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Evidence for Action: Addressing Systemic Racism across Long-Term Services and Supports

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Abstract

Long-term services and supports (LTSS), including care received at home and in residential settings such as nursing homes, are highly racially segregated; Black, Indigenous and persons of color (BIPOC) users have less access to quality care and report poorer quality of life compared to their White counterparts. Systemic racism lies at the root of these disparities, manifesting via racially segregated care, low Medicaid reimbursement, and lack of livable wages for staff, along with other policies and processes that exacerbate disparities. We reviewed Medicaid reimbursement, pay-for-performance, public reporting of quality of care, and culture change in nursing homes and integrated home- and community-based service (HCBS) programs as possible mechanisms for addressing racial and ethnic disparities. We developed a set of recommendations for LTSS based on existing evidence, including: (1) increase Medicaid and Medicare reimbursement rates, especially for providers serving high proportions of Medicaid-eligible and BIPOC older adults; (2) reconsider the design of pay-for-performance programs as they relate to providers who serve underserved groups; (3) include culturally-sensitive measures, such as quality of life, in public reporting of quality of care, and develop and report health equity measures in outcomes of care for BIPOC individuals; (4) implement culture change so services are more person-centered and home-like, alongside improvements in staff wages and benefits in high-proportion BIPOC nursing homes; (5) expand access to Medicaid-waivered HCBS services; (6) adopt culturally-appropriate HCBS practices, with special attention to family

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caregivers; (7) and increase promotion of integrated HCBS programs that can be targeted to BIPOC consumers, and implement models that value community health workers. Multipronged solutions may help diminish the role of systemic racism in existing racial disparities in LTSS, and these recommendations provide steps for action which are needed to reimagine how long-term care is delivered, especially for BIPOC populations.

Brief summary:

Caring for a diverse older population requires an understanding of how systemic racism lies at the root of racial and ethnic disparities in the delivery and quality of Long-term Services and Supports.

Keywords

systemic racism; long-term services and supports; equity; policy; disparities

Introduction

Between 2014 and 2060, the number of Americans aged 65 and older is expected to increase by 92%, leading to a growing need for health care and non-health care related services that help people with physical and cognitive limitations live as independently and safely as possible.[1] These services are referred to as long-term services and supports (LTSS). Additionally, the population of older adults will become more racially and ethnically diverse.[2] Caring for an increasingly diverse older adult population that needs LTSS requires an understanding of how LTSS are being delivered today. At present, LTSS are not provided equitably. Long-term care facilities are more racially segregated than other health care settings and disparate outcomes exist among both nursing home (NH) and home care users in more disadvantaged areas.[3–5] The COVID-19 pandemic has put a spotlight on the inequitable delivery of LTSS, with studies finding disparities in infections, hospitalizations, and deaths among NHs that primarily serve Black, Indigenous, and people of color (BIPOC) residents.[6]

Assuring that all Americans have access to high quality LTSS requires specific and intentional actions to address racial/ethnic disparities. A root cause of disparities in LTSS is systemic racism, broadly operationalized as a system of structuring opportunity based on race/ethnicity, which disadvantages some individuals and communities and unfairly advantages others.[7–9] Systemic racism has been recognized as a public health crisis and occurs on many levels, including intrapersonal, interpersonal, institutional, community, and systemic.[10] Within the context of LTSS, systemic racism can be manifested through segregation, delivery of care, government reimbursement, or other regulatory policies that exacerbate disparities.

In this paper, we document the evidence on the significant racial/ethnic disparities in NH and home- and community-based services (HCBS) in relation to systemic racism, outline existing policies that may improve or exacerbate racial/ethnic disparities, and make policy recommendations for action. In doing so, we apply the National Institute on Aging (NIA)

health disparities framework to identify mechanisms through which systemic racism is manifesting in LTSS and strategies to address it.[11] The framework calls out the role of environmental, sociocultural, behavioral and biological factors in shaping health access and outcomes over the life course, with specific examples included for LTSS outlined in Table 1. We focus primarily on environmental and sociocultural factors over the life course, specifically socioeconomic, cultural, geographic and health care disparities in LTSS. Our work builds on a recent commentary by Sloane and colleagues on systemic racism in NH care but expands the focus to LTSS more broadly, including HCBS.

Racial/Ethnic Disparities in LTSS

Nursing Homes

Persistent and significant racial/ethnic disparities (e.g., antipsychotic medication use, resident outcomes and care practices, COVID infections/deaths) have been documented in NHs despite federal regulations prohibiting the provision of disparate care to residents with similar care needs.[6,12–19] Racial segregation is a key source of these disparities.[14] First, many residents prefer NHs that are in close proximity to their homes, and due to residential segregation, NHs may have a higher prevalence of residents of their own race/ethnicity.[20] Second, high-proportion BIPOC NHs (i.e., NHs that primarily serve BIPOC residents) are structurally different from primarily White NHs, such as having fewer staff and greater reliance on Medicaid reimbursement, which may not cover the cost of care.[3,21] High-proportion BIPOC NHs also have organizational features associated with lower quality of care and life (e.g. for-profit ownership, high staff turnover).[6,12,22–25] In summary, racial segregation in NHs acts as a significant "barrier to the effective delivery of LTSS."[3] This has led to a two-tiered system where NHs that have more Medicare and private-pay residents have the resources to provide high-quality care, whereas NHs that are more reliant on Medicaid, which includes the majority of NHs serving BIPOC residents, do not have resources to provide high-quality care.[26]

Home- and Community-Based Services (HCBS)

Historically, LTSS were provided in NHs, but since the early 2000s, many states have shifted LTSS from NHs to home and community settings, which include adult day services, assisted living (AL), and care provided at home (e.g., personal care, homemaking services). Patterns of racial/ethnic inequity have been identified in HCBS access and quality. Black and Hispanic older adults are less likely to access AL services because the AL industry is predominantly driven by private-pay consumers, so areas with greater AL availability are more often located in White-dominant residential areas with higher socioeconomic status (SES).[27,28] Many states have implemented Medicaid waivers to expand AL access but eligibility for the waivers is limited.[29]

Existing research evidence on racial/ethnic disparities in HCBS is mixed and limited in scope.[4,30–33] Some studies show that BIPOC (vs. White) individuals are *more* likely to use home care services while others show they are *less* likely to use Medicare-covered home health care services and/or specific types of services like physical therapy or skilled nursing.[4,34–36] A limited number of studies have documented the existence of racial/ethnic

disparities in home health care outcomes (e.g., functional/disability status, emergency department use, hospital readmissions) and user experiences.[4,30,32,33]

Disparities in outcomes among HCBS users are the result of several factors, including those driven by systemic racism. Some research findings posit that *decreased access* is associated with the racial composition of neighborhoods while others suggest that changes in Medicare and Medicaid reimbursement policy may contribute to access disparities.[4,34,37] While decreased *access to high-quality HCBS* may be the main barrier driving these disparities, access alone may not be enough when other health and social infrastructure is lacking.[36] One study demonstrated a lack of awareness, reluctance, unavailability, and affordability of services as the main reasons for unmet need for HCBS, even though BIPOC individuals tend to have high care needs and low informal support.[38] Indeed, unawareness and lack of information about services is commonly expressed among older adults and their caregivers – many individuals do not know where to find information about or how to access HCBS, and persons with lower financial status have greater odds of limited access.[39] These barriers are especially pronounced for BIPOC older adults, who often live with disabilities and limited financial means. Other factors contributing to the disparities in HCBS outcomes include limited availability of services in rural communities, lack of culturally tailored services (e.g., lack of staff who speak languages other than English, culturally considerate home-delivered meals), and inadequate supports for family and unpaid caregivers.

In summary, while LTSS rebalancing efforts have prioritized care in community settings, this shift has failed to ensure equitable distribution of access to care settings that reflect older adults' preferences and goals.

Existing Policies that May Improve or Exacerbate Racial/Ethnic Disparities

In this section, we review existing policies pertaining to LTSS access and quality, and discuss how these can potentially improve or exacerbate racial/ethnic disparities (see Table 2 for a summary).

Changes in Medicare and Medicaid Reimbursement Practices

Reducing racial/ethnic disparities in LTSS requires financial investment in NHs and HCBS. Reimbursement for services has direct consequences for the amount of resources LTSS providers can invest in care. Higher nursing staff levels are associated with higher NH quality,[40–42] but BIPOC residents are more likely to live in NHs that rely on Medicaid reimbursement and have lower staffing levels compared to White residents.[43] Therefore, racial/ethnic disparities are inherently linked to payer-mix, reimbursement rates, and payment models. NHs are responsive to reimbursement levels, and increase staffing levels when Medicaid or Medicare increase reimbursement rates.[44,45] Enhanced Medicare and Medicaid reimbursement rates are likely to decrease disparities, especially if these rates are tied to payer-mix, increasing nursing staff levels, and quality improvement efforts.

Higher reimbursement rates may also allow providers to retain more skilled workers, improving LTSS access and outcomes.[44–52] While states increased Medicaid payment rates to LTSS providers during the COVID-19 pandemic as part of the Disaster-Relief State Plan

Amendments and other efforts (e.g., CARES act),[53] it is not clear if the current relief efforts are sufficient and if they can be continued.

Pay-for-Performance Medicare and Medicaid Reimbursement

Some state Medicaid programs have implemented pay-for-performance (P4P) reimbursement models, which incentivize providers to improve quality. While conceptually appealing, P4P models implemented in the NH setting have had mixed or no changes in measured quality.[54,55] Some P4P programs are designed so that most NHs receive performance payments, resulting in no real incentive to improve quality.[56] Other P4P programs are structured to be budget neutral, which could create a zero-sum game where some providers benefit at the expense of others that typically have greater Medicaid payer-mix and hence more BIPOC residents. If greater Medicaid payer-mix providers cannot qualify for performance payments, this will lead to fewer resources in facilities that are more likely to serve BIPOC individuals. Therefore, government reimbursement policies that at their face value attempt to incentivize improvement in quality are actually worsening disparities.

Public Reporting of Quality Measures

Public reporting of providers' quality of care is a market mechanism that attempts to improve quality through the promotion of competition for LTSS consumers. Multiple studies have found public reporting can improve quality but may also exacerbate racial/ethnic disparities by changing the relative payer-mix of providers.[57] In particular, older adults with higher socioeconomic status are more likely to seek out and obtain services from providers who have publicly-reported higher ratings, leaving providers with lower ratings with more Medicaid-reimbursed consumers and fewer financial resources.[26,57–59] The net result is that communities with lower resources, including those where older BIPOC Americans reside, tend to have lower quality providers, and in some cases these lower quality providers may exit the market, further limiting access.[57,58]

Current national reporting of LTSS quality of care on the Center for Medicare & Medicaid Services (CMS) Care Compare website focuses on quality of care and regulatory metrics such as the number of deficiencies. These measures do not address the role of person-reported outcomes such as resident quality of life or family satisfaction, which would provide consumers with information on cultural aspects of care (e.g., meals; activities).[22,31] CMS could also consider developing an overall measure of health equity, reflecting how well the provider meets the needs of a diverse population (e.g., BIPOC).

Culture Change in NHs

Culture change in NHs is an extensive transformation of how NH care is delivered, with an ultimate goal of creating a person-centered, home-like model of care.[60] Though there are various models (e.g., Green House Model), culture change is believed to increase quality of life for residents and family, and provide a more resilient workforce by empowering staff and making the NH more home-like.[61] Adopting culture change practices, such as consistent staff assignment, universal staffing, and self-managed work schedules, resulted in fewer incidences of deaths from COVID-19 in Green House Model NHs.[62]

Culture change is a promising way to improve racial/ethnic disparities but is more likely to be adopted in NHs with lower proportions of BIPOC residents.[9] Furthermore, culture change adopters are mostly distributed in states with higher Medicaid reimbursement rates and P4P programs targeting culture change measures.[63]

Integrated HCBS Programs

Multiple states have implemented integrated care programs that promise to facilitate aging in place for older adults. One of these is the Programs of All-Inclusive Care for the Elderly (PACE), which coordinates and delivers a comprehensive range of health and social services for NH eligible adults aged 55 and older. PACE has been shown to reduce inequities and align with the needs of racial/ethnically diverse older adults.[64,65] For example, Black PACE enrollees were found to have a lower mortality rate and better functioning outcomes when compared to White enrollees. Yet, the program is currently serving about 55,000 older adults even though 3 million could benefit.[65] Limited evidence exists on Black and Hispanic older adults' perceptions regarding *access* to PACE and *use* of PACE services. Addressing these gaps in knowledge is foundational to the design of interventions aimed at improving full access to and optimal use of PACE by diverse populations.

A similar integrated care program is Community Aging in Place, Advancing Better Living for Elders or CAPABLE. Originating in Baltimore, CAPABLE utilizes an interdisciplinary team and person-directed, consultative model involving home sessions by occupational and physical therapists and nurses, and funds for home modifications and assistive devices to older adults with functional difficulties.[66] The original CAPABLE program primarily served Black persons, and the program has been able to reduce hospitalizations and emergency department visits, and improve functioning.[67] CAPABLE has been implemented in 33 sites in 17 states.[68]

Policy Recommendations

Systemic racism exacerbates disparities related to educational attainment, assets, access to care, and drives residential segregation. While systemic racism can both create and perpetuate disparities in later life,[9] there are multiple policies that can be implemented now to reduce racial/ethnic disparities in LTSS (Table 2).

First, access to, and the quality of, LTSS services provided to older BIPOC service recipients is directly tied to Medicaid reimbursement. Without significant financial resources, LTSS providers cannot invest in more staff and other drivers of quality of care, and some HCBS providers may not be willing to care for residents in lower income neighborhoods. Medicaid reimbursement rates to LTSS providers should be increased, but this needs to be balanced against limited state budgets. Therefore, we recommend targeted increases to Medicaid reimbursement tied to direct care, and targeted enhanced Medicare and/or Medicaid reimbursement to LTSS providers that serve a disproportionate share of Medicaid or underserved older adults. Frameworks for these types of payment models already exist, such as Medicare using the Disproportionate Share Adjustment (42 CFR 412.106) applied to hospitals that serve a disproportionate share of low-income patients.[69] Such an approach is also consistent with our recommendation to improve access to and quality of LTSS where

people live, though a long-term goal should be to reduce segregation in health care settings. As the literature shows, providers serving the BIPOC population are predominately reliant on Medicaid, and addressing financial resources via targeted reimbursement increases is important for reducing disparities. Yet, it is important that any reimbursement increases be spent on improving LTSS users' care experiences and outcomes, and not provider profits. Therefore, policymakers should consider using mechanisms that tie any increases in reimbursement to quality improvement efforts and that hold providers accountable using this additional funding in a transparent manner.

Second, policymakers should reconsider the design of P4P incentives. These incentives should focus on improving care among LTSS providers who serve individuals with disadvantaged status due to systemic racism and that operate above and beyond a person's clinical severity and comorbidity. By tying risk adjustment or P4P payments to social determinants of health, such as SES, rurality, and race/ethnicity, more resources will be available to providers who serve these populations. Yet, some caution is warranted. Adjusting for social determinants of health would reduce the financial risk to some providers, but doing so across the board would *weaken* the incentive to improve care, and it could imply that providers do not need to meet the same standard of care for BIPOC persons or other disadvantaged persons. This requires policymakers to carefully select appropriate social determinants of health, or to develop measures of health equity that can be used to construct P4P structures that incentivize improvement instead of rewarding absolute performance.

Third, public reporting of quality is another avenue for policy change. Previous work has called for more culturally-sensitive quality measures, including quality of life and family satisfaction, to make public reporting a more useful tool for BIPOC users.[57,58] If public reporting is to help address existing disparities, CMS needs to undertake efforts that put equity at the center. We provide three specific recommendations for CMS: (1) develop an overall health equity measure which would help capture how well providers meet the needs of diverse populations; (2) calculate existing Care Compare quality scores by race/ethnicity to be used internally and shared with states to develop culturally appropriate policies; and (3) report race/ethnicity-specific quality measures on state-level report cards to incentivize action among states and tailor solutions to the local context. In addition, we recommend paying attention to more nuanced measures for staff other than nursing, such as number of hours for activity and social work staff. Previous work has found that activity staff and social workers play a key role in improving quality of life for residents but such measures are not reported.[22]

Fourth, incentives are needed for culture change adoption and promotion to more person-centered, home-like models in high proportion BIPOC NHs. While not all NHs can adopt home-like models, they can implement culture change care practices, such as consistent assignment, staff empowerment strategies, and flexible work schedules – which have been shown to benefit residents. By adopting culture change and increasing wages, NHs can decrease staff turnover. Indeed, opportunities for career growth are an important strategy for retention, which is associated with better resident outcomes. Culture change adoption

and job pay/career ladder go hand in hand because increased pay alone in an undesirable environment will most likely not yield improvements.[70]

Fifth, *access* to Medicaid-waivered HCBS needs to be expanded. While Medicaid is the primary payer for LTSS, many older adults receiving care in the home are not Medicaid-eligible, or are subject to long waitlists.[71] These challenges create an opportunity for the Medicare program to expand to cover HCBS. Medicare Advantage allows for coverage of some HCBS, but there is tremendous variation in the administration and availability of services. AL settings provide an alternative to traditional community living for older adults with disabilities, but they are not equitably accessed by BIPOC users due to caps for Medicaid enrollees and other factors. States should find ways to incentivize AL providers to accept more Medicaid enrollees.

Sixth, states should work to ensure that HCBS are culturally appropriate in order to support the goals and preferences of the older adults they serve. This might include providing culturally tailored Meals on Wheels and offering services in various languages to help support persons from diverse backgrounds. Culturally-tailored services should also include resources and supports for family and unpaid caregivers, who provide the majority of HCBS. This is especially needed for caregivers from BIPOC communities who, compared to their White counterparts, provide care to older adults with greater functional and cognitive impairment with fewer resources.[72] For example, HCBS programs could be strengthened through the implementation of caregiver assessments to document and assess caregiver needs.[73] Additionally, existing initiatives such as the RAISE Family Caregiving Council and the National Family Caregiver Support Program should specifically consider racial and ethnic disparities when making recommendations for supports for caregivers.[74,75] Finally, there is a need to increase awareness of services via models that encourage community health workers to refer their clients to HCBS; such models have been shown to be effective for Medicaid-enrolled older adults.[76]

Finally, states should better promote integrated HCBS programs that can be targeted to BIPOC users to address existing disparities in HCBS outcomes. Incentives are needed for evaluation and adoption of integrated HCBS beyond small programs (e.g., CAPABLE, PACE) that are often regionally based. These integrated programs should also be better targeted to BIPOC communities.

Multipronged solutions may help diminish the role of systemic racism in existing disparities in LTSS. These recommendations provide steps for action which are needed to reimagine how long-term care is delivered, especially for BIPOC populations. Investment in addressing racial/ethnic disparities in LTSS by governmental entities, policymakers, and providers alike is needed in order to see reductions in inequities and improvements in care access, delivery, and quality for BIPOC communities.

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Table 1.

Applying the NIH Health Disparities Framework to Racial/Ethnic Disparities in the U.S. LTSS System

Environmental	Sociocultural	Behavioral	Biological
Socioeconomic factors	**Cultural factors**	**Health behaviors**	**Physiological factors**
• Personal/family income • Wealth • Education • Knowledge • Health literacy	• Preferences for proximity of care • Preferences for facilities with similar racial composition • Preferences for care in non-residential settings	• Substance abuse • Physical activity • Diet	• Functional decline • Physical comorbidities • Mental health
Geographic factors	**Social factors**	**Coping factors**	**Role of cumulative stress**
• Neighborhood residential segregation • Area-level social disadvantage • Geographic variation in access to care	• English language proficiency • Immigrant status • Systemic racism in long-term care • Systemic ageism • Family values and norms that impact care delivery	• Acceptance/ resigna tion to lack of other options • Role of social support • Presence/absence of social support	• Premature biological aging
Health care	**Psychological factors**	**Psychological risk/resilience**	
• Availability of services • Access to services • Type of insurance (Medicare, Medicare Advantage, Medicaid vs. private pay) • Quality of care and quality of life • Government regulation and policies	• Cognition and cognitive decline • Resilience • Social isolation	• Sense of personal control/lack of control • Chronic stress • Social integration • Relationship quality	

Note: LTSS: Long-term Services and Supports

*Our approach is driven by the NIH Health Disparities Framework, which proposes that environmental, sociocultural, behavioral, and biological domains should be considered when addressing health disparities. This model is appropriate for examining the impact of racial inequities in the U.S. LTSS system, with particular attention to the role of environmental and sociocultural domains. We include examples of factors relevant for the LTSS outcomes under different domains in the model.[11]

Table 2:

Policy Evidence and Recommendations Pertaining to Racial and Ethnic Disparities in LTSS in the U.S.

Policy	Evidence on its Impact on Disparities	Policy Recommendations & Who Should Act
Medicaid and Medicare reimbursement	Payer mix and reimbursement rates exacerbate disparities.	Targeted increases to Medicaid reimbursement that are tied to direct care. Enhanced and targeted Medicare/Medicaid reimbursement to providers serving a disproportionate share of Medicaid or underserved older adults.
Pay-for-performance (P4P) program incentives	Current approach to P4P has increased the disparity between providers who serve high proportion Medicaid and BIPOC users and those who do not.	Tie risk adjustment and P4P reimbursement to social determinants of health (SDOH). Key determinants include: socioeconomic status, rurality, and/or structural racism. Focus should be on selecting appropriate SDOH or constructing health equity measures aimed at incentivizing improvement instead of rewarding absolute performance.
Public reporting of quality	Current measures are not culturally sensitive and are not useful for consumers.	CMS should lead efforts to create an overall measure of health equity that is meant to capture provider ability to meet the needs of diverse populations. Calculate existing Care Compare quality scores by race/ethnicity, to be used internally by CMS and shared with states to develop race-conscious policies. State report cards should report race-specific quality measures and measures for staff other than nurses (e.g., activity staff, social workers).
Culture change in NH	Culture change practices have been shown to benefit resident outcomes. Culture change practices that facilitate career growth opportunities for staff help improve retention.	Among high proportion NHs, adopt culture change practices such as: consistent staff assignment, staff empowerment strategies, and flexible work schedules. Provide opportunities for career growth and increased wages to improve staff retention.
Medicaid HCBS waiver programs	Information on HCBS programs for eligible older adults is not easily accessible. Some older adults in need of home-based care are not Medicaid eligible. Long waitlists limit access to Medicaid HCBS.	States should incentivize AL providers to accept more Medicaid-waivered residents. Expand Medicare coverage for HCBS to fill gaps in Medicaid covered services.
HCBS program design	Disparities in HCBS outcomes are related to a lack of culturally-tailored services. Caregivers from BIPOC communities provide a larger portion of care to older adults with greater functional and cognitive impairment.	States should design culturally appropriate HCBS programs, such as culturally-tailored Meals on Wheels, or offer non-English speaking services. Culturally-tailored services should also include resources for family and unpaid caregivers. To increase awareness of HCBS programs, develop models that utilize community health workers as referral initiators.
Integrated HCBS programs	BIPOC users have lower access to some integrated HCBS Programs.	Integrated HCBS programs need to be targeted to BIPOC users and be more equally distributed across the country. Incentives are needed for evaluation and adoption of integrated programs that go beyond small and regional models (e.g., CAPABLE, PACE).

LTSS: Long-term Services and Supports; BIPOC: Black, Indigenous and People of Color; HCBS: Home- and Community-based Services