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Addressing Systemic Factors Related to Racial and Ethnic Disparities among Older Adults in Long-Term Care Facilities

Rebecca L. Mauldin, Shellye L. Sledge, Ebonie K. Kinney, Sarah Herrera and Kathy Lee

Abstract

Disparities in older adults' care and experiences in long-term care facilities (LTCFs) such as nursing homes and assisted living/residential care communities reflect disparities in the broader society. Various policies and institutional practices related to economic opportunity, education, housing, health care, and retirement financing have created and maintain inequitable social structures in the United States. This chapter describes racial and ethnic disparities among older adults in LTCFs in the United States and the systemic factors associated with those disparities. It presents a conceptual framework for understanding the role of structural racism in the racial and ethnic inequities experienced by LTCF residents. In the framework, structural racism directly contributes to racial and ethnic inequities among LTCF residents through LTCF-related policies and practices. Structural racism also indirectly causes disparities among LTCF residents through health and economic disparities. The chapter describes current efforts that address the effects of structural racism within LTCFs and concludes with practice and policy recommendations to redress racial and ethnic disparities among LTCF residents.

Keywords: long-term care facilities, nursing homes, assisted living communities, health disparities, racial and ethnic inequities, Medicaid policy, Long-Term Care Ombudsman Program

1. Introduction

Structural racism affects individuals and communities across the life course. For older Americans, inequities in health access, quality, and outcomes caused by racism and systemic barriers in the United States can be exacerbated in later life in a variety of domains including physical and cognitive health, mortality rates, and quality of care. Systems for care in later life include long-term care facilities (LTCFs) such as nursing homes and assisted living/residential care communities. Paired with the demographic trend of increasing proportions of older adults from historically minority racial and ethnic groups [1] is a growing utilization of LTCFs by people of color [2]. Unfortunately, older adults of color in the United States experience disparities in access to quality nursing homes; access to care in assisted

living communities; quality of care and quality of life in LTCFs; health outcomes as LTCF residents; and social engagement within LTCFs. These disparities are associated with a variety of structural factors (e.g., federal and state policy related to LTCF funding and oversight, housing policies that have created racially segregated communities, and workforce practices that lead to income and wealth disparities). The growing number of people of color in LTCFs and persistent disparities within them creates an urgency to address racial and ethnic inequities in quality of care and quality of life for older adults of color living in LTCFs.

1.1 Long-term care facilities (LTCFs)

Older adults who experience chronic limitations in physical and cognitive functioning may need long-term services and supports. Long-term care encompasses a range of services and supports that assists individuals in completing activities such as dressing, preparing meals, medication management, and housework [3]. Most long-term care is provided at home by family caregivers [4]; however, long-term care is also available in long-term care facilities (LTCFs). The need for long-term services and supports increases as individuals age, as does the likelihood of not having the assistance of a spouse who can provide informal care. For this reason, and due to the aging of the population in the United States, a growing number of older adults are utilizing LTCFs [3, 5].

In the United States, the majority of the funding for long-term services and supports comes from public sources, but many people privately pay or use private long-term care insurance [6, 7]. Medicaid, a means-tested program, is the primary funder of care in LTCFs. The federal and state governments jointly fund Medicaid, but it is administered by the states. Each state sets its own eligibility requirements for Medicaid, which include income and resource limits. In contrast, Medicare is administered at the federal level, and eligibility requirements are tied to eligibility for Social Security or Railroad Retirement benefits [8].

1.1.1 Nursing homes

Nursing homes are residential communities that provide a higher level of care than can often be provided at home or through other community-based services. Nursing homes may also provide health care services such as physical or occupational therapy to help patients recover from illnesses or injuries. The median monthly U.S. nursing home cost in 2020 was \$8,821 for a private room and \$7,756 for a semi-private room [9]. Most nursing home residents pay for long-term nursing home care with Medicaid, with Medicare paying for more short-term post-acute nursing care in skilled nursing facilities [10].

Private nursing homes became common in the United States beginning in the late 1930s, after the Social Security Act of 1935 prohibited older adults who lived in public almshouses from receiving Old Age Assistance [11]. Wealthier White older adults were able to afford private nursing home care; however, this option was financially inaccessible for poorer White people and poorer people of color [12]. Public funding for nursing home care was not available until the 1950s [13]. These policy decisions created financial barriers for people of color, particularly African Americans, to access nursing home care.

In contrast to the past, today older adults of color are overrepresented in the nursing home population, representing approximately 25% of nursing home residents [2, 10]. The trend for increasing portions of residents of color in nursing homes seems to be driven in part by White older adults disproportionately accessing more appealing alternatives to nursing homes that are funded by Medicaid waivers for Home and

Community-Based Services [2] and privately paying for care in assisted living communities [14]. At the same time that an increasing percentage of people of color are using nursing homes, there have been increased closures of nursing homes across the country, with closures concentrated in disadvantaged communities of color [2].

Nursing homes tend to be quite segregated by race and ethnicity [15], a phenomenon related to past structural racism. Policies such as the 1946 Hill-Burton Act (which funded construction of “separate but equal” nursing homes) and southern Jim Crow laws combined with discriminatory practices in hospital discharge planning and nursing home admissions to create and maintain segregated nursing home systems [12, 16, 17]. In the 1960s, the Johnson administration failed to use provisions of the Civil Rights Act to desegregate nursing homes and prohibit discrimination in nursing home practices [12, 17, 18]. Housing policies such as redlining created and perpetuated racial segregation of neighborhoods which in turn supported racial segregation of nursing homes, as nursing home residents tend to come from their surrounding communities [15].

1.1.2 Assisted living/residential care communities

Assisted living or similar residential care communities are another type of LTCF. They serve older adults who cannot live alone safely, but do not need the level of care provided at nursing homes. They offer personal care and household assistance to residents in a homelike environment. Assisted living and residential care communities can range from small homes with a few residents to large communities of private apartments in large residential settings, which tend to be chain-affiliated and owned by for-profit companies. These communities generally provide communal meals and opportunities for socialization and physical activities in addition to personal care services. Assisted living communities tend to be in urban/suburban areas and communities characterized by high levels of education, income, and financial resources [2]. Licensing of assisted living/residential care communities is at the state level, with variations across the states.

Many Americans have a more favorable impression of assisted living than of nursing homes, and it the fastest growing model of residential long-term care [19]. The 2020 median monthly cost of assisted living care was \$4,300 – substantially less than care in a nursing home [9] – but prohibitive for many to pay out of pocket. Medicaid only covers assisted living in states that have Medicaid waivers for Home and Community-Based Services that fund assisted living [20]. Although most states have these waivers, the coverage is low, and smaller and poorer states are less likely to adopt Medicaid waivers [21]. Furthermore, Medicaid eligibility, benefits, cost sharing requirements, and reimbursement rates vary by state [22], and evidence suggests that racial bias within a state is related to lower levels of Medicaid spending [23]. A few states do not provide any Medicaid funding for assisted living/residential care and in others, Medicaid covers personal care, but not room and board. In states that do fund assisted living with Medicaid, low reimbursement rates and the costs of administering Medicaid deter many assisted living providers from becoming Medicaid certified [24]. Indeed, less than half of the assisted living/residential care communities in the United States accept Medicaid [10]. As might be suggested by these systemic barriers, older adults of color are underrepresented in assisted living communities [10, 25].

2. Racial and ethnic disparities in U.S. long-term care facilities

The almost half-million older adults of color who currently live in U.S. LTCFs [3] face disparities along a variety of dimensions including health outcomes, quality

of care, quality of life, and social integration compared to non-Hispanic White residents. Much of the evidence of racial and ethnic disparities in long-term care comes from nursing homes, which are federally mandated to provide detailed health outcome and demographic data for their residents. This evidence points to racial and ethnic disparities in health and quality of life outcomes, engagement with health services, and access to quality care.

In nursing homes, health outcome disparities are evidenced by findings that Black residents have a higher risk for developing pressure ulcers [26, 27] which can lead to serious medical complications, and are less likely to recover from pressure ulcers present when they are admitted [28]. There are ample examples of racial and ethnic disparities in engagement with health services and health care quality within LTCFs. Black residents have received less pain management [29], have been subject to more use of physical restraints [30], and are less likely to receive a flu vaccine [31] compared to White residents. Black residents and those categorized on medical records as coming from “other” racial groups (e.g., American Indian/Alaska Native; Native Hawaiian/Pacific Islander) were found to be less likely to have toileting plans for incontinence than White residents [29]. Depressive symptoms – which can have severe mental health consequences if depression is left untreated – seem to be underreported for Black, Latinx, and Asian nursing home residents [32].

Racial and ethnic disparities in quality of life outcomes such as cultural fit and social engagement have also been reported. For example, higher proportions of minority residents in nursing homes are associated with more quality of life deficiencies reported in the facility [33]. Chinese residents have reported a lack of culturally appropriate food, which related not only to their feelings of belonging and being valued, but also to receiving enough nutrition [34]. Compared to White residents, Black, Latinx, and other nursing home residents of color have scored lower on social engagement measures that include interacting with others, accepting invitations to group activities, being at ease in group/structured activities, and establishing their own social goals [35]. Indeed, nursing home residents of color have reported lower quality of life indicators than White residents across multiple domains, including personal attention, food, engagement within the facility and with staff, and mood [36].

Data regarding complaints received by the U.S. Long-Term Care Ombudsman Program extends our understanding of racial and ethnic disparities in LTCFs to include assisted living communities. The Long-Term Care Ombudsman Program is a federally mandated program administered at the state level that advocates for LTCF residents in both nursing homes and assisted living communities. Local ombudsmen conduct site visits, make referrals as needed, provide resident and public education, engage in policy advocacy, and receive and resolve complaints on behalf of residents. In their role as resident advocate, state Ombudsman Programs are well positioned to enhance our understanding of racial and ethnic disparities among LTCF residents. However, State Ombudsman Programs are not required to collect and report data about the race and ethnicity of the residents for whom they receive complaints; they are only required to report aggregate-level race and ethnicity data for the facilities under their purview.

A recent study of ombudsman complaints in the Dallas, TX, area collected race/ethnicity data associated with resident complaints in an examination of racial and ethnic differences in complaint types and resolution rates [37]. Residents of color were more likely than White residents to file complaints related to residents’ rights (i.e., abuse, access to information, autonomy, financial rights). Interestingly, complaints more likely to be resolved in nursing homes and assisted living communities with higher percentages of minority residents; however, this finding was related to the resolution of complaints from or on behalf of White residents living

in those communities [37]. In focus groups, ombudsmen noted they had witnessed residents of color who refrained from making complaints about care compared to complaints about rights for fears of retaliation or being branded as a problem in the community. The ombudsmen also described ways in which LTCFs did not provide culturally appropriate environments for all residents (e.g., staff who could not communicate with residents in their language). Finally, the ombudsmen provided additional information about staffing ratios at Medicaid-certified facilities noting at times that only one aid would be available to care for a dozen residents needing aid.

2.1 Between- and within-facility sources of racial and ethnic disparities in LTCFs

As described earlier in this chapter, LTCFs tended to be racially segregated which relates to disparities in access to quality LTCF care. Many of the racial and ethnic disparities LTCF residents experience arise from differences between LTCFs that serve higher percentages of residents of color, particularly Black residents, and those that serve lower percentages [27, 33, 36]. LTCFs that serve higher percentages of residents of color tend to have fewer financial and community resources and insufficient staffing, with a correspondingly high number of care deficiencies, inadequate direct care, and low quality of care ratings [33, 38–40]. Economic factors play a major role in these differences. In general, LTCFs with higher concentrations of residents of color rely more on Medicaid funding than LTCFs serving predominantly White residents and are therefore more constrained by Medicaid's lower reimbursement rates [33, 38, 39]. Indeed, the more Medicaid-reliant a nursing home is, the fewer resources it has to devote to resident-directed care and activities, improving the home environment, and other quality of life and quality of care related pursuits [41].

Although facility-level differences account for many of the racial and ethnic disparities among nursing home residents, disparities still exist within individual facilities such as in vaccination rates and quality of care [31, 42]. This can be attributed in part to an unconscious provider bias, which can lead to health care providers limiting the amount of information they share with residents of color and result in less patient-centered communication [43]. It can also be related to the fact that people of color tend to be admitted to nursing homes with worse health and greater care needs [44].

2.2 COVID-19 and racial and ethnic disparities in long-term care facilities

The COVID-19 pandemic ushered in a heightened awareness of structural racism and discrimination related to the provision of health care to older adults. Communities of color were disproportionately affected by COVID-19 infections, severe illness, and deaths [45]. The Centers for Disease Control and Prevention [46] reported that approximately 22% of the COVID-19 deaths in the United States in 2020 occurred in LTCFs. Prior to the pandemic about 63 percent of nursing homes had infection-control deficiencies [47]. Because older people of color were overrepresented in nursing home populations in general – and specifically more likely to reside in lower-quality nursing homes – this put them at an increased risk for contracting infectious diseases like COVID-19. Indeed, facility-level disparities quickly became apparent. In the early months of the pandemic in the United States, *The New York Times* [48] reported that nursing homes with higher percentages of Black or Latinx residents were twice as likely to report COVID-19 infections than those with predominantly White residents. A subsequent analysis of Centers for Medicare & Medicaid Services data through May 2020 had similar findings [49].

Nursing homes with higher portions of residents of color tended to be in areas with higher levels of COVID-19 cases and deaths. It also found that LTCFs with higher proportions of residents of color were more likely than those with low proportions of residents of color to experience COVID-19 infections and deaths and report a shortage of aids during the pandemic [49].

3. Conceptual framework for understanding role of structural racism in inequities among long-term care facility residents

To understand and address the effects of structural racism for LTCF residents, this chapter proposes a conceptual framework with elements from critical race theory, social determinants of health, and life course perspectives of inequity. **Figure 1** presents a graphical image of this conceptual model for understanding the role of structural racism in racial and ethnic disparities among LTCF residents. In this framework, structural racism directly contributes to increased racial and ethnic inequities among LTCF residents through LTCF-related policies and practices. It is also the root cause of economic and health disparities, which in turn cause racial and ethnic disparities among LTCF residents.

3.1 Direct effects of structural racism

The first tenet in our conceptual framework is that structural racism – the reinforcement of a racial hierarchy privileging “whiteness” and disadvantaging “color” through policy, systems, and institutional practices – is a direct cause of racial and ethnic inequities among LTCF residents. It is important to recognize that racism is so deeply embedded in the very fabric of U.S. society that the nation has, in a sense, become desensitized to it. Critical race theory responds to this need by shining a light on the role of race and structural racism in contemporary inequities [50].

To understand racial and ethnic disparities among LTCF residents, it is necessary to identify how structural racism directly affects their experiences. For example, the societal decisions to restrict public financing of LTCFs to Medicaid and to provide low levels of Medicaid reimbursement have created racial and ethnic disparities in access to quality LTCF care. Black, Latinx, American Indian/Alaska

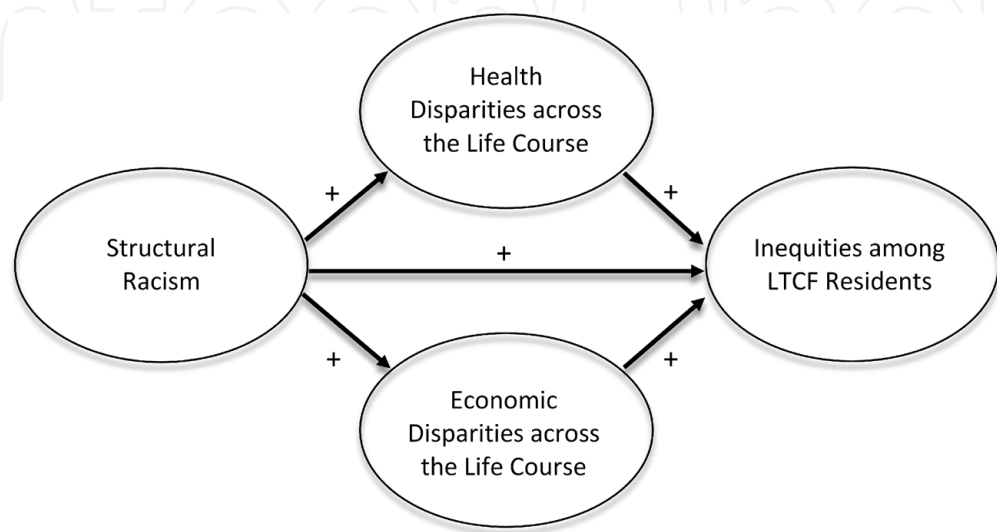


Figure 1. Conceptual framework for understanding and addressing racial and ethnic inequities among long-term care facility residents.

Native, and multiracial people are more likely to have Medicaid coverage or be dual eligible for Medicare and Medicaid [51]. As a result, LTCFs that rely on Medicaid funding tend to have higher portions of residents of color [52]. These more Medicaid-dependent LTCFs tend to provide poorer quality of care than those with more generous funding streams [27, 33, 36]. Policy decisions restricting Medicaid reimbursement rates are not color blind; low rates of Medicaid reimbursement are correlated with higher levels of racism within a state [23]. Another example of structural factors associated with inequities in health services engagement and health outcomes for LTCF residents is federal regulations that fail to specify racial equity in their oversight of residents' quality of care and quality of life [53], in essence whitewashing the unique experiences and challenges of residents of color.

3.2 Health disparities

The second component of our conceptual framework relies on the Social Determinants of Health Framework. This framework recognizes that health is a social phenomenon across the life course, determined in part by social contexts and stratification [54]. When new residents are admitted into nursing homes, those from historically minority ethnic and racial groups tend to be younger, in poorer physical health with greater physical dependency, and have higher levels of cognitive impairment and care needs than newly admitted White residents [44]. These racial and ethnic disparities in health outcomes influence the level of care needs residents have once admitted and the quality of life they can experience.

Experiencing racism at the individual or personal level leads to worse physical and mental health outcomes for people of color [55]. However, the influence of racism systemically in the United States also leads to poorer health though its impact on economic stability, education, health care systems, and social and neighborhood environments [56]. The Social Determinants of Health Framework acknowledges that structural forces such as social policies, education and public health systems, social safety nets, politics, and societal values all affect health outcomes and health equity. Intermediary social determinants of health such as housing and neighborhood physical environment, financial resources, psychosocial stressors, and behavioral factors are caused by these structural factors.

There are abundant and interrelated examples of structural factors associated with the social determinants of health and racial and ethnic health disparities [56]. Access to quality health care in the United States requires insurance coverage or the financial means to pay for services. However, discriminatory hiring practices have disproportionately excluded people of color from higher paying jobs and jobs that provide health insurance. Furthermore, a confluence of policies and discriminatory practices from Jim Crow laws to the intentional exclusion of Black Americans from Social Security coverage in passage of the Social Security Act of 1935, as well as discriminatory hiring practices have resulted in economic inequities that span decades of unjust outcomes affecting generations of families [11, 56, 57]. Discriminatory practices in the criminal justice system and the War on Drugs have disproportionately targeted and incarcerated Black men [56], removing them from the paid workforce and economic opportunity. Income and wealth are important social determinants of health on their own and as factors associated with access to health care and healthy environments. Historical policies such as redlining and current discriminatory practices in rental and housing markets combined with economic disparities lead to racially segregated neighborhoods with communities of color being more likely to be placed near environmental health hazards or contain substandard housing [56, 58]. This also reduces opportunities for people of color to generate wealth through real estate [56]. The placement of health care services

in predominantly White communities has made geographic access to health care difficult for people of color. Within health care systems, people of color experience both interpersonal and institutional racism resulting in worse care and disparities in engagement with health services [56].

The original model of Social Determinants of Health took pains to distinguish the social causes of health from unjust societal factors [54]. More recently, scholars have acknowledged the prominent role of structural racism in health outcomes [12, 56, 57]. Yearby [12] has reconfigured the original model to remove this distinction and place structural racism as a prominent root cause of racial health disparities [12]. In her reconfiguration, structural discrimination is the force that shapes aspects of social policy and systems of public health, neighborhood environments, education, and the economy. Our model for understanding and addressing racial and ethnic inequities among LTCF residents incorporates this perspective placing structural racism as an indirect effect on disparities in LTCFs by creating the conditions that result in poorer health for LTCF residents.

3.3 Economic disparities

The third feature of our conceptual model relates to the economic inequities experienced by people of color across the life course [59, 60]. It has long been acknowledged that nursing homes that serve higher proportions of Medicaid-paying residents are more likely to serve Black residents and have poorer staffing ratios and more care deficiencies [38]. This is relevant to racial and ethnic disparities because, as discussed in Section 3.2, due to economic disparities in the United States, Black and Latinx residents are more likely than White residents to have limited financial means [59, 60]. Inequality in wealth and income makes people of color more likely to rely on Medicaid for LTCF funding. This inequality is caused by systemic barriers to higher paying jobs, professional networks, educational opportunities and ownership of valuable real estate. Economic inequities can also explain why White LTCF residents compared to residents of color are disproportionately opting out of care in nursing homes in favor of receiving care in assisted living [14]. Although the homelike setting of assisted living makes it appealing [61], the cost of assisted living and the need for private pay in many assisted living communities exclude people of color with limited savings.

3.4 Life course perspective of disparities among LTCF residents

The vast majority of LTCF residents are older adults. In nursing homes, most residents are age 75 or older and in assisted living/residential care communities, over half are at least 85 years old [10]. These older residents carry with them a lifetime of experiences, opportunities, and injustices. American-born residents who are 85 years old today grew up in the United States when racial discrimination was legal and codified in many state laws. Lynchings by White people targeted Black citizens in the south and Mexican nationals along the Texas-Mexico border [62]. Many older LTCF residents were in their 20s and 30s when the Civil Rights Act of 1964 was passed. Unequal opportunities and oppression of people of color continued throughout their lifetimes and persist today.

Taking a life course perspective on the accumulated effects of inequities adds perspective to disparities among LTCF residents. The Matthew effect explains that inequalities, once they occur, become a perpetual cycle, and in the absence of advocacy, widen the gap between the advantaged and disadvantaged [63]. The Matthew effect framework closely aligns with the theory of cumulative (dis) advantage/dis-advantage [64], which has been used to examine inequities in a variety of domains

including health, well-being, and aging [65, 66]. One approach to distinguishing the two frameworks is to consider the Matthew effect (or *mechanism*) as the macro-level process of increasing societal inequality while thinking of cumulative advantage or disadvantage as the accumulated effect of positive or negative circumstances on an individual [64]. Through life course perspectives of inequality, it becomes evident that by the time older adults enter LTCFs, their financial and health status has accrued over decades. Intervention to address structural racism and its effect on economic, education, and health care systems early in life is necessary. Nonetheless, it is never too late to redress inequities, and LTCF residents deserve interventions aimed at eliminating the racial and ethnic disparities they experience.

Individuals who have experienced an accumulation of advantages early in life may find the concept of Matthew effects unsettling [63]. These very people may be overrepresented in positions of power such as policy-makers and LTCF chief executive officers as a result of their early advantages. In spite of this, it is necessary for individuals in the position to make meaningful change in LTCF disparities to recognize the accumulating effects of structural racism across the life course. Without policies or interventions in place to address the vicious cycle of compounding advantage and disadvantage, social inequities will widen [63].

4. Policies to address racial and ethnic health disparities in long-term care facilities

There are myriad federal, state, and local policies that affect racial equity in LTCFs because the long-term care system is integrally connected to systems of – and structural racism within – housing, economic opportunity, and health care. In this section, we present federal and state policies directly related to LTCFs. Federal policy applies across all states and territories and is the prevailing law in terms of citizen rights when there are discrepancies between federal and state law. State laws can vary widely, and while state law can provide additional rights and protections to citizens beyond what is provided by federal law, it cannot reduce those rights.

4.1 Existing federal policy

There are broad prohibitions against racial discrimination within federal law and regulations. Regulations of the U.S. Department of Health and Human Services (DHHS) prohibit health care providers who receive federal funding from discriminating against people of color [67]. The federal Fair Housing Act prohibits discrimination based on race, color, or national origin in assisted living/residential care communities [68].

Federal policy also works to eliminate health disparities. The Patient Protection and Affordable Care Act of 2010 mandates and funds efforts to redress racial and ethnic health disparities. The Office of Minority Health reports directly to the Secretary of Health and Human Services and works to improve the health and quality of care of people from racial and ethnic minority groups and eliminate racial and ethnic health disparities [69]. There are also separate Offices of Minority Health within six DHHS agencies and the National Institute on Minority Health and Health Disparities within the National Institutes of Health that seek to eliminate health disparities.

4.1.1 Centers for Medicare & Medicaid Services regulations

Because approximately 72% of the funding for long-term care in the United States comes from federally funded programs [10], the Centers for Medicare &

Medicaid Services is a major regulator of LTCFs. This includes regulations and guidance for Medicare- and Medicaid-participating LTCFs [70] and assisted living/residential care communities that receive funding through Medicaid waivers for Home and Community-Based Services [71]. It is important to note, however, that over 14,000 assisted living/residential care communities in the United States do not accept Medicaid funding and are therefore not subject to any regulations by the Centers for Medicare & Medicaid Services [10].

Many of the Centers for Medicare & Medicaid Services regulations specifically for LTCF operations pertain to the quality of care and quality of life of residents [53]. Overall, these regulations do not mention race and ethnicity (apart from including “insults based on race” in the definition of abuse). Rather, they speak more broadly to concerns such as residents’ rights to “a dignified existence” and freedom from discrimination in exercising rights [53]. In fact, in crafting the 2014 regulations for Medicaid waivers for Home and Community-Based Services, the Centers for Medicare & Medicaid Services noted they had received several public comments recommending specific non-discrimination protections in the policy but chose not to include them because more general provisions existed elsewhere in Medicaid policy [71]. Additionally, although the Centers for Medicare & Medicaid Services provides detailed guidelines for state surveyors of Medicare- and Medicaid-certified nursing homes and training for nursing home staff, the regulations do not specify assessments or training related to racial and ethnic disparities in LTCFs [53].

4.1.2 Long-term care ombudsman program policies

As described in Section 2, the federally mandated mission of the Long-Term Care Ombudsman Program is to advocate for LTCF residents. The federal government provides detailed regulations for state Long-Term Care Ombudsman Programs and their local-level designees, including the types of policies they must have, required qualifications for staff, and the need to submit a publicly available annual report of their activities to the U.S. Administration on Aging and their state’s government [53]. Like the provisions of the Centers for Medicare & Medicaid Services, the regulations of the Long-Term Care Ombudsman Program do not identify racial and ethnic equity as an explicit concern in their guidelines. For example, the required qualifications for Ombudsman Program staff do not include any skills or knowledge of racial health equity [53]. Another omission is in the reporting requirements which do not mandate disaggregation of complaint data by race and ethnicity which would allow the program, public, and lawmakers to evaluate racial and ethnic disparities related to residents’ complaints [53].

4.2 Existing state policy

States can create policies to license, inspect, and regulate LTCFs. In fact, they are responsible for the bulk of oversight of assisted living/residential care communities. States cannot create regulations for nursing homes that are less stringent than federal policy, but for assisted living, each state has the latitude to set its own standards. These vary widely across domains of building and occupancy requirements, training, staffing requirements, and resident assessments [72]. States differ in the ways they distinguish and treat board-and-care homes for older adults – which tend to serve older adults of color – and assisted living communities [73]. The variation of state regulations for assisted living is related to the liberal/conservative leaning of state legislatures, the states’ bureaucratic capacities (e.g., capacity of the state Long-Term Care Ombudsman Program), and even the salaries of the legislators [68].

The lack of consistency in LTCF oversight and commitment to addressing racial health disparities across the states (see for example [74]) highlights the importance of a federal response to address inequities among LTCF residents.

5. Examples of policies and practices with the potential to address racial and ethnic disparities in LTCFs

The root causes of inequities among LTCF residents lie in structural racism and ultimately need to be addressed across multiple domains of economic opportunity, housing, and health care systems. Nonetheless, there are responses at the LTCF-level that demonstrate promise to reduce the consequences of structural racism. This section presents efforts with the potential to address structural racism and reduce inequities among LTCF residents.

5.1 Universal long-term care coverage

Across the globe, some high-income countries like the United States provide universal access to LTCF benefits through social long-term care insurance (i.e., Germany, Japan, Luxembourg, the Netherlands, and South Korea) or taxpayer funded long-term care (i.e., Denmark, Finland, Norway, and Sweden) [75]. By making coverage universal, these countries avoid the inequities that arise from relegating long-term care coverage to means-tested programs such as Medicaid in the United States. Universal long-term care helps ensure that all citizens have access to long-term care regardless of their financial circumstances and removes potential stigma associated with receiving public assistance. The countries with universal long-term care coverage do not have the unique social circumstances related to race and structural racism as the United States. However, it is reasonable to expect that the equalizing effects of universal long-term care exhibited elsewhere would include reducing racial and ethnic disparities among U.S. LTCF residents.

Within the United States, the State of Washington is implementing universal social insurance for long-term care within its borders [76]. In 2019, the state legislature passed the Washington Long-Term Services and Supports Act, which funds the Washington Cares Fund. Beginning January 1, 2022, Washington employers will be required to collect 0.58% of an employee's wages as premiums for long-term care insurance. Beneficiaries of the fund can receive up to \$36,500 for a variety of long-term care services and supports including care in assisted living/residential care communities and nursing homes [76]. This program is the first of its kind in the United States and can serve as an example for other states or ultimately for a federal program of universal long-term care benefits.

5.2 Medicaid

Because older adults of color are more likely to live in LTCFs that are funded predominantly through Medicaid, the states have an opportunity to address racial and ethnic LTCF disparities through their Medicaid programs. Limited Medicaid funding results in residents of color disproportionately living in LTCFs that are under resourced and poorly staffed. However, some states' Medicaid policies have improved the quality of care or life for residents of color. One solution is as straightforward as increasing Medicaid's per diem reimbursement rates LTCFs. In a longitudinal study of nursing home citations for care deficiencies from 2006 to 2011, Li et al. [77] found evidence that increased reimbursement rates reduce disparities between nursing homes with high- and low-percentages of minority residents.

In another example, Hernandez [24] found in 2012 that the state of Oregon provided Medicaid reimbursement for apartment-style assisted living. Compared to states like Florida which, at the time, reimbursed for assisted living units with as many as two to four roommates in a room, the practice in Oregon could provide better quality of life for assisted living residents. A state-by-state comparison of policies for state funding for assisted living/residential care (see, for example, compilations like [78]) can provide additional insights into how state policy can affect older adults in LTCFs.

5.3 Private sector initiatives

Within the private sector there are also examples of initiatives aimed at awareness, education, and elimination of racial and ethnic disparities in LTCFs. In Canada, the Ontario Centres for Learning, Research & Innovation in Long-Term Care have created resources for LTCFs including a toolkit for embracing diversity; a diversity and inclusion calendar; diversity, equity, and inclusion (DEI) posters for use within LTCFs; and publications, reports, and toolkits related to indigenous culture and care for indigenous residents [79]. The toolkit for embracing diversity includes an instrument LTCFs can use to assess their LTCF and plan DEI efforts [80]. It contains detailed assessment items for DEI in seven domains: planning and policy, organizational culture, education and training, human resources, community capacity building, resident and family engagement, and service provision. It also provides a template for LTCFs to create SMART goals (i.e., specific, measurable, assignable, realistic, and time-bound) related to DEI in their homes. In the United States, the Oregon Health Care Association, the largest long-term care trade association in the state of Oregon, helps connect its member LTCFs to resources related to race and racism, including information on cultural trauma; Black, Indigenous, and other People of Color (BIPOC) mental health; bystander intervention, and racial justice [81]. While these efforts may not dismantle structural racism itself, they can affect change in individual LTCFs or LTCF chains resulting in reduced disparities for residents of color.

6. Recommendations

The process of eliminating the effects of structural racism among LTCF residents is seemingly impossible without first acknowledging the history and plight of persons of color in the United States. Inequities in access to quality LTCFs have existed since the rise of private nursing homes in the late 1930s. In the U.S. society, systems of economic opportunity, education, housing, health care, and retirement financing have created and perpetuated racial disparities in health outcomes, engagement in health care services, and quality of care. The effects of structural racism accumulate over the life course, resulting in heightened disparities by the time older adults enter LTCFs. Immediate action at the LTCF policy- and practice-level is needed to reduce the inequities to which thousands of LTCF residents of color are subjected. This section focuses on actionable policy and practice recommendations geared toward the residents and systems directly connected to LTCFs. However, as our conceptual model for understanding and addressing racial and ethnic disparities among LTCF residents suggests, structural racism is a force across the life course. To ensure future cohorts of older adults experience racial equity and justice in LTCF-settings and systems, we must conquer structural racism and its resulting health and economic disparities across the life span.

The process of effectively eliminating structural racism can seem like a daunting task. However, the examples in the preceding section demonstrate the potential for tangible results that improve the LTCF experience for residents. Because structural racism is directly and indirectly associated with racial and ethnic disparities experienced by LTCF residents, policymakers and practitioners need to employ a critical lens to understand and rectify its effects for LTCF residents. This critical approach includes four domains: awareness, acceptance, advocacy, and action related to structural racism and its effects. **Table 1** presents these domains with LTCF-related examples. In terms of *awareness*, policymakers and practitioners can increase their own and others' awareness of historical and current racial injustices related to LTCF inequities (e.g., inequitable distribution of wealth and economic opportunity, neighborhood segregation, social insurance, and health care funding). *Acceptance* of the existence of inequities and systemic barriers to affordable and quality LTCF care for people of color is also necessary. Additionally, *advocacy* on behalf of residents and vulnerable resident populations becomes a crucial tool for engaging in a participatory process to create change in systems that perpetuate racial and ethnic inequities in LTCFs. Lastly, if there is to be a reduction and elimination of policies and practices associated with structural racism, there must be *action*.

This chapter concludes with policy and practice recommendations. With diligent advocacy and action, change aimed at equity and racial justice for all LTCF residents is possible.

6.1 Policy recommendations

Several policy changes have the potential to reduce racial and ethnic disparities among LTCF residents. This section focuses on the action of implementing these policies. However, as described above, awareness, acceptance, and advocacy are preliminary and important steps for enacting these recommendations.

Domain	Examples
Awareness	Make staff and shareholders aware of the existence structural racism and its impact on residents of color through diversity training and other educational activities
Acceptance	Collect and analyze data related to racial and ethnic disparities within LTCFs and across LTCFs Internal and external dissemination of statistical reports that include statements of how historical, social, and economic factors contribute to the perpetuation of discriminatory practices
Advocacy	Advocate with and for residents of color experiencing inequitable care or quality of life Testify at state legislative hearings about the need for increased Medicaid reimbursement rates for long-term care facilities Lobby Department of Health and Human Services Officials to include requirements that state surveyors and LTCFs assess and address racial disparities
Action	Facilitate focused efforts that result in tangible outcomes including: <ul style="list-style-type: none">• developing a mission statement that promotes racial justice and takes a stand against actions that perpetuate racism.• implementing state regulations that require state surveyors to consider racial-ethnic disparities when conducting assessments and report writing• delivering programming within LTCFs that acknowledges and responds to the discrimination and life course challenges experienced by persons of color

Table 1.
Components of efforts to eliminate the effects of structural racism among LTCF residents.

An ambitious but powerful tool for reversing structural racism in long-term care funding is implementing a universal social insurance for long-term care. In 2018, 70% of Americans over the age of 40 supported this proposal [82]. Although universal long-term care coverage would not eliminate the root causes of current racial and ethnic disparities in LTCFs, it would increase access to care in LTCFs and reduce reliance on Medicaid and its low reimbursement rates for disadvantaged older adults, including many people of color.

Increased Medicaid reimbursement rates for LTCFs are another way to reduce racial and ethnic disparities among LTCF residents [77]. The percentage of Medicaid funding that was spent on long-term care dropped from almost 50% in 1985 to only 30% in 2015 [83], during a time when the percentage of older adults in the United States was increasing. This trend could be reversed and funding priorities could reflect a greater emphasis on supporting LTCFs. To overcome fiscal objections to increasing Medicaid reimbursements for LTCFs, Chisolm et al. [39] suggest increased reimbursement rates could be targeted to LTCFs with high percentages of residents paying for care with Medicaid. Both approaches merit serious consideration, particularly when backed with federal funding as opposed to state funding, which would help LTCFs in states with low levels of income and resources.

Reforms such as a new social insurance program or increased federal funding from Medicaid would require legislative action, but many other policy changes could be made within the executive branches of government (e.g., within the U.S. Department of Health and Human Services). Because the Centers for Medicare & Medicare Services regulates Medicare- and Medicaid-certified nursing homes (as well as some aspects of Medicaid-certified assisted living/residential care communities), it has the ability to transform LTCF practices. For example, regulations could add training in racial and ethnic disparities in LTCFs to the mandatory staff training requirements staff. Similarly, The Centers for Medicare & Medicare Services should add to their current guidance for state surveyors of nursing homes to include information about identifying and reducing racial and ethnic disparities. At the state level, state health departments could bolster regulations for state inspectors of LTCFs to include considerations of racial and ethnic disparities in assessments and reporting.

The Long-Term Care Ombudsman Program has long advocated for LTCF residents [84]. However, reporting practices vary by state and some state programs do not collect and report race and ethnicity data related to the complaints they receive and resolve [53]. The Patient Protection and Affordable Care Act of 2010 requires programs that receive federal funding to collect and analyze data related to their participants' race and ethnicity. We recommend extending the spirit of the Affordable Care Act to regulations for the Long-Term Care Ombudsman Program's reporting responsibilities. If the ombudsman programs were mandated to collect, analyze, and report race and ethnicity data related to the individual complaints they receive, it would facilitate tracking, understanding, and addressing potential racial and ethnic disparities in LTCFs, including assisted living communities, across the United States.

6.2 Practice recommendations

Organizations and individuals should take steps to increase awareness, acceptance, advocacy, and action related to structural racism and racial and ethnic disparities among LTCF residents. Organizations such as local Long-Term Care Ombudsman Programs, LTCF trade organizations, and LTCF companies can help increase awareness of staff, residents, and the public by including racial justice in their mission statements. They can not only hire staff from more diverse

backgrounds or bilingual staff members, but also ensure their staff receive diversity training, including training on the disparities across and within LTCFs and the systemic factor associated with the disparities. As part of acceptance of disparities, LTCF administrators can ensure their organizations analyze and report data related to racial and ethnic disparities among their own residents. Organizations and individuals can advocate for policy reform to their state and federal legislators, officials at their state department of human services, or the U.S. Department of Health and Human Services. It is also potentially empowering for teams across organizations and agencies to form partnerships to address racial and ethnic disparities within LTCF systems. For example, LTCF social workers and Long-Term Care Ombudsman staff and volunteers could work together to reduce disparities and bring cultural inclusiveness to LTCF residents and staff [53]. Finally, within individual LTCFs or LTCF chains, administrators can ensure that their services and group activities are appealing to and affirming of minority residents, that food options and building design are culturally appropriate; and that minority residents are empowered to raise concerns about their care and quality of life [85]. Some of these recommended efforts at the LTCF-level will require careful interrogation of assumptions of what is considered normative in LTCFs (e.g., book collections with only White authors) and could be supported by diversity, equity, and inclusion equity tools such as the toolkit from the Ontario Centres for Learning, Research & Innovation in Long-Term Care [79].

Conflict of interest


The authors declare no conflict of interest.

Author details

Rebecca L. Mauldin*, Shellye L. Sledge, Ebonie K. Kinney, Sarah Herrera
and Kathy Lee
The University of Texas at Arlington, Arlington, TX, USA

*Address all correspondence to: rebecca.mauldin@uta.edu

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