-term LTSS need (e.g., rehabilitation). For many older adults—especially older adults of color, those who are low income, and/or in geographically underserved areas—access, availability, and affordability of LTSS continue to be barriers.

**Demographic shift in LTSS use over the years**

Like many aspects of health care, the current LTSS system was initially developed to primarily meet the needs of white older adults. However, over the past several decades, the population using LTSS has evolved because of policy changes, changing demographics, and cultural dynamics. In 2018, nearly one-quarter (23 percent) of older adults identified as Black/African American, Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, and/or Hispanic/Latino; this share is projected to increase to 34 percent by 2040. There has been a significant increase in older adults from Black/African American and Hispanic/Latino groups using LTSS, resulting from changes in family dynamics, finances, and the complexity of the care needs of this population. The shifting racial and ethnic composition of the older adult population has added complexity to the goal of providing high-quality, person- and family-centered LTSS that both meet individuals’ needs and align with their goals and preferences. Although racial and ethnic disparities in clinical outcomes in LTSS have been studied and documented for decades, research focused on racial and ethnic inequities in access to and availability

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and affordability of LTSS is more recent.\textsuperscript{9,10,11,12,13,14} Additionally, there is a growing recognition of racial and ethnic disparities among paid and unpaid caregivers of these older adults, many of whom are women and are disproportionately Black and Latino.

**Inequities defined**

The aforementioned inequities—access, availability, and affordability—that older adults experience are underscored by problems with affordability of and access to quality LTSS, limited to no choice of care setting and providers, poor safety and quality, ineffective community integration, and limited access to family caregivers or supports for family caregivers disproportionately affecting older adults of diverse racial and ethnic backgrounds.\textsuperscript{15} Inequities are perpetuated by structural racism, underinvestment, and limited data to inform evidence-based strategies. Structural racism is defined as “the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice.”\textsuperscript{16} Structural racism produces systemic disadvantages (e.g., unequal access to LTSS), which affect the social determinants of health.

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\textsuperscript{9} Feng, Zhanlian, Mary L. Fennell, Denise A. Tyler, Melissa Clark, and Vincent Mor. “Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options.” *Health Affairs* 30, no. 7 (2011): 1358–1365.

\textsuperscript{10} Travers, “Adapting Andersen’s Expanded Behavioral Model of Health Services Use to Include Older Adults Receiving Long-Term Services and Supports.”

\textsuperscript{11} Travers, Jasmine L., Mary D. Naylor, Norma B. Coe, Can Meng, Fangyong Li, and Andrew B. Cohen. “Demographic Characteristics Driving Disparities in Receipt of Long-Term Services and Supports in the Community Setting.” *Medical Care* 59, no. 6 (2021): 537.


health (e.g., transportation, housing, income, wealth, and the physical environment) and, ultimately, shape health outcomes. This is driven by a combination of multiple interpersonal (e.g., biases), structural (e.g., socioeconomic), and societal (e.g., politics) factors.

Building a high-performing LTSS system centered on equity

To optimize care access, delivery, and outcomes for all older adults, a high-performing LTSS system that centers on equity is critical. Building this system will require a robust data infrastructure that, along with stakeholder engagement, allows for ongoing assessment of inequities and successful interventions to eliminate these inequities. Evidence describing how the health of racially and ethnically diverse older adults differs across states, and LTSS settings will inform design improvements in these services and more efficient supportive measures, thereby improving health outcomes. Moreover, within these interventions to improve equitable care for older adults, it is necessary to focus on building an empowered, well-compensated, educated workforce.

To this end, AARP aims to advance targeted research, data-driven interventions, and policy and practice reforms to achieve more equitable outcomes across LTSS for beneficiaries and family caregivers through AARP’s LTSS State Scorecard. The 2023 State Scorecard looks across five domains: affordability and access, choice of care setting and provider, safety and quality, support for family caregivers, and community integration to measure state-level LTSS system performance.

Disparities in LTSS

LTSS constitute a broad range of health, personal care, and supportive services that meet health and personal care needs and allow people to live as independently as possible. The need for LTSS is generally defined based on functional limitations regardless of the cause, age of the person, where the person is receiving assistance, whether the assistance is human or mechanical, and whether the assistance is paid or unpaid. Unpaid family caregivers furnish the majority of LTSS* that older adults receive, and as a result enable older adults to live independently in their setting of choice. LTSS include care received in residential care settings such as nursing homes and assisted living and in the community via HCBS.

- **Nursing home** care is delivered in skilled nursing facilities that provide 24-hour residential care for older adults or younger people with disabilities.
- **Assisted living** includes housing, support services, and health care that are delivered in a residential care setting that is meant to be less institutional than a nursing home facility and does not require 24-hour care.
- **HCBS** are delivered in the home and community and include, but are not limited to, home health care and home care, caregiver training, home-delivered meals, transportation, home repairs, and other services. HCBS can be provided by paid and unpaid caregivers.

A growing body of evidence documents the existence of racial and ethnic disparities in nursing homes, assisted living, and HCBS regarding affordability and access, choice of care setting and provider, safety and quality, support for family caregiving, and community integration, as summarized in the following sections.

from the viewpoint of users of services and their families. This issue brief highlights research on inequities in LTSS related to the Scorecard’s five domains. This issue brief further outlines potential data sources to assess these inequities and discusses implications for how AARP plans to address these inequities through the Scorecard.

**Affordability and access**

Affordability of and access to quality nursing homes, assisted living, and HCBS have been key barriers between older adults, particularly Black/African American and Hispanic/Latino older adults.

**Nursing homes**

Nursing home care has been described as a two-tiered system wherein Black/African American and Hispanic/Latino nursing home residents are more likely to be segregated in nursing homes of the lower tier that provide poorer quality of care and are primarily Medicaid reliant when compared with their white counterparts. Lower-tier facilities, where most residents are covered under Medicaid, have fewer nurses, lower occupancy rates, and more health-related performance deficiencies. In many cases, Medicaid provides a lower reimbursement rate than other sources such as Medicare and self-pay. Over the years, the number of nursing homes serving Black/African American and Hispanic/Latino older adults has declined, furthering inequities in access and availability. Residential segregation, one manifestation of systemic racism in housing and community development, has been described as a key factor influencing existing racial and ethnic disparities in nursing homes. Black/African American and Hispanic/Latino older adults residing in segregated neighborhoods may not have high-quality care options in their area, particularly if they are Medicaid beneficiaries.

For those who do not qualify for Medicaid, it can be difficult or impossible to afford services. This is true for other Medicaid-based services, such as home-delivered meals, home health care, nonemergency medical transportation, and adult day care services. For those who do have Medicaid, copays can also be a significant burden. Further, staffing, which has a direct correlation to quality, is lower in nursing

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19 Shippee, “Evidence for Action: Addressing Systemic Racism Across Long-Term Services And Supports.”


21 Mor, “Driven to Tiers: Socioeconomic and Racial Disparities in the Quality of Nursing Home Care.”


homes located in socioeconomically deprived neighborhoods, possibly due to factors such as poorer transportation and unfavorable living environments.26

**Assisted living**

These disparities are also seen in access to assisted living settings. In recent decades assisted living (AL) facilities have gained popularity; the population in those facilities has increased from 521,500 residents in 11,459 facilities in 1998 to 811,500 residents in 28,900 facilities in 2016 (National Center for Health Statistics, 2019). Most AL facilities do not provide services that are eligible for Medicaid, leading to a higher proportion of private pay financing for services compared with that of nursing homes. AL facilities are not regulated by the Centers for Medicare & Medicaid Services (CMS) because they do not receive reimbursement from Medicare or Medicaid for services. This has led to AL facilities being regulated differently state by state and also excludes AL residents from surveys and studies conducted by CMS. Although the literature on assisted living disparities is small due to lack of data, several studies report barriers to accessing AL for racially and ethnically diverse residents compared with access for white peers. Many of these barriers are attributed to AL facilities being built in higher-income and predominantly white communities, limiting access for racially and ethnically diverse older adults who, because of systemic racism, typically are socioeconomically marginalized as well.27,28

**HCBS**

Black/African American and Hispanic/Latino older adults have unequal access to quality HCBS, such as home health, adult day services, adult foster care, and home-delivered meals.29,30 The socioeconomic status and residential location of Black/African American and Hispanic/Latino older adults, along with their increased levels of disability, have also affected this group’s ability to access quality and/or sufficient services. Additionally, higher disease burden such as obesity, comorbidities, and coronary artery disease, which are more prevalent among older Black/African American and Hispanic/Latino adults, may require more hours of care than are available and/or covered.31 For example, location is tied to decreased access to health care providers, healthy foods, and subsidized housing, along with longer

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wait-list times, all of which tend to be more problematic in Black/African American and Hispanic/Latino communities.\textsuperscript{32,33,34,35}

Limited knowledge and communication of available HCBS have also driven inequities. Evidence suggests that racial differences affect both who is assessed for and who receives the LTSS for which they are eligible.\textsuperscript{36} One potential explanation for the disparities in assessment for LTSS is observer bias. Assessment for LTSS is only as good as the tools and the people doing the assessment. Many of the tools in use don’t capture the cultural and other elements of care of all populations. In addition, if staff are not trained to recognize and reduce their bias, then assessments are affected. Furthermore, individuals from racial and ethnic Black/African American, Hispanic/Latino, Asian American/Pacific Islander and American Indian/Alaskan Native groups may not accept services because of mistrust of health care providers, lack of providers who look like them or speak their language, or entities not providing access to resources (e.g., food) that are culturally acceptable.

**Choice of care setting and provider**

Black/African American and Hispanic/Latino older adults face racial and ethnic inequities in the choice of settings of care and home health providers.

**Nursing homes**

Studies report racial/ethnic inequities in choice of setting for nursing home residents, even as nursing homes have become more racially and ethnically diverse. Between 1999 and 2008, the proportion of Black/African American, Hispanic/Latino, and Asian older adults using nursing home care increased by 11 percent, 55 percent, and 54 percent, respectively, while 10 percent fewer white older adults accessed such care.\textsuperscript{37} A continued increase in Black/African American and Hispanic/Latino older adults moving into nursing homes compared with that of white older adults between 2011 and 2017 has been noted.\textsuperscript{38}

More specific to role in choice of settings, qualitative work has shown that Black/African American older adults lack a role in choice of settings when compared with their white counterparts.\textsuperscript{39} For example,

\begin{enumerate}
\item[Choi, Yeon Jin, Eileen M. Crimmins, Jung Ki Kim, and Jennifer A. Ailshire. “Food and Nutrient Intake and Diet Quality among Older Americans.” \textit{Public Health Nutrition} 24, no. 7 (2021): 1638–47.]
\item[Shippee, “Evidence for Action: Addressing Systemic Racism Across Long-Term Services And Supports.”]
\item[Feng, Zhanlian, Mary L. Fennell, Denise A. Tyler, Melissa Clark, and Vincent Mor. “Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options.” \textit{Health Affairs} 30, no. 7 (2011): 1358–65.]
\item[Travers, Jasmine L., Karen B. Hirschman, and Mary D. Naylor. “Adapting Andersen’s Expanded Behavioral Model of Health Services Use to Include Older Adults Receiving Long-Term Services and Supports.” \textit{BMC Geriatrics} 20, no. 1 (2020): 1–16.]
\end{enumerate}
Black/African American older adults more commonly share that their entry into a nursing home was a result of a paternalistic choice or being tricked into the nursing home placement, as opposed to being a part of the decision making. By contrast, when older white adults do use nursing homes, they more commonly share that their decision to enter a nursing home is autonomous or collaborative. These shifts in nursing home use and lack of role in choice of settings among Black/African American older adults are rooted in systemic and structural issues. These issues include fewer resources in Black/African American communities to inform older adults of available options and support long-term care planning, fewer services such as assisted living in communities where Black/African American older adults live, difficulty in interpreting information on available options among Black/African American older adults, bias among providers in supporting Black/African American older adults in decision making, restrictions imposed by Medicaid on what is covered such as assisted living, and a significant wealth gap between Black/African American and white older adults that prevent Black/African American older adults from being financially equipped to have choices in long-term care settings.

**Assisted living**

The increase in use of nursing homes by Black/African American and Hispanic/Latino residents has been suggested to have been in part driven by lack of access to more desirable care settings in the community, including assisted living. A considerable proportion of white older adults can transition into assisted living and other preferred settings of care that primarily require private payment. However, these options and settings are not readily accessible to older Black/African American and Hispanic/Latino adults, as these groups are more likely to fund their LTSS through Medicaid. Black older adults are less likely to move to AL and more likely to move into a nursing home than white older adults in the community. Assisted living is also not readily available in neighborhoods where older Black/African American adults reside.

**HCBS**

Finally, racially and ethnically diverse older adults face barriers in choice of settings and provider in HCBS. The majority of Medicaid spending by states is on institutional care, which they are mandated to provide, but most HCBS are offered as a state option. States have flexibility on how their Medicaid dollars are spent, and some have focused on rebalancing efforts. The rebalancing efforts, however, are not required to be informed by the needs of diverse groups; as a result, the system continues to perpetuate inequities. This has resulted in growing disparities in who has access to and receives the care they need to stay in the community. The result has been that older adults and especially older adults from these diverse communities have less access and availability of HCBS to support transitions back to the community.

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42 Feng, “Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options.”

Programs of All-Inclusive Care for the Elderly (PACE), an exemplary model of a successful program based on HCBS, provide a comprehensive, coordinated set of health and social services to people 55 years of age and older who are eligible for nursing home placement. PACE enables adults to remain in their homes, has reduced inequities in care and outcomes among Black/African American and Hispanic/Latino older adults, and has been widely accepted in these communities.\textsuperscript{44,45} However, the requirements for PACE create barriers to accessing and affording the program. PACE is fully covered only if the individual qualifies for Medicare and Medicaid. Further, availability is limited because programs are not readily available in all communities.

Another key factor driving inequities in the choice of setting and provider for HCBS is the supply of direct care workers, including home health aides, to care for these older adults. In the United States, there are over 3.3 million home health and personal aides, and millions more are needed to support the requirements of older adults in HCBS in the coming years.\textsuperscript{46} They receive little formal training and experience for the skill required for their jobs, with a mean hourly wage of $14.87 and a median hourly wage of $14.51.\textsuperscript{47} Racially and ethnically diverse groups and immigrants, who are underrepresented across all sectors of the US workforce, are overrepresented in the direct care workforce. In 2017, 62 percent of home care workers identified as Black/African American, Hispanic (any race), Latino (any race), Asian, Pacific Islander, or other. Nearly one-third (31 percent) of home health workers are not US citizens by birth.\textsuperscript{48} Currently, an estimated 25 percent of home care workers are foreign born, and this percentage is much higher in diverse communities on the East and West coasts of the United States. Direct care workers’ racial or ethnic backgrounds, as well as other demographic identities (e.g., nationality), have implications for the poor working conditions to which they are exposed. Moreover, Medicaid reimbursement rates remain low, especially in high-poverty states with greater proportions of Black/African American, Hispanic/Latino, Asian American/Pacific Islander and American Indian/Alaskan Native, residents, which can result in high staff turnover and fragmented care for older adults.\textsuperscript{49} Language barriers and financial limitations create challenges in testing performance and enrolling in training, thus affecting supply of direct care workers. Taken together, care delivery for older adults is threatened by the lack of an adequately staffed, empowered, compensated, and satisfied workforce to care for this population. Moreover, direct care workers from these backgrounds are more likely to work in racially and ethnically diverse communities, thus contributing to the inequities experienced by older adults in these communities as a result of a shorter supply of workers who lack adequate resources, support, and training to provide quality care to older adults.

\textsuperscript{44} Travers, Jasmine L., Sara D’Arpino, Christine Bradway, Sarah J. Kim, and Mary D. Naylor. “Minority Older Adults’ Access to and Use of Programs of All-Inclusive Care for the Elderly.” Journal of Aging & Social Policy 34, no. 6 (2022): 976–1002.


\textsuperscript{46} Spetz, Joanne, Robyn I. Stone, Susan A. Chapman, and Natasha Bryant. “Home and Community-Based Workforce for Patients with Serious Illness Requires Support to Meet Growing Needs.” Health Affairs 38, no. 6 (2019): 902–09.


Safety and quality

Safety and quality specific to poor care, scarce services, staffing issues, and inappropriate health care use are other areas where racial and ethnic inequities are seen across LTSS.

Nursing homes

Among nursing home residents, Black/African American and Hispanic/Latino adults report worse quality of care and quality of life. A large body of evidence documents disparities in quality of care: Black/African American residents are more likely to be physically restrained than their white counterparts,\(^50\) are less likely to have their pain treated,\(^51\) receive influenza and pneumococcal vaccines less often,\(^52\) and are more likely to develop pressure ulcers.\(^53\) Nursing homes with a higher proportion of Black/African American residents have higher rates of antipsychotic use,\(^54\) an issue that the Centers for Medicare & Medicaid Services have flagged as an important policy priority. Finally, Black/African American and American Indian adults also report a significantly lower quality of life compared with that of their white counterparts.\(^55\)

HCBS

Among users of Medicaid HCBS, Black/African American or Hispanic/Latino older adults are more likely to receive lower-quality HCBS, as indicated by fewer hours of direct care, fewer skilled services, and worse outcomes. Black/African American, Hispanic/Latino, and Asian Medicare home health patients are less likely to achieve functional improvement through home health care than their white counterparts, who otherwise are similar with respect to health status and functional limitations.\(^56\) Among home health patients with diabetes, Black/African American patients receive fewer nursing and clinical therapy visits, and Hispanic/Latino patients receive less physical therapy and home health aide services.\(^57\) In terms of health care utilization, there are disproportionate rates of hospitalizations and readmissions among racially and ethnically diverse older adults for users of HCBS.\(^58\)


African American, Hispanic/Latino, and Asian Medicare home health patients are more likely to utilize emergency department services or to be rehospitalized than their white counterparts.\(^{59,60}\)

**Staffing ratios and turnover**

Another measure of safety and quality in nursing homes pertains to staffing ratios and staff turnover. These are rooted in the underpayment, understaffing, and undervaluing of the nursing home direct care workforce. The direct care workforce in nursing homes is made up of mostly women and people of color,\(^{61}\) and a plurality of direct care workers (DCWs) identify as immigrants. Among certified nursing assistants (CNAs), the primary providers of direct care to nursing home residents, 86 percent are women and 59 percent are people of color, with nearly one in five (18 percent) living in poverty and more than two in five (44 percent) managing personal financial responsibilities (e.g., rent, childcare, medical bills) on low incomes.\(^{62}\) Beyond the hands-on services and support DCWs provide to residents on a daily basis (e.g., bathing, eating, toileting, dressing, and walking), DCWs provide emotional and spiritual support to nursing home residents, gaining insights into residents’ unmet health and social needs. DCWs are undervalued, as reflected not only by their low wages nationwide, making an annual mean wage of $32,090 in the nursing home setting,\(^{63}\) but also by their experiences of disrespect, verbal and physical abuse, and exclusion from important decision-making activities. CNAs experience a significant amount of discrimination in the workplace and that race was a main factor in explaining social-based discrimination toward CNAs, with more than 56 percent of CNAs reporting that they experienced racist speech and acts by nursing home residents.\(^{64}\)

Moreover, there is a significant shortage of CNAs, which is even more severe in nursing homes serving a high proportion of Black/African American residents and in nursing homes located in socioeconomically deprived neighborhoods.\(^{65,66}\) Other areas of concern for CNAs are the significantly high turnover among this workforce, reflecting the poor environments that they work in, as well as the limited education and training they receive to care for an increasingly complex resident population.\(^{67,68}\) By and large, nursing

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59 Fashaw-Walters, “Out of Reach: Inequities In The Use Of High-Quality Home Health Agencies.”


64 Travers, “Exploring Social-Based Discrimination Among Nursing Home Certified Nursing Assistants.”


homes in socioeconomically deprived communities have poorer working conditions and, as a result, experience higher rates of turnover. This affects the quality of care residents receive.

**Support for family caregivers**

Despite providing the largest bulk of care for older adults, support for family caregivers is often limited, especially among racially and ethnically diverse groups. Family caregivers are often unprepared to care for their older adult loved ones, and services such as respite, financial support, and counseling groups are not always readily available or made known to them, depending on their location and relationship type (e.g., child, spouse, neighbor, friend). For example, Black/African American, Hispanic/Latino, Asian American family caregivers report varying awareness of HCBS and preferences by service type (e.g., homemaker services, nutrition, transportation), leaving many of these family caregivers to not use these services or to use them later in the caregiving process. Further, cultural barriers identified specifically among Asian family caregivers included caregivers not wanting outsiders coming in, services being unavailable, and inability of caregivers to find qualified providers.

More than half of today’s family caregivers are employed, yet federally and in most states, family leave is unpaid, making it difficult for many employed caregivers, particularly low-wage workers, to take time off for caregiving. Family caregivers can experience severe financial consequences when caring for an older adult: loss of income because of the need to work limited hours or leave the workforce altogether, cost of paying for additional help to provide care, and need to cover everyday expenses (e.g., food, transportation, clothes, medications, copays, housing, utilities). These changes affect the ways in which older adults engage with LTSS in that they must now increasingly rely on paid LTSS to support their care needs. For older adults who opt to self-direct their HCBS, increasing Medicaid reimbursement for family caregivers and legally responsible persons could have positive implications for equity in HCBS. Particularly, family caregivers are able to be paid in many states for the care that they provide to older adults. There is an urgent need for programs and services that are accessible, affordable, and tailored to the needs of diverse communities of caregivers.

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**Community integration**

Older adults have the right to be integrated into the community in which they reside; however, disparities affect racially and ethnically diverse older adults’ abilities to age in place, especially in the support of transitions from hospital to home, where home health and HCBS support are critical. Black/African American patients are more likely than white patients to be readmitted to the hospital within 30 days of a home health discharge. Even for Medicare home health services, studies report inequities in the timely initiation of home health services after hospital discharge among adults 65 and older. Several factors may contribute to racial disparities in hospital readmission after a transition from home health care, including disparities in access to needed health services, socioeconomic status, health literacy, and cultural beliefs and practices.

**Implications for the Scorecard and available data sources**

As demonstrated by the review of the literature, persistent racial and ethnic inequities exist in the access to and use of HCBS and nursing home care. These disparities are driven by a variety of factors related to access, availability, and affordability, including changes in family dynamics leading to decreased informal support; limited knowledge and communication of available LTSS; fewer community-based options in underserved, predominantly Black/African American, Hispanic/Latino, and low-income communities; costs of services; and Medicaid investment in community HCBS. One key strategy to address these inequities is to measure and report LTSS access, availability, and affordability by race and ethnicity. Reporting and measuring LTSS systems for racial and ethnic groups at the state level are important to understanding who is receiving LTSS, monitoring the quality, and improving equity in LTSS delivery. As supported by various frameworks and called for by various consumer groups, listing measures of quality by race and ethnicity is of interest to consumers, can guide state quality improvement, and can help address existing disparities.

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80 Shippee, “Evidence for Action: Addressing Systemic Racism Across Long-Term Services And Supports.”


As such, data specific to LTSS quality by race and ethnicity are critical to the feasibility and effectiveness of measuring who is receiving services in state LTSS systems. By providing data on use of services by race/ethnicity, we can further understand if gaps exist in the quality, access, availability, and affordability of care. The Scorecard has historically employed several public- and private-sector data sources to measure state LTSS systems across each dimension. However, it has not measured LTSS system performance through an equity lens or explored potential disparities that exist by race and ethnicity. Several data sources may be able to help achieve this goal, fostering an approach where equity across communities is integral to a strong state LTSS system. Currently, even when measures are reported by race and ethnicity, several groups have been excluded because of low numbers. The Scorecard makes every attempt to include these groups when possible. It is also important that each dimension of the Scorecard list quality measures by race and ethnicity, with documented disparities in affordability and access, choice of care setting and provider, safety and quality, and community integration. Given the significant racial and ethnic disparities in caregiver support, it is also important to report scores for different racial and ethnic groups in the dimension of family caregiving. In table 1, we review current and potential new data sources analyzed in the Scorecard and discuss the degree to which they can or cannot help in measuring equity.

**TABLE 1. KEY DATA SOURCES FOR THE 2023 SCORECARD**

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Sample Indicators</th>
<th>Does the source include race/ethnicity data?</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Community Survey</td>
<td>• Low-income people with disabilities with Medicaid&lt;br&gt;• Home health aide supply&lt;br&gt;• General population data (e.g., as a dominator for other data sources)</td>
<td>Yes</td>
</tr>
<tr>
<td>CMS Care Compare for Home Health</td>
<td>• Home health hospital admissions</td>
<td>No</td>
</tr>
<tr>
<td>CMS Care Compare for Nursing Homes</td>
<td>• Nursing home staff turnover*&lt;br&gt;• Nursing home staffing*</td>
<td>Yes</td>
</tr>
<tr>
<td>CMS LTSS Spending Data</td>
<td>• Medicaid LTSS spending balance</td>
<td>No</td>
</tr>
<tr>
<td>CMS Minimum Data Set</td>
<td>• Nursing home antipsychotic use&lt;br&gt;• Nursing home residents with pressure sores</td>
<td>Yes</td>
</tr>
<tr>
<td>Genworth Cost of Care</td>
<td>• Nursing home cost&lt;br&gt;• Home care cost</td>
<td>No</td>
</tr>
<tr>
<td>National Center for Health Statistics LTC Survey</td>
<td>• Adult day services supply&lt;br&gt;• Assisted living supply</td>
<td>No</td>
</tr>
<tr>
<td>PHI Direct Care Workforce State Index</td>
<td>• LTSS worker wage competitiveness*&lt;br&gt;• LTSS worker wage pass through policies*</td>
<td>No</td>
</tr>
<tr>
<td>State Policy Data (qualitative)</td>
<td>• Family caregiver support indicators</td>
<td>Varies</td>
</tr>
</tbody>
</table>

*Denotes new indicator for the 2023 Scorecard not featured previously.
Operationalizing equity in the LTSS Scorecard

In the 2023 Scorecard, the Scorecard team scores and ranks states based on an equity-informed approach for those indicators that have data stratified by race/ethnicity available. In consultation with experts in the field and with the Scorecard National Advisory Panel, the team’s approach operationalizes the Scorecard definition of LTSS equity. Specifically, the Scorecard scores a state’s performance in a given area based on the performance of its lowest-performing group and ranks states by each of their respective lowest-performing groups relative to the national average.

Limitations and other considerations

This revised version of the Scorecard aims to address gaps in eliminating disparities and to expand its current scope to include measures of racial and ethnic equity. Although this is an important step, additional aspects need to be considered. First, an intersectional approach is needed that includes other measures of equity, such as sexual and gender orientation, in addition to existing measures. Second, the Scorecard aims to promote data transparency; however, sensitivity around nursing homes and other providers that serve a high proportion of Black/African American and other racially and ethnically diverse residents should be considered for how data are used by each state. Further, there are unintended consequences to consider. For example, states may look to close sites of care that repeatedly have poor quality outcomes and report high disparities for these groups, as opposed to investing in improving care in these sites. Finally, it is important that data metrics by race and ethnicity be provided for different care settings and not just nursing homes, for which data are currently available. Such metrics should be used to construct an overall measure of racial and ethnic equity for racial and ethnic groups in each respective state. For nursing homes, such reporting would happen at the facility level, aggregated to the state level. For HCBS, different sources of data need to be used to assess consumer satisfaction (which is currently missing) and other quality metrics by race and ethnicity. This work needs to happen in partnership with various stakeholders to identify the necessary sources of data for HCBS.

Conclusion

Understanding current demographic trends and the interactive effects of age, race, and ethnicity, as well as other aspects of identity, has implications for LTSS system performance specific to equity. Looking ahead, stakeholders will be challenged to develop and implement equity-focused, evidence-based strategies to meet the growing demand for high-quality, person- and family-centered LTSS in institutional and community-based settings. The acknowledgment of structural racism as the root causes of racial and ethnic disparities across the LTSS continuum is a first step toward achieving health equity, as color-blind policies and data systems perpetuate and reinforce systemic racism within and across care settings. Moreover, eliminating disparities and inequities in LTSS, from unequal access due to neighborhood-level factors to institutional bias, will require a multipronged approach that includes research, provider training, legislative reform, and advocacy. Identifying these issues as they exist by race and ethnicity is critical. The Scorecard will be a catalyst for building a high-performing LTSS system centered on equity.

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