Disparities of Assisted Living Availability:

Investigating the Relationships Between Structural Racism,

Public and Private Governance, and Assisted Living Location

by
Lindsey Anne Smith

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Dissertation Committee:
Neal Wallace, Chair
Paula Carder
Robin Lynn Baker
Kali S. Thomas

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Abstract

This dissertation study investigated the relationship between structural racism, assisted living (AL) location, and public and private governance. Market demand and property values have driven the development of ALs in the US, possibly leaving them more vulnerable to historic redlining and land covenants than nursing homes, which were constructed under federal subsidy programming. Based on this history, the 'racism as a root cause' framework and theories of structural racism inform the study conceptual model, wherein structural racism causes disparities in access to AL, but public and private governance factors moderate this effect. The empirical relationships put forth by this model were assessed using an observational, cross-sectional approach, relying on linear and comparative analytic methods.

The first aim used a random-effects linear probability model to estimate the relationship between AL location and the racial opportunity gap (a measure of structural racism), adjusting for known AL predictors. Results demonstrate a significant linear association between AL presence and the interaction between the racial opportunity gap and census tract racial demographics.

The second aim relied on a similar model to data regarding the operators and size of AL residences in each county in the US was collected. Governance factors investigated for moderating effects include corporate chain ownership, assisted living size, financing, service funding, and regulatory measures. The presence of small or medium ALs not operated by a corporate chain was associated with improved access for Black communities.

In the third aim I used a Boolean descriptive analysis conducted using the coincidence analysis algorithm to identify patterns of public and private governance factors associated with geographic access to AL, given the level of structural racism impacting AL presence. Higher

levels of access occurred where either factors increasing costs were not present, or they were present in combination with a factor associated with increases in revenue. Additionally, certificate of need laws, which limit market entry, were associated with lower access to AL for the full population, but appear to lower the availability of AL for census tracts disadvantaged by structural racism at a higher rate.

Dedication

For my teachers

Acknowledgments

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Chapter 1 Introduction

America's population is both aging and becoming more diverse, amplifying existing inequalities and bringing to light the role of systemic prejudices in both creating and perpetuating disparate health outcomes.[1] Alzheimer's disease and related dementias (ADRD) are both disparate health outcomes and contributing factors to the disparate health exposures of caregivers.[2] ADRD disproportionately impacts women and Black older adults, both as caregivers and people living with dementia (PLWD).[3] Unequal exposures to causes of non-communicable diseases, such as environmental toxins and stress—combined with unequal access to care—create and perpetuate these disparities.[4,5] Policymakers use the phrase long-term services and supports (LTSS) to describe a variety of paid and unpaid services provided to older adults and people with disabilities with activities of daily living, whether in their homes or residential settings. While researchers have not identified a cure for ADRD, appropriate LTSS may help manage ADRD progression.[6] Assisted living has become a popular community-based residential LTSS solution that is well-suited to the challenges faced by PLWD and their caregivers.[7] Unlike nursing homes, Black-White disparities in moves to assisted living communities (ALs) are not explained by individual enabling and need factors.[8] Additionally, though a larger proportion of White older adults than Black older adults report a preference for receiving LTSS in an AL, over 20% of Black older adults preferred AL care over home care and institutional care options.[9] However, ALs are less likely to be located in counties with higher proportions of Black residents, low-income residents, and residents with lower education attainment.[10]

1.1. Study Context

I conducted this study to meet the dissertation requirements of the Health Systems & Policy doctor of philosophy and the Oregon Health & Science University – Portland State

University School of Public Health. As the author and doctoral candidate, I conducted the research work primarily on my own, though I regularly consulted members of my dissertation committee. Theoretical work and research in sociology,[11] psychology,[12] and education[13,14] has long-established researcher positionality as particularly important to investigating racial and ethnic inequalities. Recent studies have applied this in public health contexts, and public health researchers have also emphasized the importance of positionality, particularly for any work relying on critical race theory, which the analytic frameworks of this study are built upon.[15–17] Therefore, I would like to define, from the outset, my position racially.

I am a White American woman and have no experiential knowledge of racial oppression. As a White woman in America, I have lived experience with white supremacy and the harm done to communities through mechanisms of systemic racism. According to White racial identity theory, White researchers must investigate tools to address the damage of white supremacy.[18,12,19] Historically, some of the work of White researchers studying minoritized populations has been based on inappropriate or harmful assumptions.[20] To mitigate this possibility, while the background and problem definition for this dissertation study describes racial disparities impacting Black older adults, the research itself focused on the mechanisms that theoretically enact racism.

1.2. Background

Alzheimer's Disease and Related Dementias

ADRD describes a category of conditions that results in impairments to memory or thought-process, primarily affecting older adults. Current estimates show that ADRD affects 5.8 million people or 10% of adults over age 65 in America. By 2050, researchers project an increase to 13.8 million, as the older adult population increases from 56 million to 88 million.[21] In 2017,

the Alzheimer's Association found that unpaid caregivers spent 18.2 billion hours caring for PLWD. In 2017, Americans spent $259 billion on health and long-term care associated with ADRD. These conditions are highly taxing for the individuals that develop cognitive impairment as well as their families and caregivers.[22]

Dementia Disparities

ADRD is not spread equally within the American population. Black older adults are twice as likely to develop ADRD when compared to Hispanic older adults and one and half times as likely compared to White older adults.[21,23] In addition to higher incidence rates, Black older adults experience differential consequences of ADRD onset due to differences in access to adequate health care, social supports, housing, and economic resources.[21,22] Current research suggests that America's history of racism and ongoing racism at the cultural, structural, and individual levels causes the disparities in ADRD prevalence, consequence, and health impact.[23–26]

Cultural racism refers to the ideological and cultural norms and resulting environment that deem socially defined racial groups inferior.[27] For PLWD, cultural racism impacts how people and institutions conceptualize their aging and value them as members of society.[28,29] The preceding theory of institutional racism identified the policies and practices of institutions as a source of racism.[30(pp3-5)] Structural racism expands on this concept, considering not only institutions but additionally systemic interactions across institutions as the second pathway through which racism generates racial health disparities.[31,27,32] For Black older adults, these structures have disadvantaged them throughout their life course, resulting in differential exposures to stress, environmental toxins, and other likely contributors to cognitive health.[33–38] For PLWD, structural racism limits their access to LTSS and support for their families and

caregivers. Finally, individual or interpersonal racism refers to the racially charged interactions between people.[27,31,32]

Our understanding of the disparities impacting PLWD is shrouded in the bias of current research. Scientific racism, or the concept that race and racial differences are genetic, has resulted in science that considers race, not racism, the source of race-based differences in health. In addition to racist conceptualizations of the differences between Black and White people, the dearth of Black, Indigenous, or people of color identified researchers has resulted in a research agenda that prioritizes White people's needs, norms, and lived experiences.[39–41] Previous research has tied many of the disparities caused by differential consequences of ADRD to structural racism. This racism has taken many forms, including dehumanization, unpaid or underpaid labor, denied voting rights, inadequate access to education, reduced access to housing, and mass incarceration. All of these factors impact the social position of Black Americans and the resulting inequalities in access to health care and social supports when a Black person develops ADRD.[23]

Racism may likewise be a source of the increased risk for developing ADRD that Black older adults experience. Evidence of race-based differences in brain pathology is inconsistent, even though Black Americans are much more likely to develop symptomatic ADRD. These findings imply that the same physical changes in the brain may have differential effects.[23] No current evidence has identified a direct causal link between racism and ADRD, as limited research has investigated racism as a causal factor for ADRD. However, studies have found that experiences of discrimination accounted for differences in immune response, neurotoxicity, and self-reported cognitive function.[42–45] Additionally, Coogan et al. (2020) found a significant correlation between institutional racism and subjective cognitive function.[45] This is particularly

relevant now, as initial research indicates that the neurotoxic response experienced by Black Americans may be a significant factor in the disparity between COVID-19 infections and deaths.[26,46]

LTSS Provision

Long-term services and supports (LTSS) refer to a broad range of services aimed at promoting health and wellbeing by assisting with functional limitations. People providing LTSS may assist with activities of daily living (ADLs) such as getting dressed, attending to hygiene, or eating. LTSS services also encompass instrumental activities of daily living (IADLs), which include help with cleaning and managing finances.[47,48] The prevalence of ADRD conditions, and the large-scale impact these conditions have on the American population, makes it essential to provide appropriate care and housing for this vulnerable population.[49]

Researchers have estimated that friends and family members of older adults provide three-quarters of all LTSS,[50] with 42 million caregivers providing an estimated $450 billion worth of services without charge.[51] There are two primary categories of residential settings for LTSS provision, nursing homes and residential care communities. Residential care settings refer to ALs, adult-foster, and other residential LTSS types.[52(p1)] In 2016, there were 15,600 nursing homes with an average of 34 licensed beds per 1,000 older adults and 28,900 residential care communities providing 20 licensed beds per 1,000 older adults.[52] As a result of population aging and a decrease in available family caregivers, the demand for formal and residential LTSS has been increasing and is projected to continue to grow.[50–53]

Older Adult LTSS Preferences

The biomedicalization of aging and innovations in healthcare has resulted in older adult care needs that are increasingly technical, leaving many families unable to provide the necessary care.[54,55] Several studies have surveyed older adults to ascertain where they would like to receive LTSS and whether they would prefer to receive care from family, friends, or paid caregivers.[56–58,9,59–62] While the majority of older adults prefer to stay in their homes; preferences vary based on gender, age, race, ethnicity, marital status, education, income, disability, and the intersections of these characteristics.[56,58,9,61]

Table 1.1 Older Adults' Preferred Care Option by Race

Race	*Own home family help*	*Own home paid help*	*Living with adult child*	*Assisted living or CCRC*	*Nursing home*
Non-Hispanic White	27.8	29.5	6.0	29.3	7.4
Non-Hispanic Black	36.1	22.8	7.1	20.2	13.8
Hispanic/other	36.9	16.7	7.2	22.3	16.9

Note: Excerpt from Kasper et al. (2019), analysis of NHATS 2012, n = 1,783

A 2018 study using the National Health and Aging Trends Study dataset found that 57% of adults preferred to stay in their home, 28% favored an AL or a coordinated care residential center (CCRC) environment, and less than 10% reported they would rather live in a nursing home or with an adult child. Black non-Hispanic similarly preferred to stay in their home (59%), move to ALs or CCRCs (20%), reside in a nursing home (14%), and reside with an adult child (7%). When initially surveyed in 2012, the Black older adults already receiving care were significantly less likely than the White respondents to report an alignment between their preferred LTSS setting and where they were currently receiving care. However, there were no

race-based differences in care arrangement alignment for respondents who began receiving care three years after the survey.[9]

There have been many theories to explain the differences reported in preferences between Black and White older adults. Guo et al. (2018) found that among a majority low-income African American sample of older adults, those with higher ADL needs had a higher preference for residential care.[58] Bradley et al. (2004) found that African American respondents were more likely than White respondents to have intentions to rely upon informal care. However, they also found that psychosocial factors fully attenuated this distinction. The factors explaining the differences included a strong social norm for adult children living near their parents to assist them and the perceived ability, or inability, to obtain and afford informal care.[56] Similarly, Jenkins-Morales found that enabling and need factors did not account for disparities in moves to ALs, unlike moves to nursing homes.[8]

Together these studies show that many Black older adults are interested in residential care settings like ALs, especially when they can stay geographically near family members. The average capacity of AL additionally varies by race;[63] however, there is no current data regarding Black older adult preferences for small, medium, or large ALs. Finally, researchers have not explored a potential factor—the barriers to financing and developing properties in Black neighborhoods.[64(p9)] Financing and development have played a sizeable role in the market for long-term care, a limitation for Black older adults who, due to structural racism, are more likely to live in neighborhoods with low property values.[65]

LTSS Demand and Shift to HCBS

LTSS demand is increasing, particularly for PLWD. As of 2010, the estimated ratio of potential caregivers to adults 80 years of age and older was 7 to 1, whereas, by 2030,

demographers project this ratio will decrease to 4 to 1.[55] Historically, there have been limited options for residential care outside of the home. After World War II, institutions, such as hospitals and skilled nursing facilities (SNFs), provided residential LTSS. For people unable to afford private home care, these medical settings remained the only options for residential care until the 1980s. Public and private developers commonly constructed institutional care settings in large cities, often inaccessible to families. Moreover, scientific and journalistic investigations have criticized institutions for resident abuse and neglect and have cited the regulatory emphasis on safety at the expense of resident wellbeing.[66,67] In response, activists and entrepreneurs began providing LTSS in non-institutional settings.[53]

Medicaid is the largest payer for LTSS, as Medicare only covers short-term rehabilitation, not the cost of LTSS. Significant challenges facing the financing of LTSS include the cost of care for those experiencing cognitive decline, an increase in the population in need of LTSS due to population aging, and workforce shortages.[68,69] In the late 1970s, there was a shift to LTSS provision that allowed for "aging in place.[70] States began piloting home and community-based services block grants and then Medicaid waiver programs to use Medicaid funds to pay for care that facilitated aging in place. Community-based care includes ALs, in-home personal care, adult foster care, and services such as adult daycare.[53]

The Assisted Living Model

Dr. Keren Brown-Wilson is often credited with founding the AL model popularized on the west coast of the US in 1979 in Portland, OR as an alternative to nursing home-based care. She based this concept of residential LTSS provision on the social service model, providing care in a home-like environment, accommodating a high level of resident autonomy.[71] Simultaneously, Paul and Terry Klaasen began the model of AL popularized on the east coast, a

converted nursing home where they lived.[70] AL now generally refers to a model of LTSS provision wherein residents live in a shared housing setting and can both maintain more autonomy than in a nursing facility and still access aid for ADL limitations.[70] There are currently no definitive findings demonstrating a difference in the quality of life between ALs and skilled nursing facilities. However, these settings can be less expensive than nursing homes, and care providers for PLWD in ALs are less likely to restrain residents physcially.[72] The AL model was designed to provide a care environment that is home-like in nature and allows for aging in place, which makes this setting accommodating to the needs of PLWD.[73]

As developed, the philosophy of resident autonomy and person-centered care provision drives care provision in ALs.[70] This focus on resident autonomy has been at odds with market drivers for LTSS, such as the preferences of the children of older adults for safety over autonomy and the role of liability insurance and associated costs.[74] AL license types vary from state to state, but the most common specialized kind of license or certification is memory care or dementia care units. These residences are a growing type of AL that often follow differential regulations.[75] Though an annualized total is unavailable, point-in-time surveys indicate over 800,000 people live in ALs on any given day in America, with over half of these residents age 85 or older.[52]

ALs are lower cost than nursing homes. Some studies have also shown higher resident satisfaction, as the AL home model provides residents more independence than the medical-based nursing home model.[76] Current findings indicate that shifting towards utilizing ALs more broadly for PLWD could improve outcomes and decrease the costs of ADRD.[77] However, current incentivizing policy structures are not in line with prioritizing AL options.[78]

Multigenerational Families and LTSS

Black older adults have less access to quality formal LTSS compared to White older adults.[79,6,80,26,81] According to life-span and lifecourse perspectives, an older adult's access to LTSS affects both their wellbeing and that of their family members across generational cohorts.[82] For under-resourced families, access to community-based LTSS assistance promotes the caregiving generation's health and wellbeing while allowing the older generation to continue playing an essential role in the lives of their younger family members.[83] This has implications for the care provided by adults to children and the emotional support and knowledge transmitted from grandparents to the younger generations. Additionally, direct care workers providing long-term care are disproportionately low-income women.[8] So, states may target the unequal impacts of dementia on Black older adults by providing quality LTSS to older adults with dementia in their communities. According to the social production of disease model, this intervention theoretically also impacts the vulnerability to disease experienced by the generation providing care and the exposures to disease experienced by the caregivers' children.[84]

Assisted Living Regulations

Although ALs have grown in use, consumers' and policymakers' understanding of the differences between ALs and SNFs is often still lacking. The federal government, through the Centers for Medicare and Medicaid Services, governs SNFs. There are state certificate-of-need policies and nurse practice acts that apply to SNFs. However, the relatively homogenous regulatory standards for SNFs have led many policymakers and families to assume that the federal agency similarly monitors ALs.[85] State agencies regulate ALs. Neither the Social Security Amendments of 1965, which created Medicare and Medicaid, nor the amendments that followed, specified ALs as reimbursable care settings.[86] As a result, the Centers for Medicare

and Medicaid Services have limited jurisdiction in regulating community-based settings, and each state has taken a unique approach to license ALs.[87]

The US Department of Housing and Urban Development (HUD) and the US Department of Agriculture have funded programs that sometimes subsidize AL residents directly through housing vouchers or indirectly through loans to develop ALs.[88,89] HUD supports AL development through the Assisted Living Conversion Program and Section 232—Mortgage Insurance for Long-term care facilities, including ALs.[90] Additionally, named according to the section of the housing act they correspond to, HUD funds programs that subsidize the rent of older adults and may pay for a service coordinator through Section 202 Senior Housing, and to a lesser extent Section 8, Section 221 (d)3. Section 236.[91,92] The Low Income Housing Tax Credit (LIHTC) program, which funds most affordable housing in the US, also finances senior housing projects, including some ALs, which made up 32% of projects supported from 1995 to 2013. While states administer these funds, HUD collects and makes available standardized data on all funded projects.[93]

Licensing and regulation vary by state, but generally, ALs are an option for individuals who do not need 24-hour skilled nursing care but need assistance with ADLs or IADLs.[94] All states differentiate between different levels of care or types of AL through licensing, certification, or other disclosure requirements.[95] ALs, like other health service settings, vary significantly in the services, facility needs, staff, resident demographics, and payment sources. To accommodate this variation, state agencies license multiple types of AL, provide additional options for certification or specialty disclosure, or both.[95,96]

Theoretically, these opportunities for differentiation between ALs allow for appropriate variation in service delivery while also maintaining sufficient monitoring and enforcement of

applicable standards for resident protection.[97] Evaluations of the impact of license and certification approaches for substance abuse and neonatal care facilities have found that differences in licensing and certification approach significantly impact the quality of care provided.[98,99] There are not currently published results regarding differences in resident outcomes in ALs based on the licensing approach. However, Cornell et al. (2020) did find a significant difference in the demographics of counties that have and do not have ALs with a dementia care designation.[10]

Assisted Living Industry

The nodal governance framework (NGF) suggests that we must take the role of provider organizations into account to understand the impact of public policies.[100] This is likely particularly important in ALs as state-to-state policy variation introduces an ambiguous public regulation environment for private companies operating across state lines.[52,101] Researchers typically categorize providers according to profit and nonprofit status; however, many more factors, including participation in a chain and whether the provider company is publicly traded, are regularly used to differentiate between ownership governance types within the assisted living industry.[102] In the decades preceding AL development, congress passed legislation to allow for a mutual-fund-type approach to real estate investment in the US.[103] This alteration of the tax code in 1960 has played a significant role in AL development and, combined with the barriers to payment for these services directly with Medicaid funding, has contributed to the locations and availability of ALs currently experienced by older adults.[104]

The US Department of Health and Human Services funded nursing home facility construction through the Hill-Burton Act between 1946 and 1971. In comparison, AL construction has never been invested in at the same scale as a type of care setting providing

health services at the federal level. As a result, the AL market has been more highly dependent on property development markets.[105–107] Without federal intervention, it is possible that structural racism has impacted the AL market through mechanisms such as redlining and covenants.[108,109] While public discourse frames these policies in terms of their impact on homeownership and home values; research has also demonstrated their impact on risk assessments and capitalization rates.[110] As a result, the structures corresponding to AL development, investment, and ownership may have had a significant influence on ALs' geographic location. With most ALs located in majority White neighborhoods, Black older adults may feel unwelcome there, fearful of interpersonal racism, or hesitant to move into a community farther from their family and friends.[64(pp9, 72-75)]

Assisted Living Disparities

Although elderly Americans are an increasingly diverse population, AL residents are a largely privileged population that is more White and more economically advantaged than the elderly American population as a whole.[111] This is reflected in a growing concern regarding the equity of access and care in ALs.[8,78,112] Forty-eight states now use Medicaid waivers to fund AL residential care and services, a number that has grown consistently since the introduction of waivers in the eighties.[113] The disparities in AL availability warrants concern for the continued use of these public funds if ALs do not serve the needs of all communities in the state equitable.[78]

AL is far from homogenous in the form it takes. AL has evolved from the initial care models designed in the eighties and may vary drastically based on the state and the service provider.[52,70,114] The misconception that AL as a model does not meet the needs of Black older adults is reflective of the history of care provision. Like most social services, the systemic racism

of American culture and policymaking has heavily influenced the evolution of ALs.[115] The current AL model does not preclude providers from creating a model of AL that meets the needs of Black older adults. Instead, this context emphasizes the need for ALs developed specifically within Black communities to meet the needs of PLWD in those communities.[116]

Racism as a Cause of Disparate Health Outcomes

Historically, research investigating disparities and inequalities between populations has regularly used race as an explanatory or potentially causal variable.[15] Founded on a long history of scientific racism, researchers have long considered race to be a descriptor of innate differences between subpopulations.[39] The current understanding of race does not support this approach. While people of different races have different lived experiences due to racism, race is a socially constructed characteristic not identifiable in human genetics. Observable biological differences can be attributed to systemic racism and its impact on biology through epigenetics and human development via historic and ongoing policies, practices, and cultural norms meant to oppress Black people.[46,117–120] Based on the current science, racism, not race, is the likely causal variable researchers should associate with race-based health disparities.[121]

Black PLWD experience multiple marginalized identities intersecting, resulting in a complex lived experience of oppression. According to intersectionality, the dehumanizing effects of racism impact all communities, but enact disparate levels of harm on communities and people who are Black, Indigenous, and People of Color (BIPOC).[122,123] The term intersectionality was first introduced by Kimberlé Crenshaw in 1989,[124] though the idea that marginalized identities may "mutually reinforce" one another dates back to the 1830s in the writings of early Black feminists, including Sojourner Truth.[125(pp16-17)]

Agénor (2020) identifies the lack of studies investigating the role of social inequality instead of social identity as one of the critical opportunities for future directions in intersectional population health research.[126] While methodologically sound, the practice of using racism instead of race in analyses is not yet commonplace, and researchers have only recently developed measures for estimating racism at the population level.[32] However, investigating the role of structural racism in this setting is vital for furthering knowledge of the specific health disparity and testing these novel measures in policy research.

Population health approaches promote considering health at the population level by measuring health outcomes as an average and considering the distribution of health outcomes within a population.[127,128] From this perspective, curative advances in healthcare that are inaccessible due to access issues may negatively impact the health of a population due to the increase in spread or inequality in health outcomes.[128,129] Studying AL as an intervention for the aging population brings up conflicts of interest between the mean health of older adults and the distribution of health inequality. Although older Americans as a population encompass a highly diverse range of people, ALs provide care to a largely privileged population that is more White and more economically advantaged than the older American population as a whole.[130]

Older adults who utilize ALs are primarily private pay.[52] This necessitates higher levels of financial wellbeing than the average older American. Increasing the efficacy of care within ALs necessarily risks improving the average health of the population accompanied by an increase in health inequalities.[101] To shift AL policy to increase overall population health and decrease health inequalities, the policies targeted should be most influential on the care outcomes of dual-eligible (low income) and racial minority residents.[131,132]

1.3. Problem Statement

In a recent survey, 20% of Black older adults preferred to receive care in an AL or CCRC.[9] However, Black older adults are significantly less likely to move into AL than White older adults. Recent work found that after adjusting for enabling factors, like income and family supports, as well as need factors, like medical acuity and ADL needs, the disparities between Black and White older adults who moved to NH settings was accounted for. However, none of these factors account for the Black-White disparities in moves to AL.[8] It's possible that this disparity may be accounted for by ALs' geographic locations. ALs are significantly less likely to be located in counties with higher proportions of Black residents.[10] Additionally, AL development has received minimal government support in most states. As a result, private governance has been the primary driver of AL availability. However, few research studies have documented private governance mechanisms in the AL industry.

It is not clear what the relationship is between structural racism, the theoretical driver of race-based disparities, and AL availability. It is also unclear what policymakers and regulatory agencies can do to respond. Theories of governance suggest taking into account variation in corporate governance, a common mediating or confounding variable when investigating the efficacy of public policies in addressing a policy problem.[133] This aligns well with the intersectionality framework, which emphasizes identifying sources of power. The proposed study investigates the combinations of structural racism, corporate ownership structures, and public policies associated with disparities of AL availability.

1.4. Research Question and Aims

What are the combinations of public and private governance approaches that limit or expand the impact of structural racism on disparities of AL availability?

Aim 1: Measure the relationship between structural racism and AL availability.

To determine the extent to which a measure of structural racism accounts for race-based disparities of AL availability, I combined an existing dataset of AL locations and the racial opportunity gap (ROG) for each county, an existing measure of structural racism within a community; then created a random intercept linear probability regression model to estimate the association between the ROG as it intersects with the racial demographics of the census tract and AL availability.

Aim 2: Determine the extent to which private governance factors are associated with AL availability.

To describe the private governance relationship, I first used text mining to collect AL corporate ownership data; second, I used a random intercept linear regression model to estimate the association between the private governance characteristics and AL availability; and third, I used the same model to analyze racial demographic-specific groups.

Aim 3: Identify combinations of public and private governance factors that differentiate AL availability, given the level of structural racism.

To identify combinations of state-level policies and corporate ownership structures that strengthen or attenuate any association between structural racism and AL availability, I used Boolean description and the coincidence analysis (CNA) algorithm to compare combinations of levels of structural racism and governance factors with AL availability.

1.5. Theory and Framework

Based on the Racism as a Root Cause (RRC) framework, I investigated the white supremacist structural racism that theoretically undergirds the resource allocation that serves as a barrier to AL service provision.[134,135] An RRC approach must prioritize a specific racialized

group, focus on policies and systems, value sustainable and long-term impact, and aim to repair historical injustice. The RRC framework informs this work's grounding in history and theory and investigates Black-White ROG and the role of specific policy mechanisms.[135] The intersectionality theoretical framework applied to quantitative population health studies provides further guidance on key components to include in the study framing, methods, and analytic approach.[126]

Intersectional Population Health

This is a population health study using an intersectionality theoretical framework, as applied within a critical realist paradigm. Intersectionality is the concept that various social identities intersect in complex and synergistic ways, resulting in differential impacts of inequality on multiple social identities one cannot distill down into homogenous categorical experiences. The legal theory of intersectionality posits that the proposed solution to intersectional oppression is not simply reversing those inequalities. While it is essential to recognize the differences inherent in the intersections of identities compared to each identity individually, Crenshaw instead advocates for systems that recognize the intrinsic damage that these inequalities do to all people within the population.[125,136] As a result, investigating the likely causes of inequalities may benefit all members of society. While the concepts and ideas behind intersectionality have been present in dialogue surrounding oppression and power for centuries,[137] the practice of using intersectionality as a theoretical framework for population health is relatively nascent, arising within the past decade.[126]

Social constructionists from the "anti-categorical" tradition first used intersectionality as a research framework. Many researchers reject the categorization of social identities in favor of conceptualizing an individual qualitatively. More recent research has taken the intersectionality

framework and approached it using a critical realist lens.[138,139] From a critical realist perspective, knowledge is relational.[140] As such, using this lens in conjunction with the framework allows investigators to map inequalities and analyze them in a way that reveals overlapping inequalities and how power structures may cause them to vary across dimensions.[141] This methodologic expansion paved the way for applying intersectionality in quantitative population health studies,[126,139] the approach used here.

When operationalized as a theoretical framework, Collins and Bilge (2016) have identified six core ideas of intersectionality: social inequality, power, relationality, social context, complexity, and social justice.[137] I applied these to the availability of ALs, to better understand the relationships between the likely drivers of inequality and the resulting health disparities. This study investigates how an existing inequality is reified or ameliorated through policy by capturing data regarding power sources in this context. To identify the sources of power in this context, I relied on both critical race theory and nodal governance theory.

Intersectionality's core ideas of relationality and complexity determined the methods for this study, particularly for aim 3. While linear regression is valuable for much of the work of this study, it does not allow for equifinality, a core tenant of complexity theory, and strength of the CNA approach.[142] Equifinality refers to the concept that multiple combinations of factors can achieve the same outcome.[143] Using a set-theoretic method like CNA allows for identifying these combinations, unlike a linear approach.

Structural Racism Framework

The structural racism framework relies upon systems theory, which emphasizes the importance of relationships and nonlinearities. A structural perspective of racism shifts from conceptualizing racism as impacting specific institutions to acknowledging racism's complex and

reciprocal interactions across many domains and institutions at the macro, meso, and micro levels.[144] This system has been fundamental to how property ownership has been determined in the US and informs ongoing inequalities in the availability of resources and investments within communities. ALs are, by their residential nature, a property-based service.[145] As with other property-based social or health services, the role of structural racism through individual prejudices embedded within racist policies and practices such as redlining and land covenants has resulted in highly inequitable distributions of property development, ownership, and power.[146,147] Thus, structural racism is a measure of power to consider in the context of racial disparities and as a potential explanatory factor for geographic disparities more generally.[148]

Nodal Governance Framework

I have determined the likely sources of power in the AL context using the Nodal Governance Framework (NGF), which identifies a need to expand the conception of regulation and governing to include regulation from private entities and social mechanisms of control.[149] Much of health policy research is still based on the assumptions of the Westphalian model, which imagines a strong sovereign central government serving as a direct regulator of citizen behaviors.[150,151] Approaching this work from a decentered theory of governance such as NGF acknowledges the roles of corporate and social capital and control that have become incredibly influential in America's current neoliberal governing approach.[152] The NGF consists of sites—"institutions that harness ways of thinking and acting"[133(p165)]—classified as public, private, or civil governing bodies.[153] Each of these can be acknowledged for analysis and intervention.

Convoys of Care Model of Assisted Living

This study relies upon the Convoys of Care model of AL care.[154] Kemp et al. built this model upon the social-ecological framework, Convoy Model of Social relations, and convoy

theory. This approach depicts social networks and social supports as layers operating within an environment across the lifecourse.[155(p58)155(p58)] Plath (1980) introduced the concept with the term "convoy," referring to the peer groups of Japanese boys in a study of student cohorts.[156,157] The model was designed to capture formal and informal social relations and supports via a heuristic that is inclusive and applicable to all ages.[155(pp58-61),156] The concept of convoys as applied to ALs allows for recognizing formal and informal care provision in the AL.[154,158] This aspect of AL care accommodates ALs in many cultures and contexts and makes the geographic location of ALs particularly important to care equity.

Kemp et al. (2013) describe AL care convoys as situated within the macro social, political, and economic contexts, the regulatory context, then nested within the AL industry, community, and AL influences. This model identifies the macro-environment as driving the availability of resources and supports at lower levels and nests formal and informal caregivers within individual and interpersonal, AL-level, and community sources of authority and control, which exist in the AL industry and the regulatory contexts.[154154] While I am not relying on a socio-ecological conceptual model, the strength of the Convoys of Care vision of care provision is the emphasis it places on members of the care network that are not AL staff members. While it is likely important for non-staff caregivers to access and provide social care, in ALs, it is the norm for both social and medical care to be provided by informal and formal external members of the care network.[158] The essential nature of care network members outside of the AL physical residence makes geographic proximity to family an issue for all aspects of resident care. It may have severe repercussions for resident care outcomes.

1.6. Methods Overview

This study identifies policies and regulatory actions associated with high and low health inequity levels in geographic access to AL care. I carried out this work through three aims which identified 1) correlations between disparities in AL availability and measures of structural racism, 2) the extent to which corporate ownership structure mediates this relationship, and finally, 3) specific combinations of state policies can increase AL availability, given the corporate ownership structures and the level of structural racism present.

This work relies on nine datasets; eight of these were already existing, and one I developed as part of my dissertation work. The datasets include: 1) AL names and addresses from state regulatory directories collected by Thomas et al. (2018),[159] 2) State AL ADRD care-related regulation analyses, by license type—a dataset created using the Health Services Regulatory Analysis process,[96] 3) population age and race characteristics for each census tract from the 2019 American Community Survey, 4) *National Statistics by Parent Income Percentile, Gender, and Race* dataset of linked Census Bureau data summarized by Chetty et al. (2020),[160] 5) Medicaid waiver type and applicability as summarized by the Government Accountability Office,[161] 6) Rural-urban classification from the US Department of Agriculture,[162] 7) HUD records for LIHTC, affordable multifamily housing, and senior housing development,[163] 8) State certificate of need programs,[164] and 9) AL ownership characteristics. Datasets one and two were collected and analyzed as part of Dr. Thomas's study, *Do State Regulations Affect the Outcomes of Assisted Living Residents with Dementia?* (NIA R01AG056646), which investigates the relationship between state regulations and the care outcomes of PLWD. Dataset four is publicly available from Opportunity Insights, a nonprofit organization located at Harvard University.[165] Datasets three, five, six, seven, and eight are publicly available from government and policy

tracking websites. Finally, I sourced the ninth dataset as part of the work of the second aim by combining web scraping, public industry lists, consumer resource directories, and corporate records in the NexisLexis legal database.

In aim 1, I geocoded an existing dataset of AL addresses and bed capacities (dataset 1) to calculate the number of AL units for each census tract. I joined these data with descriptors of the rural-urban status of the census tract using dataset six as well as the percent of the population aged 65 or older, median income, and median home value, from dataset three. Datasets three and four contain race and age-based demographic data and the intergenerational mobility data used to compute the ROG.[160] The ROG is a validated cross-sectional measure of structural racism that uses the difference between Black and White children's economic status compared to the financial position of their parents to calculate economic mobility. The ROG is the difference between this calculation of economic mobility for White and Black children. As a measure, it aims to estimate the level of structural racism in a community by capturing the extent to which White children have access to greater economic mobility than their Black peers, even when their parents make similar incomes.[32,160] I used a multilevel random effects linear regression approach to describe assess the relationship between AL presence in a census tract and the interaction between the county ROG and census tract racial demographics.

Given that providers determine AL location and what form of care is provided, in Aim 2, I collected data regarding AL ownership structures. Aim 2 enabled a deeper look at the intersection of structural racism and private governance — governance enacted through the actions of private companies.[100] I identified the ownership structures driving the private governance for each community in the dataset. I created dataset nine by joining dataset one to business profiles using a combination of location, mailing address, AL name, and owner name.

All business profiles were sourced from Data Axle, a proprietary B2B marketing database, and linked in R using the 'tidytext' and 'ggmap' packages. Internal revenue service (IRS) data regarding tax exemption status was sourced from the IRS website and joined using descriptors in the business profiles. Finally, business profiles were linked to corporate hierarchy listings in the NexisUni database for each of the largest 50 AL providers in 2019, according to Argentum, a trade organization. Additional covariate data were sourced from datasets three and six. I used the resulting dataset and a similar approach to aim one to assess the relationship between the percent of capacity provided by small, medium, or large as well as nonprofit, top-50-chain, or other for-profit AL operators and the presence of ALs at the census tract level.

The primary method for aim 3 of this research is Boolean descriptive analysis relying on the coincidence analysis (CNA) algorithm, a set-theoretic comparative method developed to analyze the effect of conditions on outcomes in the context of complex causal relationships.[142] CNA relies on Boolean algebra to distinguish combinations of chains of conditions necessary versus sufficient to achieve an effect.[166] CNA findings allow for equifinality, as dissimilar combinations of study factors can simultaneously accomplish the same outcome.[142] This is of particular importance for research conducted to inform the design of policies serving significantly different populations in highly dissimilar policy arenas.[167] I used CNA to identify independent combinations of factors that result in AL availability.

The findings from aims 1 and 2 informed the model for aim 3. According to the convoys of care model, policy and industry mediate structural racism. If had not found an association in aim 1, that would not preclude an association between structural racism and AL availability once the analysis took industry's role into account. Similarly, according to the concept of equifinality, if I had not identified associations in aims 1 or 2, the use of CNA in aim three may have still

identified combinations of structural racism, ownership characteristics, federal funding, and state policies which have an impact on AL availability. While identifying associations between each of these factors and AL availability was theoretically likely, according to the theories presented here, combined associations could be present even without individual associations.

I combined my findings in aims 1 and 2 with dataset 2, an existing dataset that describes care-relevant aspects of AL regulations associated with each AL in the directory. Using addresses, I joined datasets 5-8, which list the applicable Medicaid waivers, rural-urban designation, and state certificate of need programs according to AL license type and the addresses of all ALs. The AL's in these datasets include residential care settings receiving funding from state LIHTC programs, HUD multifamily housing subsidy programs, or HUD development funding or financing.[163] Regulatory restrictions and Medicaid waiver availability vary by the location, resident demographics, licensing, certifications, and disclosures applicable to each AL. Using a CNA approach, I identified combinations of state policies and corporate ownership structures associated with geographic access to ALs for Black older adults in communities disadvantaged by high levels of structural racism as measured by ROG.

1.7. Purpose and Significance

According to a 2017 report from the National Academy of Sciences,

> [The] the more fundamental root cause of health inequity, is the unequal allocation of power and resources—including goods, services, and societal attention—which manifest in unequal social, economic, and environmental conditions, also called the social determinants of health. [...] The factors that make up the root causes of health inequity are diverse, complex, evolving, and interdependent in nature. It is important to understand the underlying causes and conditions of health inequities to inform equally complex and effective interventions to promote health equity.[168(p99)]

An expert panel of scientists writing about the drivers and ramifications of health inequity identified both the source of health inequities — "the unequal allocation of power and resources," as well as the pathways to health equity, which stem from understanding "the underlying causes and conditions."[168(p99)] This study aims to begin this work in the realm of AL care access by elucidating viable policies to reduce the inequities identified.

AL is one of the primary models of care states have used over the past 40 years to rebalanced their systems of LTSS from institutional to home and community-based services.[70] However, studies of AL availability and resident demographics have revealed disparities of accessibility.[10,111] ALs can be significantly less expensive than nursing homes[102] and among PLWD, studies have found that residents are less likely to be hospitalized or physically restrained.[72] Following the guidance from the National Academy of Sciences, to address this disparity, we must first understand the underlying causes and conditions that have led to the current condition.[168] While there are racial disparities in the availability of ALs and the prevalence and impact of ADRD, according to the theory of intersectionality and structural racism framework, the structural drivers of inequity may influence or modify the health and wellbeing of all people within a society.[125,144]

Using an intersectional population health methodology, this study investigated to what extent structural racism, corporate ownership structures, and state policies are responsible for the disparities in AL availability. The results of this study may be helpful for developing guidance for rulemakers and policymakers at the state and federal levels. Rulemakers are agency staff that write and update enforceable regulations based on statutory law, judicial proceedings, and public input.[169] While rulemakers must first and foremost comply with statutory law in rulemaking, there is significant leeway for interpretation and prioritization within the written rules and the

enforcement of those rules. Previous political movements and policy research has identified the rulemaking process and setting of enforcement standards as an opportunity for addressing health disparities.[99,170] Studying the role of the AL regulations and public subsidy programs as they intersect with structural racism and corporate ownership structures allowed me to identify policy interventions potentially relevant to rulemakers and policymakers that future studies can further investigate.

This work may inform future investigations into disparities in LTSS provision and accessibility of ALs for racial minority populations. For future studies of disparities in the accessibility of LTSS, these results could inform confounding variables, model design, and scope. This work can inform future work exploring other components of health service accessibility, including affordability and appropriateness, aiming to diminish the disparities of AL availability. Researchers have not determined the drivers of this disparity. Elucidating the potential sources is critical for taking steps to address this inequality. Additionally, if this combination of approaches reveals novel findings, it could inform methodology development at the intersection of population health and health policy. This study relies upon a novel measure of structural racism, the ROG. If this approach proves fruitful, others could replicate it to address disparities in the availability of other health services.

In sum, this study aims to take initial steps towards uncovering the drivers of disparities in AL availability. I aim for this line of research to eventually inform policymakers and rulemakers at the state and federal levels aiming to increase equal access to this vital important health service. Given the current prevalence of ADRD and its disproportionate prevalence among minoritized populations, access to effective and affordable LTSS for all PLWD is important for the health and wellbeing of these older adults, that of their families, and other

caregivers. By improving LTSS access, I hope to contribute to addressing disparities in the impacts of ADRD on health.

Chapter 2 Review of the Literature

2.1. Chapter Organization

This chapter provides a review of the literature that informs this dissertation study. It includes a review of the literature for each of the following areas:

The Role of Assisted Living in the US

Residential Long-Term Services and Supports Policy

Types of Assisted Living Public Governance

Assisted Living Private Governance

Racism and Racial Disparities in Assisted Living

Gap in Research

After summarizing the existing literature informing the research question, I will describe the theoretical bodies of work informing the study conceptual model. This study relies on multiple theoretic frameworks including racism as a root cause, intersectionality, population health, structural racism, nodal governance and the convoys of care model of assisted living (AL). Finally, I will restate and connect the proposed research question and study aims which I developed. These sections are as follows:

Conceptual Frameworks

Conceptual Model

Research Question and Aims

2.2. The Role of Assisted Living in the US

Defining Assisted Living in Relation to Other Residential Care

In this section, I will describe the role of assisted living (AL) in relation to other types of residential long-term services and supports (LTSS), the prevalence of ALs, resident demographics, and resident health characteristics. According to the Andersen Healthcare Utilization Model, predisposing, enabling, and need factors determine who uses a health services, like ALs.[171] The second half of this section will investigate the enabling factors that may account for the variation in AL use.

AL is a residential care setting where staff offer LTSS in a home-like social setting. These communities offer older adults an environment that emphasizes autonomy and choice but also offers assistance with activities of daily living (ADLs), accommodating hired third-party care providers, including home health and hospice.[52] These community-based care settings may offer economies of scale compared to the provision of care at home.[172] In comparison to nursing home (NH) residents whose care is provided by certified nursing assistants and nurse staff, AL residents receive care from paraprofessional direct care workers. This base level of care and the home-like environment makes ALs well suited for providing care to people living with dementia.[173] Though ALs vary based on license and provider types, this flexible model of residential care has gained in popularity and now serves as an important option for older adults in need of residential-based LTSS.

ALs are an option for individuals that do not need 24-hour skilled nursing care, but do need assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are activities essential to living, such as bathing, eating, and using the toilet. IADL limitations are more difficult to clearly define, as they include other “instrumental”

activities such as using a phone or handling personal finances.[94] ALs utilize a social service frame to provide older adults with both ADL and IADL assistance. In contrast to institutional care settings, where care plans revolve around healthcare provision, ALs focus on meeting the functional needs of the resident. The original AL models used this approach to increase resident autonomy and wellbeing, rejecting the medical model which prioritized healthcare services.[74]

While this dissertation study does not include NHs, ALs developed in response to NH, so understanding the definition of NH care is important to understanding what ALs are not. NHs include three types of facilities that can be either state operated or non-state operated. NHs can be skilled nursing facilities (SNFs), which provide medical care and as such are reimbursable through Medicare. Though rare, NHs can be nursing facilities (NFs); these do not provide reimbursable medical care, but do have certified nursing assistants (CNAs) available on a that provide 24-hour care. NFs can reimburse for care through Medicaid but not Medicare.[174] Finally, SNF/NFs are facilities that can reimburse through Medicare and Medicaid, as they have both medical care and ongoing LTSS provided by certified staff.[174] NHs have been defined by their qualifications for CMS funding, and as such, they are regulated through CMS regulatory oversight mechanisms. In contrast, the use of federal funds in ALs has been limited, as has been the corresponding federal oversight.

AL Community Prevalence

While NH use still exceeds AL use, reliance on care in ALs has expanded across all states. In 2016, the National Center for Healthcare Statistics (NCHS) identified 837,800 AL beds in residences with 25 or more beds. The survey estimated 811,500 residents are served daily by residential care communities with 4 or more beds. While this estimate includes residences with capacities as small as 4 beds, 84% of the providers surveyed had bed capacities of 25 or more.[52] If empty beds were distributed equally across residences of different sizes, an estimated 681,600 residents would be served in ALs with 25 or more beds on any given day. Estimates of the count of AL residents according to the capacity of the AL they live in are currently unavailable.

Table 2.1: Assisted Living Resident Characteristics

	Bed Capacity		
Age Group %	**4-25**	**26-50**	**50+**
Under 65	16	7	4
65-74	13	10	11
75-84	27	30	31
85+	44	52	54
Sex %			
Female	67	72	71
Race/Ethnicity %			
Non-Hispanic White	80	88	80
Medicaid Use %			
Medicaid Payment	25	18	14
Medical Conditions %			
ADRD	51	44	39
Heart Disease	32	35	35
Depression	37	32	29
Diabetes	19	18	18
ADL Needs %			
Bathing	76	64	60
Walking or locomotion	59	56	56
Dressing	58	44	47
Toileting	51	35	38
Transfer	38	25	28
Eating	34	18	16
Healthcare Use % (last 90 days)			
Fall	12	22	24
Emergency Dept Visit	14	14	14
Overnight Hospital Discharge	7	9	9

Source: 2016 National Study of Long-Term Care Providers[63]

Resident Characteristics

While ALs are licensed and operating in all 50 states and Washington DC, the characteristics of residents vary. One factor that has been used to categorize and better understand variation across ALs is capacity. The Long-term Care Provider and Service User survey conducted by NCHS classifies ALs according to size, relying on the four categories: small (4-10 beds), medium (11-25 beds), large (26-100 beds), and extra-large (more than 100 beds).[52] However, NCHS also groups residential care settings into small (4-25 beds), mid-capacity (26-50 beds), and large-capacity (50+ beds) in some analyses including Caffrey and Sengupta's brief describing variation in resident characteristics by community size. They found that for mid-capacity and large-capacity ALs, resident characteristics are very similar, as demonstrated in table 2.1. The greatest differences are seen in age, race/ethnicity, Medicaid use, and ADRD diagnosis. id-capacity ALs have more residents under 65 compared to large residences (7% versus 4%), a larger percentage of non-Hispanic White residents (88% versus 80%), and more residents that rely on Medicaid (18% versus 14%). Additionally, more residents of mid-capacity ALs have an ADRD diagnosis compared to large-capacity AL residents.[63] In contrast, small communities have younger, more racially diverse populations and higher rates of ADRD and depression.[63]

Fabius and Thomas described AL resident characteristics according to the race of Medicare beneficiaries living in ALs in 2014. As detailed in table 2.2, the authors found that Compared to White AL residents, Black residents were younger, a greater proportion were male, had originally qualified for Medicare due to disability, and additionally qualified for Medicaid. The

rates of congestive heart failure did not vary between White and Black residents, but a greater proportion of Black residents had diagnoses of ADRD, chronic obstructive pulmonary disorder, hypertension, depression, and diabetes. More White AL residents had arthritis diagnoses.[111] This study found that Black older adults entered ALs with higher medical acuity than their White peers despite their younger ages. The higher care needs of Black residents may equate to higher staffing and support needs.

Across many studies of AL resident characteristics, resident acuity has been investigated. Initially, it was argued that ALs had lower regulatory needs because of the lower levels of medical needs in ALs compared to NHs.[175] In a 2002 study Spillman, Liu and McGillard identified a significant difference in the population served in ALs between 1992 and 1998. Their study found that AL residents were both aging in place and that ALs were accepting older adults and adults with higher care needs. As a result, they claimed that AL residents were beginning to serve older and more frail populations, sparking fears that ALs may start to serve as a replacement for NHs.[176] However, since that time

Table 2.2: Comparison of White and Black Assisted Living Resident Medicare Beneficiary Characteristics

	Race	
Age Group %	**White (95% n=422,191)**	**Black (5% n=19,827)**
Under 65	6	26
65-74	12	25
75-84	28	25
85+	54	24
Sex %		
Female	69	57
Original Medicare Qualifier %		
Age	87	56
Disability	13	42
Dual Eligible	25	74
Medical Conditions %		
ADRD	41	53
Arthritis	47	40
Pulmonary Disorder	19	22
Congestive Heart Failure	33	33
Hypertension	74	81
Depression	32	35
Diabetes	29	53

Note: Adapted from Fabius and Thomas (2019)[111(p705)]

no studies have verified this initial finding. Without standardized national data, it is not currently possible to ascertain whether AL residents are increasing in acuity.[177]

Care Access

To understand variation in resident makeup, its necessary to determine whether variation in resident makeup is due to characteristics of the care provided or factors that serve as barriers or facilitators to accessing ALs. Many researchers from a variety of disciplines have identified dimensions of health service access. Penchansky and Thomas (1981) identified the dimensions as: accessibility, availability, acceptability, affordability, and adequacy.[178] Levesque et al. (2013) completed a synthesis of research on care access and updated these dimensions to clarify the differences between them. They identified the five dimensions as availability, approachability, acceptability, affordability, and appropriateness and described these in terms of both characteristics of the health service (location, outreach, norms, costs, and quality) and characteristics of the individual and community engaging with the health service (transport, health literacy, values, and ability to pay and engage).[179] Saurman (2015) additionally argued for the inclusion of awareness as a sixth dimension.[180]

For an AL to be accessible to a population, it must be meet the needs of the community and individual people based on geographic location and capacity (availability), transparency and outreach (approachability), norms and cultural values (acceptability), costs (affordability), and the quality of care and ability of the care to meet the needs of potential residents (appropriateness). Finally, community members must be aware that the AL is present and accessible (awareness). While all of these dimensions of access to ALs are essential, this study focused on AL availability.

Geographic Distribution

A recent study analyzed the geographic accessibility (availability) of ALs by presenting the penetration of ALs in each county in the US The study found the highest concentration of AL units per older adult in Oregon, Washington, Minnesota, Wisconsin, and Iowa with limited AL use in west Texas and parts of West Virginia.[10] The distribution of ALs in America is not equal – distributed according to the number of older adults in the community – or equitable – distributed according to the prevalence of older adults with LTSS needs. Counties with the most ALs compared to those with the fewest per capita have higher education attainment levels, more adults aged 85 and older, higher median home values, and more of the county population is made up of White residents.[10] An obvious cause of this distribution is AL affordability, particularly because ALs have long been majority private pay. However, Medicaid use in ALs has expanded significantly in the last decade, and a recent paper from Jenkins, Morales and Robert found that a smaller proportion of Black older adults than White older adults moved into ALs, even after taking into account need and facilitators like wealth.[8,52] This finding supports the concept that AL residential makeup is significantly impacted by AL accessibility, and specifically geographic accessibility.

While traveling to a nearby county to seek AL care may seem inconsequential to some, geographic location has been identified as a key factor to both AL use and care quality. [132,158,181] The importance of informal care in ALs necessitates physical proximity to care partners including family and friends. Without this local AL availability, older adults in need of residential LTSS may not choose to move into an AL, or may be unable to advocate for their needs if living distantly from their care networks.

Takeaway

AL is a model of residential LTSS wherein supervision and assistance with ADLs and IADLs is provided to older adults in a community setting. The flexible and easily adapted nature of this approach to LTSS is largely made possible by a reliance on both formal and informal external care providers including home health, hospice, family, and friends. ALs are largely private pay, though an increasing number of residents rely on Medicaid funds. A high proportion of AL residents are people living with dementia or cognitive impairment. The level of medical acuity experienced by residents varies widely from minimal assistance with ADLs to end-of-life care. The majority of AL residents are women, 85 or older, White, and need assistance with walking and bathing. ALs are more likely to be located in counties that have higher home values, a higher proportion of White residents, and a higher proportion of residents with college degrees. This has negative implications for the accessibility of AL care for Black older adults.

Types of Assisted Living

Definitions of what is considered an AL vary from state to state, and similarly models of care provision vary across AL providers. The variable regulatory approaches states have taken to licensing ALs have grown out of and allowed for many types and versions of ALs. Variation in regulatory approaches and AL care models evolved iteratively, likely both influencing the heterogenous landscape of residential services referred to as 'assisted living.' Many studies have set out to categorize both the models of care and models of AL licensing. The characteristics of AL care and regulatory models used to differentiate between types of AL licenses and care practices may impact the barriers and facilitators for AL market entry. While there is not one consistently accepted set of categories or classifications of ALs, these studies do capture some of the important aspects of variation across ALs in the US

Models of AL Care

Hawes and Phillips (2000) developed one of the first and most highly cited AL typologies, classifying ALs as high or low service and high or low in privacy. This study considered ALs "low privacy" if residents shared rooms, and "low service" if the AL did not have an RN on staff and provide nursing care.[182] Other attempts to categorize and describe this variation in AL care approaches includes Park et al. (2006), who conducted an investigation of the clustering of ALs by capacity-level structure, process, and case-mix and found that residence capacity and resident age as well as nursing care were statistically meaningful mechanisms for categorizing ALs.[183] When grouped according to co-occurrence of these community characteristics, Park et al. identified 5 clusters of ALs: 1) high Medicaid, 2) high ADL impairment, 3) High cognitive impairment with nursing, 4) low impairment with strict admission, and 5) moderate structure, process, and resident acuity.[183] Types of ALs have also been differentiated based on whether the services provided are dementia oriented[184] or oriented towards mental illness services.[183]

Stone and Reinhard (2007) described six models of AL: 1) independent housing with services, 2) freestanding market-rate ALs, 3) freestanding low-income ALs, 4) nursing home expansion into ALs, 5) continuing care retirement communities (CCRCs), and 6) comprehensive health and long-term-care models.[185] The independent housing with services model consists of service coordination in an apartment complex type setting. This model developed as public senior housing providers responded to the growing care needs of aging residents.[185(p25),186] Independent housing with services settings were built on existing public housing infrastructure, which was initially funded for older adults, then expanded to include all low-income Americans.[187] However, due to the lack of federal funding for AL services through Medicaid and

increasing cuts to the Housing and Urban Development (HUD) Section 202 low-income housing for the elderly program has led this type of AL to dwindle in popularity.[93,188(pp49-51)] As a result, this type of AL makes up only a small percentage of the AL market.

In contrast, both market-rate and low-income ALs are usually purpose-built. These communities vary in the types of services available, with some providing minimal supervision and assistance and other on-site nursing services.[185(p26)] Many nursing home providers expanded or converted existing nursing homes to accommodate AL residents. These facilities may have a special wing or floor within a building that houses a nursing home designated as an AL. Providers have used expansion into ALs as a mechanism for market diversification and meeting the needs of consumers who do not want to move into a skilled nursing environment.[185(p27)] CCRCs are usually purpose-built campuses that have a range of housing and service options designed to meet the needs of older adults as they age. These campuses may include independent living or private cottages to meet the needs of older adults requiring less assistance and ALs and NH facilities where residents can access more care as they age.[185(p27)] Finally, the comprehensive health and long-term care models are ALs integrated with a hospital to facilitate care transitions and allow residents to remain in the ALs without transitioning to a skilled nursing setting.[185(p27)]

Brown-Wilson (2007) describes four models of care: hybrid, hospitality, housing, and health care which she describes as both reflective of care and regulatory approaches. The hybrid model emphasizes the ability to accommodate various service levels in a residential setting based on a philosophy of consumer autonomy. The hospitality model provides a concierge-type set of services with minimal direct health service provision. The housing model relies on low-income senior housing, similar to Stone and Reinhard's housing with services. Health care model ALs are usually NH or boarding homes converted to be ALs. These residences have strict move-in

and move-out criteria, specifically providing care to residents that are below a NH level of care.[189]

Model of AL Regulation

The models of regulated ALs also vary both within and across states. Differences between regulated models of care result in differences in requirements such as staff training and staffing levels, allowances such as allowing residents that need skilled nursing care into the AL, and restrictions. Mollica identified three models of AL regulation: institutional, housing and services and the service model. The institutional model is more similar to NH settings, offering shared bedrooms and bathrooms. The housing and services model offers apartment-type units and allows for a wide range of service needs. Finally, the service model is a regulatory approach where the service providers are licensed to provide care in buildings that are licensed separately.[190]

Geographic Distribution of Types of ALs

While the distribution of these various types of AL care has not been documented, disparities in the availability of dementia-specific or memory care were recently identified. Counties with dementia-specific ALs were more urban and had higher education attainment rates, and median home values.[10] While counties with less AL penetration had both larger Black and Hispanic populations, of counties with ALs, those with dementia-specific care settings had larger Hispanic populations but few counties with larger Black populations had ALs with these specialized care settings.[10]

Takeaway

The types of care settings that are described as ALs are highly heterogenous. Researchers have various approaches to categorizing both the models of assisted living care and regulatory

approach. A consistent thread across approaches is the difference between ALs that were purpose-built compared to those that were low-income senior housing or those that were previously NHs. The extent to which the setting is designed to accommodate aging in place, and whether the AL provides health services versus allowing or partnering with third party service providers further differentiates these care settings. While the distribution of memory care has been documented, the ways that these other models of care are distributed across states has not yet been documented.

Assisted Living Financing

There are two primary components to funding for an AL. The first component is funding for real estate development, the cost of building or improving the physical infrastructure where care is provided. The second component is funding for operating costs including staff salaries for care provision, food, and supplies.[191] The costs associated with the capital investments in property, are generally fixed or "sunk" costs. These costs often occur before the AL opens for business or after a major renovation. The variable costs are those that accompany operations. Operating costs for an AL include the costs of supplies and staffing necessary for maintaining the physical space, managing the AL, and providing care to the residents.[101]

Resident fees, government funds, nonprofit entities, for-profit entities, and both public and private investors fund both capital and operating AL costs, depending on the AL financing model. Capital financing is usually funded at the AL level, in the form of financial support for an organization. In contrast, operating costs are funded through funds disbursed to organizations and through individual resident-level funding. These various approaches to financing are accompanied by corresponding sources of accountability, decision-making power, and economic security. Theoretically investors would be drawn to funding ALs where the profit from the

operations is likely to cover the cost of the capital investment in the shortest amount of time.[192] How this is achieved varies significantly based on financing model and sources of capital and operating funding.[191]

Takeaway

AL financing can be described according to two broad categories: capital and operating costs. Various sources of funding are used to cover these costs. Secure funding sources for both capital and operating costs are important for ALs to enter a market and be sustained over time.

2.3. Residential Long-Term Services and Supports Public Policy

Public Policy History

While older adults have long needed assistance with ADLs as they age, the AL model is relatively new. The challenges to AL access are best understood through the context of the American welfare system and previous forms of residential LTSS. This section describes some of the history that led to the introduction of ALs and the current care, regulatory, and funding models.

Early American Welfare

The first "home for the aged" in the US was opened in Philadelphia in 1823, as a more humane alternative to the workhouses popularized in Great Britain.[193] The federal government's first foray into funding for the care of the older adults was deeply bound in many layers of moral valuations of deservedness. In 1862, legislation was passed that aimed to recruit and retain Union soldiers by creating a long-promised pension system for the Union veterans and their families. This policy was the first to base payment on disabilities incurred in service in combination with the service member's rank.[194] After many revisions, this system eventually provided pensions to the majority of living Union veterans of the Civil War and created the basis for the welfare

system that continues today. The system set a precedent for income redistribution based on achievement, service, and physical need—omitting means as a factor. Like later systems, this first wide-spread American pension system created clear winners and losers, serving additionally as a mechanism to reward the Northern states for their defeat of the Confederacy, reinforcing the political nature of welfare policies in the United States.[195]

Social Security

Because of the industrial revolution, 1920 was the first year that more Americans lived in urban areas than rural areas. The Great Depression revealed the new set of economic risks that accompanied industrialization. Care for people with disabilities and older adults became increasingly difficult as families spread out to seek work, creating a policy window for passing welfare legislation. In addition to these pressures, the social insurance movement, started in Germany in the late nineteenth century, had already resulted in some form of social insurance policy implemented in over 30 countries, covering much of Europe. In 1935 President Roosevelt signed the Social Security Act into law, stating—"[this law] will give some measure of protection to the average citizen and to his family against poverty-ridden old age." [196]

Hill-Burton Act

Near the end of WWII, President Truman passed the Hill-Burton Act, known formally as The Hospital and Construction Act of 1946. Hill-Burton infused $1.6 billion dollars hospital and healthcare facility construction across America. Construction funds were distributed based on population and resulted in a significant expansion in the availability of healthcare facilities. While the act originally allowed for segregated hospitals and likely under-allocated funds to Black and Indigenous communities, it was successful in substantially expanding access to care, even for these marginalized Americans.[197] In 1954, legislation expanded the Hill-Burton Act to

include NHs. As a result, NHs followed a similar trend in construction and capital support to hospitals. While the act originally allowed for the construction of segregated facilities, a 1964 ruling found this practice unconstitutional. After the ruling, there were significant efforts to integrate facilities.[197]

In contrast to NHs, ALs were never eligible for Hill-Burton funds. States and nonprofits have engaged in attempts to make ALs more available to all communities; however, there has never been a large-scale investment in making ALs available across the US comparable to Hill-Burton for NHs. Without widespread federal funding for infrastructure, ALs have been more susceptible to market pressures.[198]

The Older American's Act of 1965

Private funding and philanthropic entities provided most residential LTSS before President Johnson signed the Medicare and Medicaid Act into law in 1965. The private health insurance market appeared as the cost of medical care increased during the first half of the 20th century. By 1951, employer-based insurance covered over half of hospital patients in America. However, without participating in the labor market, employer-based insurance left older adults uninsured despite increasing medical costs. In the early fifties, the first proposal of a public health insurance plan that would cover only older adults was brought to congress. In 1965, congress finally passed a bill to provide insurance to older adults via amendments to the Social Security Act.[86]

In 1935, Roosevelt chose to leave health insurance out of Social Security in order to get it passed. Between 1935 and 1965, there were multiple attempts to pass a national healthcare plan, each of which lobbying efforts shut down. The American Medical Association (AMA) funded nation-wide campaigns to sway the public away from national healthcare, fearing government

oversight would limit physician fees and autonomy. The AMA argued against national healthcare plans; they introduced the threatening concepts of "nationalized doctors" and "socialized medicine" to the political discourse. Post-World War II, mounting social pressures paired with a booming economy made providing medical insurance to older adults politically feasible. Disability insurance was passed in the 1950s, as a means to provide benefits to workers unable to continue working due to injury. Those covered were originally conceived of as deserving workers who, due to unseen forces, were forced out of the workforce early. This policy reinforced one already popularized, the idea of working as a means to accessing healthcare, and healthcare as a good only available to those willing to earn it.[170,199,200]

This political narrative of deservedness allowed Presidents Kennedy and Johnson to frame Medicare and Medicaid as pro-worker policies to extend healthcare to a dependent deserving population.[200,201] Lyndon Johnson passed Medicare and Medicaid into law with strong support from labor unions in 1965 as part of the Great Society initiatives. Medicare was designed to allow retired workers to continue to access healthcare, where Medicaid was meant to address additional ongoing care needs of low-income older adults—providing nursing home care to those unable to pay for or care for themselves.[202]

Medicare and Medicaid began paying for NH care. Medicare covers beneficiary costs provided in SNFs and Medicaid pays for beneficiary care in NFs. With these additional funding sources, the NH industry expanded rapidly during the 1960s and 70s. As a result, most middle and low-income older adults found NHs were their only affordable option for medical care and supportive housing. The media reports of abuse and neglect in NHs resulted in negative associations with the institutional setting. Politicians criticized the medical-model based LTSS

provided in these settings and consumers rated it poorly. In response, states began the search for alternatives.[203]

The residential facilities that did not transition to the NH model continued providing services, even though they were not reimbursable, for low-income residents.[199] The AL model of residential care developed out of these settings. ALs were developed as an alternative to institutional services in the late 1970s.[204] The AL model began as a rejection of the NH model, due to the demand for more flexible care settings that allowed older adults to age in place without living in a hospital-like setting. Consumers demanded more resident autonomy and a care setting that could focus on quality of life. The rejection of the medical model led to the development of the first AL models of care.[189]

Introduction of Assisted Living

CMS funded a 10-state pilot of programs with the potential to provide NH alternatives in the late 1970s and early 1980s via the National Long-Term Care Channeling Demonstration and Evaluation. Advocates hoped that the experiment would reveal mechanisms for savings at both the federal and state levels.[53,205] In addition to the abuse reported in both private pay and state-funded NHs, rapidly expanding costs concerned both fiscal conservatives and liberals. CMS funded pilot programs to identify alternative ways of administering Medicaid and Medicare to fund LTSS. However, the high costs of NHs combined with negative public sentiment led congress to fund a waiver system before the pilot programs returned results.[202]

The Omnibus Reconciliation Act of 1981 introduced home and community-based service (HCBS) waivers to section 1915(c) of Title XIX of the Social Security Act.[206] The 1915(c) waiver allows states to limit the statewide-nature of Medicaid provisions, covering community-based services for a subset of Medicaid participants in the state. States could begin offering

HCBS to some residents, but could cap the number of people the program covered as long as they kept the cost of services budget neutral.[207]

As ALs grew in popularity, it also gained attention as a care setting in need of appropriate regulation. Oregon is recognized as the first state to define and license the AL model. As conceived by Keren Brown-Wilson and Richard Ladd, submitted the first proposal for state-regulation to the State of Oregon in 1985. The pilot consisted of the provision of care services in an apartment-type setting for older adults that would otherwise be cared for in NHs. Oregon officially licensed ALs in 1990 and was included in a review by Hawes, Wildire, and Lux in 1991 as "an explicit subset of residential care."[189] However, while ALs soon became an option for older adults across the country, not all states licensed ALs, and the regulatory scope and prescriptiveness of these licenses varied widely.

Concerned advocates called for national regulatory standardization, these calls to action culminated in a report from the Government Accountability Office (GAO) in 1999 which cited a need for the federal regulation of ALs and a report from the Institute of Medicine on improving the quality of long-term care.[208,209] As a response, the US Senate Special Committee on Aging convened a national meeting to establish guidelines and recommendations for federal and state AL policy. The resulting assisted living workgroup report describes over one hundred recommendations and the support and dissent for each. The consensus from this meeting was that the AL industry would work to self-regulate and states would maintain their authority to set AL regulations that met the needs of their older adult residents.[1]

Olmstead Ruling

Another important shift in LTSS provision arose out of a Supreme Court case—Olmstead v. LC. Ex rel. Zimring.[210] While President George H. W. Bush signed the Americans with

Disabilities Act (ADA) into law in 1990, the Olmstead decision significantly expanded the ADA's implications for LTSS. Olmstead found that unnecessary institutionalization of people with disabilities violates the ADA. The court ruled that states must provide LTSS in the "least restrictive environment possible."[211] The ruling stood in stark contrast to the 75 percent of public funds for long-term care being spent on institutional care at the time.[212] Since the ruling, states have struggled to shift more LTSS to the community; for the care of older adults, ALs have been one of the primary mechanisms used to further this goal.[78]

Legislation in 2012 significantly changed the administration of OAA, as it merged the Administration on Aging into the Administration for Community Living (ACL). The ACL serves the needs of both older Americans and people with disabilities. The services provided under OAA are not means-tested and provide access to some LTSS that low- and middle-income older adults could not access otherwise. Services provided by the Aging Services Network include transportation, Meals on Wheels, and Elder Rights Services. The ACL administers and funds these and other community-based programs under Title III of the Older Americans Act, often with financial assistance from Medicaid.[213,214]

A 2014 CMS administrative rule applies to ALs. It set forth requirements for all HCBS settings, including ALs, to operate in a non-institutional manner.[215] This rule established a set of expectations states must comply with, but did not change how CMS oversees states' monitoring and enforcement after they fund waivers.[161] CMS requires state agencies to demonstrate they have policies that meet applicable federal rules to receive federal approval of their HCBS waivers, which states must be renew every 3-5 years. CMS does not oversee how or to what extent states enforce these rules or whether these rules are upheld by ALs that receive funds.[216]

Federal regulators rely on states to implement the rules; the autonomous state agencies enforce their regulations through monitoring and oversight.[217]

Takeaway

ALs have evolved as an alternative to institutional care that has become especially important to the provision of LTSS in wake of the shift towards community-based services. However, unlike NH, there were no government-sponsored programs investing in the capital costs of building ALs, which limited their distribution to locations supported by the market for residential LTSS. The Olmstead ruling requires states to deinstitutionalize residential LTSS, but the availability of community-based services like ALs in the communities' older adults live may limit these efforts.

Public Policy Process

Political Discourse in Assisted Living Regulation

The core tensions of the AL policies arise out of a disagreement over power and authority that has persisted since America's founding. Is it best for decisions to be made at the federal level, where all factions are more likely to enjoy representation?[218] Is it best to make decisions at state and local levels, where people implementing the policies have lived experience that allows them to more effectively and efficiently implement and adapt to complex and ever fluctuating needs?[219] The crux of this disagreement has been argued thoroughly since the founding of the country.[220] This tension has two components – the extent to which a policy is programmed, or specified in detail in how it should be carried out, and at which polycentric level of governance the decisions are made regarding the financing, implementation, and assessment of the specified program.[221]

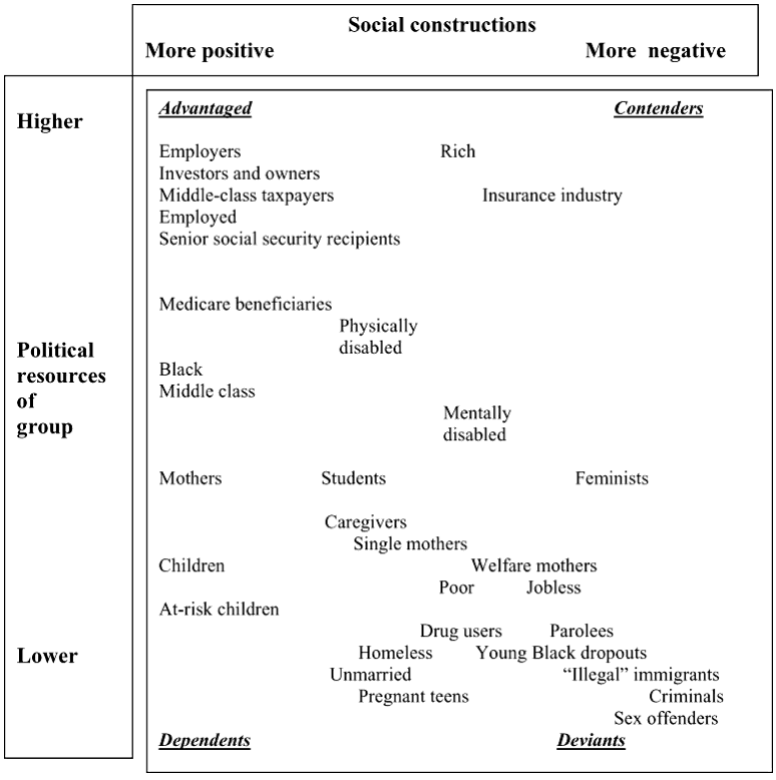
In a recent article, Stone recalls that the greatest tension in LTSS financing is the same today as it was thirty years ago. When she served on the US Bipartisan Commission on Comprehensive Health Care, also known as the Pepper Commission, Stone describes the group's greatest tension as one of problem definition.[222,223] On problem definition, Kingdon claims, "conditions become defined as problems when we come to believe that we should do something about them."[224(p109)] While everyone agreed that the condition was a deficiency of finance mechanisms for LTSS, the group disagreed as to whether this was a problem of medical care provision or a problem of "functional-quality-of-life needs." The first group saw the need for LTSS as something that could be addressed through health insurance, where the payments are defined by the disease state. In contrast, the second group conceived of the gap in LTSS as an issue to be addressed according to functional need, and potential paid forms of housing and assistance to provided based on needs reported by the individual.[222] The Pepper Commission ended up recommending that a national social insurance program provide coverage for HCBS.[226,227] Unfortunately, neither their policy recommendations nor choice of problem definition were adopted.[201]

The social construction of political power framework can be used to understand this gap between research and actions taken by policymakers. The framework is illustrated with a two-by-two matrix of strong and weak power in conjunction with positive and negative social construction. As illustrated in figure 2.1, the resulting four categories are: the positively constructed, politically powerful "Advantaged"; the positively constructed, politically weak "Dependents"; the negatively constructed, politically powerful "Contenders"; and the negatively constructed, politically weak "Deviants." [228] This construction can inform the implied levels of benefit and burden the policy will shift onto the target population.[200]

Stone's account refers to the medical lens and to the functional lens, which was first popularized by the disability movement. The medical or biomedical lens is rooted in Edmund Vincent Cowdry's biological theory on aging and the idea of homeostasis disruption.[229,230] It has come to represent a perspective in which aging and its accompanying disabilities, are problems to be solved by healthcare and biomedical research-based interventions.[54] From a biomedical perspective, older adults are constructed in two groups – the able bodied, those "successfully aging" and those with disabilities.[231] The able-bodied older adults are seen through the biomedical lens as dependents, whereas older adults with disabilities are constructed as deviants. The biomedical institutions are constructed as advantaged, with a responsibility to move more older adults from the position of deviant to the position of dependent.

Given this construction, we would expect benefits to older adults with disabilities to be highly undersubscribed (lacking sufficient prescriptiveness) and burdens to be highly oversubscribed (overly prescriptive). In contrast, the benefits to biomedical institutions would be oversubscribed and burdens

Figure 2.1: Schneider & Ingram's Power and Social Construction Framework



"Power and Social Constructions of Target Populations." as presented by Schneider and Sidney, based on the original work of Schneider and Ingram (1993; 2009).[200,225]

undersubscribed. In this sense, subscription is the extent to which the benefit or burden is programmed into the policy via regulations or financially incentivized or punished.[200] This implies that given the biomedical lens, more funds would be allocated to biomedical institutions for research and treatment. This is reflected in the initial Medicaid policy which gave preference to institutional and hospital care. The benefits to the biomedical institutions are oversubscribed while the undersubscription of benefits to the disabled older adults led to widespread neglect and abuse, especially for those who are also low-income and/or a racial minority.[232]

While many policy analyses have identified forms of institutional oppression in policy, few have broken out regulations as separate from the statutes, and analyses are often unclear as to which they are utilizing as source material.[233] Ingram and Schneider identified both the policymaking and rulemaking processes as potential opportunities for target group misalignment, identifying deinstitutionalization movements, including the movement from nursing homes to community-based care, as one realm, in particular, that suffers from target group controversy.[228] In investigating target group misalignment, Ingram and Schneider identified the rulemaking process as potential exposure to bias through both implicit and explicit means.[228] However, most policy analyses still fail to include the rulemaking process as a variable in identifying drivers of potential institutional oppression.[234]

From the perspective of Stone's functional quality of life lens,[222] older adults are seen as part of a society made of families and relationships. The role of informal care is important to this lens, as it is acknowledged that without governmental provision of LTSS, many older adults would either go without care or rely more on family and friends to provide unpaid care. From this perspective, it is important for older adults to both receive the care necessary to maintain quality of life and overcome any barriers brought on by the physical and social environments not

designed for their abilities. It is also essential that their paid and unpaid caregivers receive necessary supports, to allow them to similarly thrive.[235] From this perspective, older adults with the means to ensure their quality of life and well-being are constructed as advantaged and those without such means are constructed as dependents.

The goal of policies from this lens is to provide older adults and their caregivers with the resources they need to maintain their humanity and quality of life. Given the implied undersubscription of benefits to the low- and middle- income older adults and implied oversubscription of benefits to the high-income older adults, we would expect policies that focus on shifting more older adults into the advantaged category and expose the benefits of current policies to biomedical institutions. The more recently introduced 1915(j) and (k) type programs do reflect this construction to some extent. Their requirement that services be person-directed and inclusive of families points to a shift in power structures. If HCBS policy continues to shift in this direction, we would expect more programmed policy rights for older adults.

Support for Medicaid funding of LTSS has shifted as the perception of low-income older adults has shifted from the realm of dependents to deviants. Efforts to rein in federal spending on Medicaid were previously framed as the federal government attempting to renege on their promise to provide for workers in old age, reflecting the popular view of this population as dependent and deserving of aid.[236] Both Medicare and Medicaid were put into place as programs of the federal government under the Social Security Act. However, Medicaid was later framed as a welfare program. This was in large part due to the linking of Medicaid with Aid to Families with Dependent Children (AFDC). Any families that qualified for AFDC automatically qualified for Medicaid, thus Medicaid became synonymous with the political debate surrounding welfare

for working-age families and the associated stigma due to the shift in the perception of Medicaid recipients as deviants.[206]

Despite the negative perceptions of Medicaid and the deviant status of Medicaid beneficiaries, the Medicaid program has persisted. Policy program durability is described by Thompson as the ability of a program to continue to exist and avoid policy erosion over time through formal legal specifications, program resources, program outputs, and outcomes.[206] The use of waivers as a form of "executive federalism," or governing without new legislation,[237] is a form of legal durability that has become an important aspect of how Medicaid has proliferated over various political regimes, continuing to grow in LTSS provision in ALs. The extent to which this durability is positive and the impacts of the policy effective are as much a question of implementation as they are a question of policymaking.[206]

Assisted Living Regulatory Change Strategies

The process of determining the public and private institutions governing ALs, and the rules these institutions enforce is essential to understanding the AL policy process. Given a rules-based view of regulation, the traditional approach, political advocacy leading to the creation of new laws is the strategy for anyone that wishes to change institutional behavior.[238] An example of this approach to policymaking specific to AL is the introduction of dementia-specific training for all direct care staff in Oregon.[239] This law was passed as a result of advocacy from Alzheimer's Association Oregon Chapter and the Oregon Health Care Association.[240]

These organizations not only took a rules-based approach, but also looked outside of the legislature for opportunities to improve quality of care through regulation. The advocacy groups support Oregon Care Partners, a platform that provides free high-quality training in dementia care online.[240] While this aspect of their work may not initially look like regulatory advocacy,

regulatory theorists Drahos and Krygier (2017) recommend taking "a broader view of regulation that include[s] non-legal forms of norm-making, along with the idea that private sovereignty over such norm-making matter[s] to regulatory outcomes."[238(pp3-4)] Alternative approaches could additionally include working with companies that provide training platforms to AL providers, supporting unions to ensure workers receive sufficient training and support from the AL providers to do their jobs well or providing the public with information regarding the training that various ALs require of their staff. This network view of regulation encourages us to recognize the ways that government, industry, and the public work together to create the processes that encourage, discourage, prevent, or punish to create institutional change.[238]

Takeaway

AL policymaking reflects tensions that have always been at the core of American politics. Tensions between federal versus state authority and responsibility have led to a system of executive federalism wherein the federal government funds Medicaid, but via waivers, allows states to determine how the funds are spent. This misalignment of funding and authority powers muddies the waters of accountability resulting in an environment that is especially difficult for disadvantaged but negatively constructed older adults in need of support. A network view of governance allows for a more complete analysis of the policy space, due to the inclusion of civil and private stakeholders. Their inclusion in an analysis may better enable clarity in understanding the relationships between governance stakeholders and AL accessibility.

2.4. Types of Assisted Living Public Governance

ALs are governed by local, state, and federal entities through two primary mechanisms, funding and regulation. The largest sources of funding come from the federal government; however, the greatest sources of regulation are the state regulatory agencies. The incongruence

between the funding and regulatory sources results in mixed sources of accountability and many differences across states in both funding access and regulatory protections.[201]

Distributive Assisted Living Policy

For residents receiving public assistance, care costs are often broken up into room and board costs and costs associated with care provision. For private pay residents, their payment to the AL operator ideally covers both the costs associated with capital financing and the operating costs.[241] While public funding has played a much larger role in NH property development and operational costs, public funding for ALs continues to increase as they have gained in use and popularity.[161] Federal and state agencies both provide funding for AL services; however, states provide more funding for individual residents, covering operating costs, where the federal government provides the primary funding for capital costs at the AL level. However, even federal funding for capital funding is limited, relying primarily on investors for this component of AL financing.[191]

Federal Distributive Assisted Living Policy

Historically, ALs have been largely private pay however, 49 of the 50 states and Washington DC now have Medicaid HCBS in place to reimburse the costs of the care provided.[242] Medicaid, funded by the Department of Health and Human Services, is not the only source of federal funding in ALs. Table 2.3 describes the services funded by each department. HUD and the US Department of Agriculture (USDA) both have programs to fund AL capital projects but these funding sources are limited and not widespread in use.[243]

In comparison to state Medicaid plans, Medicaid waivers give states greater choice and autonomy in determining fund dispersal but result in greater variation in levels of oversight for ALs across the country.[244] In 2002 only 36 states had waivers, and 11% of AL residents relied on

Medicaid.[245] By 2016, 48 states had waivers or state plans covering ALs for 17% of residents.[52] A GAO report commissioned by Senators Elizabeth Warren (D-Mass.), Orrin Hatch (R-Utah), Susan Collins (R-Maine), and Claire McCaskill (D-Mo.) found that in 2014, 48 state Medicaid agencies spent over $10 billion in funding for AL services, which funded the care of over 330,000 older adults and accounted for 12.4% of Medicaid spent on HCBS in all settings that year.[113] The rate of Medicaid use in ALs will likely continue to increase as more states come into compliance with the Centers for Medicare & Medicaid Services (CMS) 2014 final ruling that states must create a plan to move people who rely on LTSS into the least restrictive environment possible.[215] The composition of residents in ALs may shift as a result. A recent study found that compared to AL residents enrolled only in Medicare, AL residents who are dually enrolled are younger and experience higher rates of disability, ADRD, and chronicity.[242]

Table 2.3: Federal Funding in Assisted Living

		Capital Costs	*Service Provision*		
			Nutrition	*LTSS*	*Rent Subsidy*
IRS	Low-Income Housing Tax Credits	S	-	-	-
HUD	Office of Multi-Family Housing	X	-	-	X*
DHHS	Administration on Aging	-	S	S	-
	Centers for Medicare & Medicaid Services	-	S	S	-
USDA	Food and Nutrition Service	X	X	-	-

Note: S = Administered by states, X = Funding dispersal and management; *Older HUD funded projects do not include rent subsidy[89,243,246]

The increase in the level of public funds distributed to ALs through Medicaid raises the issue of accountability and the extent to which the federal government, either directly or indirectly, holds accountable AL providers. CMS does not provide direct oversight in ALs, as ALs are not included in the definition of long-term care facility.[247] Instead, CMS requires state

agencies to demonstrate they have regulations that meet applicable federal rules to receive federal approval of their HCBS waivers.[216] However, regulations are just one component of regulatory stringency, the second piece is the oversight, which includes the monitoring and enforcement activities accompanying the rules.

Medicaid and Assisted Living History

The federal government funds LTSS in-home and community-based services settings through four departments and five programs. Table 2.3 describes the types of services funded by each department. While these services are funded, due to the use of waivers, some of these services are accompanied by greater opportunity for federal oversight than others.[243] State Medicaid waivers give states greater choice and autonomy in determining fund dispersal, but simultaneously result in greater variation in levels of accountability and regulation across the country.[244,248]

At a median cost of $4,300 per month, the issue of cost and funding sources is an essential question for any prospective AL resident.[249] Although there have been efforts to encourage and regulate the sales of private long-term care insurance, these efforts have largely failed to be adopted broadly.[116] High income older adults are able to afford long-term care insurance, life insurance conversion programs, or to pay out of pocket for AL care. Programs have been developed to easily allow older adults to use the equity from their homes to pay for ALs.[250] The composition of residents in ALs may shift as a result. A recent study found that compared to AL residents enrolled only in Medicare, AL residents who are dually enrolled are younger and experience higher rates of disability, ADRD, and chronicity.[242]

Medicaid has become an important payer for LTSS, including AL care. Medicaid funds are often used by both low-income older adults, who qualify for public subsidy programs based

on their low-income, as well as middle-income older adults. It is increasingly common for middle-income older adults to "spend down," using their savings to pay for care until they are impoverished, and can then qualify for Medicaid.[251] Other public resources for AL funding include Veteran's benefits or help from family. Finally, many older adults use their social security to fund at least some of the costs of staying in ALs. Many states have special programs to supplement social security payments for those residing in ALs, an option for funding that is less often tied to medical acuity or functional need than Medicaid.[101,191]

Medicaid is often thought of as the welfare component of the American healthcare funding. However, older adults and people with disabilities bill for two thirds of all Medicaid expenditures, with the majority of these costs associated with long-term care. Medicaid differs from Medicare in that it is means-based, not age-based, and is administered by the states via matching funds dispersed to states from the federal government.[252] Under Medicaid, states must cover nursing home care and some home health benefits, but are not required to cover the costs of assistance with ADL or LTSS provided at home or in the community.[201] States are allowed to provide this coverage under their state plan, but prior to the introduction of HCBS waivers, the federal government provided no matching funds for these services.[253]

Medicaid's "institutional bias" was due to the prominence of the biomedical model of care when it was enacted in 1965.[252] Medicaid eligibility is based on both functional and means-based need. Older adults living below 75 percent of the poverty line with few assets qualify for supplemental security income (SSI), which includes full access to Medicaid benefits. Receiving Social Security income makes most older adults ineligible for SSI; however, states can extend Medicaid to cover non-SSI eligible older adults.[206]

Medicaid State Plans

Personal care services are an optional component of Medicaid that may be offered through Medicaid state plans without a waiver, funded by both state Medicaid and federal matching funds. These services are provided to people with disabilities who need assistance with ADLs and IADLs.[254] While personal care services is usually discussed in the context of personal attendant or assistant services for people living with disabilities of all ages, this source of funding is used in some ALs.[255] It cannot cover only housekeeping or medical care, but can cover both direct assistance with ADLs and IADLs and cuing or directing individuals to undertake tasks. The services and provider types vary by state, but can include AL operators or more commonly third party providers.[256] Personal care services may also be administered through HCBS 1915(i) waiver programs; however, 1915(i) waivers allow states to offer services only to a specific population subgroup.[215]

HCBS Waivers

Access to care at home and in community settings has proven to be beneficial for those served and less costly due to the uncoupling of medical services from housing and social supports.[53] Unfortunately, it is still far from universally available, with a disproportionate number of low income communities relying on either informal or institutional care.[78,257] Researchers have found that AL care provided to people funded through HCBS is more similar to institutional care than services that are privately funded.[6,114] Additionally, HCBS services are less available and appear to have lower utilization rates for a number of marginalized groups, including racial minorities, LGBT older adults, low-income residents, and people living in rural America.[201]

HCBS waivers are unique to each state resulting in wide variation in the policies governing these settings as well as variation in the public funding mechanisms in use.[258] All 50 states and Washington DC now have at least one HCBS Medicaid waiver in place to allow for spending Medicaid funds in community settings instead of institutional settings, though only 48 allow HCBS funds to be spent on AL care.[161,259] Two types of waivers are used regularly by states to administer Medicaid programs – demonstration waivers and programmatic waivers. Demonstration waivers generally are authorized under section 1115 of the Social Security Act, whereas programmatic waivers are authorized under section 1915. Demonstration waivers, as a tool for policy learning and research, require extensive evaluation, whereas programmatic waivers require little to no federal evaluation but are more programmed in nature. States may apply for multiple waivers and often apply for multiple waivers of the same type. Each waiver waives a specific requirement of the federal program and allows states to either not comply with specific requirements for a specified population or receive federal funds for the provision of services that would not otherwise be covered.[244]

Under 1915(c), states can include individuals with incomes up to 300% of the SSI limit who meet functional requirements for institutional care.[260] The services covered under the waiver are expanded to include case management, home health and personal care, adult day care, rehabilitation services, respite care, and community settings such as ALs. Additionally, states can request coverage of other specific services that fall under the category of home and community-based care. States using the 1915(c) may implement caps on the number of individuals served, using a waitlist to control costs. States can also cap individual budget allocations, disallowing coverage after an individual has met the maximum for the year.[258]

The Deficit Reduction Act of 2005 introduced two new waiver options – the 1915(i) and (j). The 1915(i) waiver was created to offer the option of HCBS to people who do not meet the functional requirements necessary to qualify for institutional care, but do meet the means-test and do have a functional need for care. The concept behind the addition of the 1915(i) was that individuals who do not yet meet the functional impairment requirements necessary for care under 1915(c) may benefit from HCBS, saving future costs and improving older adult quality of life. Though the 1915(i) targets adults with mental health and substance use disorders under age 65, it has been used to fund AL care for older adults.[215,261]

Waiver 1915(j), also known as "Cash and Counseling," allows states to fund self-directed personal assistance services with Medicaid funds.[258] States are able to make these services available to those who already receive services under 1915(c), which restricts services to those who would otherwise qualify for institutional care.[215] While the majority of people covered by this waiver have been physically or mentally disabled adults under 65, it has also been used with older adult populations. People using 1915(j) services are able to hire their own caregivers and use Medicaid funds to pay them.[262]

The Affordable Care Act (ACA) created a new category of HCBS not previously available, the Community First Choice (CFC) or 1915(K). These plans provide states with quite different options from their predecessors.[215] They require states to provide HCBS to individuals at or below 150% of the poverty level who would otherwise functionally qualify for care under the existing state plan for LTSS.[263] This means that the functional need requirements are necessarily higher than the (i), as individuals must be unable to manage their ADLs without access to nursing care. States are required to provide funded services, including AL care, to anyone who qualifies both functionally and financially.[215]

States that use the CFC receive a 6% increase in matching funding from the federal government. However, because states may not limit their target group or put a cap on the number of individuals covered, they must cover the difference in cost if costs exceed the 6% of additional funding. If states are able to provide HCBS to everyone who qualifies for less than the cost of institutional care plus 6%, they are able to keep their savings. This option for states is unique in that it mandates that all care paid for via CFC is self-directed in nature and inclusive of families in decision making. It is also accompanied by a mandate for the funding of staff training and development.[87] The 1915(K) removes the state option to waive "state-wideness" while increasing state fiscal autonomy.[264]

HCBS is now used widely. In 1988 HCBS accounted for around 10% of Medicaid LTSS costs. In comparison, as of 2013, over 50% of Medicaid LTSS costs could be attributed to HCBS.[265] This metric includes both care for older adults and people with intellectual and developmental disorders and state uptake has varied drastically. As of 2013, Oregon had the highest HCBS use at 79% of Medicaid LTSS costs, and Mississippi had the lowest at 26%.[47] Specific to ALs, 49 of the 50 states and the District of Columbia now have Medicaid waivers or state plans in place to reimburse the costs of the care provided. In 2016, 17% of residents rely upon Medicaid to fund at least some aspects of their care, and 49% of ALs reported meeting the criteria to receive Medicaid reimbursements for care.[52] In comparison, in 2002 only 36 states had waivers or state plans, and 11% of AL residents relied on Medicaid.[245] [266] These numbers will likely continue to increase as more states come into compliance with the CMS 2014 final ruling that states must create a plan to move older adults and people with disabilities into the least restrictive environment possible, in line with the Olmstead ruling of 1999.[215]

Housing and Urban Development (HUD)

The Housing Act of 1959 established Section 202, a HUD program that provides capital grants to non-profit organizations to build or renovate facilities to be used as "supportive housing for the elderly." In 1990, a HUD funded service coordinator, a staff position that provides information about community resources but does not provide services to residents, became an option for these units. This funding stream led to an early unlicensed model of assisted living in which senior housing providers coordinated services for older adult tenants, subsidized by HUD funding. These buildings were often existing low income housing where tenants' rent was subsidized, and varying levels of assistance with transportation, meals, housekeeping, and minimal other ADL support were provided.[89] Project HOPE for Elderly Independence was a similar grant that relied on low income family housing, Section 8 (now called the Housing Choice Voucher program). Neither of these programs were widely adopted, and have been for the most part, discontinued due to the lack of matching funds, a necessary component of the programs.[187,188] Another HUD program, the AL Conversion Program, was developed to provide funding to convert properties into ALs. However, the program was underutilized, as only the conversion of the facility, not the supportive services post-conversion were covered by the grant.[267]

The Consolidated and Further Continuing Appropriations Act of 2012 and its amendments created the Rental Assistance Demonstration (RAD) program. RAD is a HUD program aimed at addressing the issue of aging public housing infrastructure. Growing capital needs have reduced the availability of section 8 and section 202 housing units available. RAD allows existing properties to be converted into either a project-based voucher (PBV) or project-based rental assistance (PBRA) Section 8 contract. Regional public housing authorities have

been funded to develop projects that update existing properties for low-income housing and housing for older adults. The PBRA RAD programs are accompanied by rent supplement funding as well as support services funded through financed equity of the property and have been piloted for use in ALs.[268] Finally, HUD also provides fixed-rate mortgage insurance to skilled nursing and assisted living facilities under section 232 and 223(f) programs.[269] Though these funding and development mechanisms are limited in use and funding for support services, they are the primary means of HUD financing in ALs currently.[270]

HUD additionally collects data for all low-income housing tax credit (LIHTC) properties, and specifies which census tracts states can develop these properties within. LIHTC funding is dispersed by the Internal Revenue Service (IRS) and administered by states. State programs vary; however, all funded projects must be reported to HUD for public reporting purposes.[271,272] LIHTC funding has been used to fund the development of subsidized ALs; however, rent or service costs must be covered by state, local, or nonprofit sources of funding.[88]

United States Department of Agriculture (USDA)

The USDA funds Community Facilities Direct Loan (CFDL) grants and loans, which provide public entities, nonprofits, and federally recognized tribes with matching funds for community facility costs in rural areas. The projects, often managed by community development financial institutions (CDFIs), can include building or renovating facilities, the provision of community support services, public safety services, education services, and utility infrastructure and equipment. These low interest direct loans and grants are awarded through a competitive process to communities with populations under 5,500.[273] In recent years, the growing demand for senior housing in rural areas has led some CDFIs to use these funds for the construction or conversion of facilities to ALs. CDFIs have also used CFDLs for ongoing resident care

subsidies.[274,275] Unfortunately, the availability of these funds for LTSS is limited, and ALs built or sustained via this approach are rare.

State Distributive Assisted Living Policy

States rely on a number of different programs to assist their residents in financially accessing AL services. These include state sponsored benefit programs, social security supplements, and AL financing programs that allow older adults to reverse mortgage their homes or convert life insurance benefits.[101,250] Optional state supplements (OSS) to supplemental security income (SSI) are available in 42 states and Washington DC. For 12 of these states, the program is administered by the Social Security Administration, whereas the other 31 programs are administered by the states themselves. OSS consist of additional payments to either the resident or the AL for qualifying low-income older adults. This means that if a resident is enrolled in the OSS program, they will receive an additional dollar amount from the state each month, usually as part of their SSI benefit. This allowance is designed to make AL care more affordable, as it can be used towards room and board costs. [101]

Takeaway

Unlike NHs, Medicaid can only be used in ALs via state waivers. Although Medicaid waivers are available in most states to pay for AL care, the types of services paid for, number of older adults covered, and eligibility criteria vary considerably by waiver type and policy. This variation contributes to the variation in affordability of ALs within and across states. While HUD and USDA funding has been used to fund ALs in the past, currently both of these funding sources are relied upon on rare occasions through pilot grant mechanisms only. As a result, federal funding is indirectly used to cover operating costs, but is largely unavailable for the

capital costs associated with market entry, property, and facility construction or conversion costs for ALs.

Regulative Assisted Living Policy

According to the 2001 Institute on Medicine report on long-term care, there are five primary reasons to regulate long-term care settings. First, the physical and cognitive disabilities experienced by residents can make self-advocacy difficult, and as a result, residents are more vulnerable to abuse and neglect. Second, the multi-morbidities experienced by older adults in need of LTSS can be so complex that assistance from someone with knowledge and skills in directing care may be necessary, creating an information asymmetry between the resident and the person making important decisions regarding their health. Third, the LTSS workforce, and in particular the AL workforce, consists of paraprofessionals who may have insufficient training for care provision. Fourth, the invisibility of LTSS due to the relative isolation of residential LTSS environments creates a space in which public observation and intervention is less possible. Finally, the residents in residential LTSS settings may lack choice in providers and services, which limits the efficacy of market forces.[209]

Statutory policies are just one piece of the system that must take action to regulate providers to ensure this balance of protections is maintained. After politicians pass a bill into law, it becomes a statute. Policymaking refers to the political process whereby policies are enacted by statutory designers and elected officials. Rulemaking takes place after a statute has been passed into law. This process is completed by regulatory or executive agency staff, with opportunities for public input.[276] For the statute to be enforced, it must be translated into administrative code or regulations. It is this code, written by state agency officials, that is enforced by agencies and disseminated to the public for compliance.[277] Statutes and court cases

may additionally be relied upon if a provider is sued. However, pursuing legal action requires the party experiencing harm to have powers that are often inaccessible to AL residents. Pursuing legal action is not just an issue of means, but also of time and cognitive ability, all of which may disadvantage people living in ALs, particularly people living with ADRD.[204,278]

Government oversight of ALs varies significantly across jurisdictions. States vary in what they regulate, how they survey ALs, and how often these surveys take place. Without either consistency in state regulatory oversight or federal oversight, residents living in these care settings are left responsible for reporting neglect and abuse. While the AL model does prioritize resident independence and autonomy, the high level of residents who are people living with ADRD may make it difficult for residents to serve as self-advocates. In a purely residential setting, people living with ADRD rely on care networks including family and friends for assistance with decision making and care advocacy.

AL residents are able to pay for medical services with Medicare, such as doctor visits or home health, as they would if they were living at home. However, these funds are not used to pay for services provided by the AL. To utilize Medicaid funding to reimburse the costs of care or room and board in an AL, a state must utilize a federal waiver or otherwise cover the costs with state funds.[161] ALs do not submit claims to Medicare or Medicaid, although depending on state policy, both sources of public social insurance funding may indirectly pay for care within an AL. With no direct federal funding, ALs operate without the direct regulation of federal policy.[161] State reliance on waivers for AL Medicaid funding has allowed states to develop unique approaches to AL regulation and programming, but this variable regulatory environment may be a barrier to equitable AL access and provision.[198]

Federal Regulative Assisted Living Policy

ALs are largely governed at the state level, unlike NHs. There are some federal rules that apply to ALs if the community relies upon funding or loans backed by the Federal Housing Administration or HCBS Medicaid funds. Additionally, the long-term care ombudsman program provides oversight in long-term care settings including ALs.

Centers for Medicaid and Medicare

While almost half of residential care settings are "certified or designated" to provide Medicaid services, this "certification" is not a federal certification and varies widely from state to state based on each state's Medicaid waiver program. ALs are specifically not covered by Medicaid and Medicare certification rules detailed in CMS federal code, nor are they surveyed for compliance related to CMS rules by state surveyors as are NHs.[161] CMS does not consider ALs long-term care facilities. As detailed in the regulations Mauldin et al. cite, "For purposes of this subpart, facility means a skilled nursing facility (SNF) that meets the requirements of sections 1819(a), (b), (c), and (d) of the Act, or a nursing facility (NF) that meets the requirements of sections 1919(a), (b), (c), and (d) of the Act."[247]

In contrast to ALs, CMS sets standards for items that must be included and a minimum frequency for NH surveys.[216] If the NH surveyed receives Medicare (SNF) or both Medicare and Medicaid (SNF/NF), state compliance surveyors report results to a regional federal CMS office. This office certifies facilities to continue operating and providing reimbursable care to Medicare and Medicaid beneficiaries. If the facility is enrolled only in Medicaid (NF), the state agency certifies compliance, determining whether the facility may continue providing Medicaid-funded care.[279] CMS may cite states that continue certifying facilities to receive Medicaid funds to noncompliant NH without appropriate corrective action.[216]

Long-term Care Ombudsman Program

The Long-Term Care Ombudsman program started as a demonstration program in 1972. After multiple iterations of the pilot program, the 1978 amendments to the Older Americans Act made the ombudsman program a requirement for each state. Each state has a program which identifies and investigates resident complaints, provides information about LTSS, and represents resident interests in policy and rulemaking processes.[280] This program is mandatory in each state, and is staffed by both trained professionals and volunteer advocates. In 2006, the Older Americans Act (OAA) added ALs to their definition of long-term care facilities. As a result, ALs are now within the jurisdictions of the Long-term Care Ombudsman Program. In 2018 this program worked to resolve nearly 200 thousand complaints initiated by residents and their families.[281] This program provides resident protections when a complaint is filed, an essential protection for resident rights. While the ombudsman program offers legal protections, it is not mechanism for regulatory protections of residents. It does not monitor or oversee ALs, and does not have the resources or jurisdiction to ensure quality of care across LTSS care settings.[282]

Occupational Safety and Health Administration

The Occupational Safety and Health Act of 1970 created the United States Department of Labor's Occupational Safety and Health Administration (OSHA) to protect the working conditions in America through monitoring and oversight, training, education and assistance.[283] While OSHA does not regularly inspect ALs,[284] 22 states have their own state plans, meaning they have their own programs to monitor workplace safety in place of federal monitoring. These 22 states take varying approaches to oversight, some of which include AL inspection.[285,286]

State Regulative Assisted Living Policy

State regulations vary, but all states have multiple ways of licensing and certifying ALs. States use terms that include "assisted living," "residential care," "personal care," and "adult care" to refer to a residential setting with the provision of 24-hour staffing and services that allow older adults to age in place.[96,287] The models of care licensed in some states includes small care settings sometimes referred to as adult foster care as well as larger settings with capacities between 20 and multiple hundreds of residents.[287] This study focused on larger care settings, while acknowledging the importance of smaller settings for future research.

State Licensing

All states license ALs and have some regulatory mechanism for differentiating two or more types of ALs with accompanying variance in the applicable rules. The names of these licenses, scope and prescriptiveness of regulations, and level of oversight and enforcement vary both within and across states.[96] The rules that accompany the AL license cover topics including residency agreements, necessary disclosures, admission and discharge, scope of services, staffing and staff training, as well as additional service components such as food and laundry, and facility standards such as requirements for private units, accessibility, and fire safety.[287] Regulations that increase the costs of care via requirements for more highly qualified staff or specific staffing ratios have the potential to decrease the financial accessibility of ALs.

In determining whether to enter or continue operating in a market, AL developers must assess the costs of building and operating in relation to the rates they can charge for care. In the assisted living workgroup report on the national convening of AL stakeholders in 2003, industry professionals identified rules seen as potential barriers to care provision. These rules included: state certificates of need or license moratoria limiting the number of licensed ALs, rate-setting

for AL Medicaid payments standardized across states based on the standards met and care provided, the disallowance of shared units or living spaces, and building codes that add cost without adding to quality of care or safety protections of the residents. These stakeholders also supported policies including the provision of supplemental SSI to subsidize AL costs for those eligible for Medicaid and ensuring that subsidy amounts through HUD vouchers and state programs reflect fair market costs.[288] While the subsidies are distributive policy, the regulations that govern their distribution and the enforcement of accompanying requirements are regulative and often incorporated into AL licensing rules.[289] As evident in the opinions of the industry professional in the 2003 convening, rules that increase the cost of opening or operating an AL or unnecessarily limit who can live in these settings may have the potential to impact geographic accessibility of ALs.

State Oversight

The type of state agency monitoring ALs varies from state to state due to the differences in how states structure state agencies. For instance, in Colorado, the Department of Public Health & Environment's licenses ALs, whereas in California it is the Department of Social Services, and in Florida, the Department of Elder Affairs. The frequency of inspections required in each state varies from once a year to every 5 years: 20 states require annual inspections, 23 states conduct inspection every 15 months to 2 years, and 8 states conduct inspection every 3 to 5 years.[175] Some states require that inspections take place on a schedule, whereas others primarily rely on reports of non-compliant behavior. For states that have requirements for annual or semiannual inspections, recent survey findings indicate that cuts to state budgets have led to significant decreases in the frequency of visits.[290] The nature of these inspections vary as to whether they are announced, which rules are covered, and what training the surveyors have.[291]

While oversight mechanisms are not known to influence a provider's likelihood to enter a market, the extent to which state agencies enforce regulations through monitoring and oversight measures may influence whether an AL closes due to regulatory non-compliance.[97]

Takeaway

While the federal government provides funding for AL care through many mechanisms, there is little oversight of ALs accompanying these funding streams. The lack of oversight from CMS conflicts with the concept of regulatory compliance and has called into question the need for more federal involvement in AL regulation. States are the primary regulators of ALs; however, the extent to which they engage in monitoring and oversight activities varies. AL policy developed separately in each state, with no two states using the same licensing mechanisms or sets of governing rules.

The scope and prescriptiveness of the AL regulations in each state may impact the types of care that can be provided in a setting and how expensive operating an AL is. Additionally, most states have regulations regarding the buildings and physical infrastructure of an AL. States that allow for and license NH conversions or board and care style ALs likely have different types of AL operators entering the market than those that do not. Finally, states may have programs that either restrict building ALs through certificate of need laws or encourage AL market entrance through state funded pilot programs or capital bonds.

2.5. Assisted Living Private Governance

According to a network governance perspective, a system of governance includes mechanisms of control and management from governments, private entities, and social groups.[149] The Nodal Governance Framework further clarifies that "governance is a social adaptation accomplished in significant part through the creation and operation of 'nodes' […] points on a

network."[292(p341)] From this perspective it is essential to consider all nodes, whether they are nodes within the government bodies within the network, or private governance nodes such as corporations or professional interest groups. In AL governance, the relatively low level of public funding and oversight has resulted in an industry where private governance, enacted through the actions and norms of corporate entities, has theoretically been highly impactful.[191]

The Assisted Living Market

AL market entry has been shown to impact the case-mix of NH residents, specifically decreasing the number of low-acuity residents in NHs.[293] However, AL market entrance has been largely determined by consumer demand, as consumers find ALs preferable to NH at a margin of six to one. ALs largely compete with one another for residents.[101] Approaches to competing with other ALs include the availability of ancillary or third-party services, programming for older adults in the community, partnerships with home health providers, and ADRD or disease-specific services or activities.[294,295]

Corporate Ownership and Assisted Living Availability

The AL industry developed over the past 40 years, starting in the late 1970s, growing rapidly in the late 1990s and early 2000s, before plateauing until a post-recession increase in development again in the late 2010s.[102(p32)] The National Investment Center (NIC) considers investment-grade properties those that charge market rates or accept Medicaid, have at least 25 beds, and professional management.[102,296] As of the fourth quarter of 2019, NIC reported over 9,000 ALs, which made up 38.4% of the senior housing market.[296(p6)] NIC and other industry professionals often break out memory care ALs and analyze their performance separately. Of the 9,000 ALs, 1,400 were memory care and 7,200 general ALs.[102(p32)] NHs (42.9%), Continuing Care Retirement Communities (7.7%), and Independent Living (11%) make up the remainder of

the 23,500 investment-grade senior living properties. AL's proportion of senior living properties has grown over time, as has the return-on-investment and average value per unit,[102] topping at over $225 thousand in 2019.[296]

Table 2.4: Assisted Living Buyer Types

Type	Description
Cross-Border	Internationally-based buyers or capital partners
Institutional	Banks, insurance companies, retirement or hedge funds, mutual or index funds
Private Equity	Businesses or privately held corporate entities that operate and develop commercial real estate
Public Listed/REITs	Real Estate Investment Trusts, Real Estate Operating Companies, AL operators or AL property firms that are publicly traded or have publicly traded funds
User and Other	Government, education, or religious institutions

Note: Types of AL buyers according to *Senior Housing Market Insight*, a trade report.[296]

An AL owner and AL operator are the two businesses that makeup an AL. These two entities may be the same, but often, they are not.[102(p32)] The properties are the component of each AL that solicit investor interest, as the properties are tradeable assets. There are multiple ways of classifying AL corporate entities. Property buyer types include cross-border buyers, institutional, private and public equity and users. User organizations are usually nonprofit organizations that use the property to carry out the mission of the organization, see table 2.4. Institutional in this context does not refer to institutional care, but to institutions that manage investments such as banks, insurance companies, and investment funds. These broad categories describe property buyer types, not necessarily operator buyers.[296,297]

Operators are the organizations that provide the services within an AL. Researchers typically describe them in terms of their profit and chain status, as well as their size and services provided.[52,298] In contrast, NIC classifies according to their relation to the AL property owner, as

summarized in table 2.5. Owner-operators own the AL real estate and manage the operations. These operators can be people or businesses. In smaller ALs, an individual owner-operator may even live on site. Owner-investors similarly own both the property and the business that manages the operations of the AL. However, owner-investors hire or contract out the management of the community, focusing primarily on the capital aspects of the business. Finally, a landlord-tenant relationship describes those settings where the property-owning entity collects rent from the operator, but otherwise is not involved in the operations of the AL.[299]

Table 2.5 Types of Relationships Between Owners and Operators

Owner role	Description
Owner-Operator	Owner and operator are the same individual or entity, some owner-operated communities may even be owner-occupied, meaning the owner lives on site
Owner-Investor	Owner owns both the land and finances the operations, but relies upon another individual or entity to manage the AL
Landlord-Tenant	The AL is leased by an operator, investors own only the land not the operations

Note: Types of relationships between the owner of the real estate and the operator of the AL services according to an industry blog and forum.[299]

One of the primary funding mechanisms for AL properties is the real estate investment trust (REIT). REITs are a mechanism in the Internal Revenue Code that allow for group investment in properties, allowing passive investors to contribute funds to real estate development projects while still getting the tax benefits they would be afforded if they invested their capital by purchasing a second home.[300] President Eisenhower signed legislation creating the REIT structure in 1960 to incentivize urban development and allow middle class Americans to invest in real estate. The typical REIT AL ownership in the early aughts was a landlord-tenant relationship, wherein the REIT owned the property and was paid an annual rent and rent escalation, this arrangement is referred to as a triple-net lease.[301]

In 2007, congress reformed the REIT legislation to allow for a different owner-operator relationship than the triple-net lease permitted. The new REIT Investment Diversification and Empowerment Act (RIDEA) funding structures allow a group of investors to use a REIT to continue to gain the tax benefits of the structure while shifting the relationship to one closer to an owner-investor. In the RIDEA structure, the REIT can access operating income in addition to rent for the properties, without managing the AL. These agreements often involve lower rent rates, but higher dependence on a high net operating income compared to the older triple-net model of investment in AL properties.[301] The RIDEA structure has resulted in an increase in AL owners that are owner-investors and a decrease in the landlord-tenant model.[102,300]

Industry Oversight

Industry self-regulation is an additional important regulatory approach to take into account. There are two primary approaches industries have taken to self-regulation, individual self-regulation, where the company in question regulates itself, and group self-regulation. Group self-regulation is a system whereby a group of professionals or an industry network sets and enforces standards for operation. This form of regulation has proven to be important across many industries and can include accreditation or quality achievements.[302] To promote quality in long-term and post-acute care organizations, the American Health Care Association (AHCA) and National Center for Assisted Living (NCAL) National Quality Award Program was established in 1996 and is overseen by an independent board.[303]

NHs and ALs can apply each year for the award program, which assesses organizations based on the eight Baldrige criteria for organization quality improvement. While no studies assess this program's association with quality for ALs, a comparison of NHs that did not participate in the program, participants, and gold or silver awardees found gold and silver

awardees had significantly fewer CMS deficiencies.[304] NCAL lists ALs that achieve gold, silver, or bronze awards on their website and gives them the authority to display the award on corporate materials. Currently, the goals for participants of the program include reducing staff turnover, increasing customer satisfaction, reducing hospital readmissions, and reducing off-label antipsychotic use.[303]

Takeaway

AL is a form of residential LTSS, but also part of the growing senior housing industry. The various approaches to structuring the relationship between the property owner and the operator of the AL services have shifted over time. We know little about how these models of AL ownership influence AL availability, as researchers have largely categorized ALs according to profit status and size.

2.6. Racism and Disparities in Assisted Living

ALs serve as a mechanism for either facilitating, maintaining, or creating barriers to improved health and wellbeing for older adults in need of residential LTSS. The accessibility of ALs for older adults in need of these services mediate the impact of disability and disease on health and wellbeing. While there are racial disparities in the health status of older adults before they enter AL care, these disparities can be mitigated, worsened, or additionally initiated based on service and AL quality and whether older adults in need of AL services can access them.[198]

Historical Context of Racism and Disparities

The concept of race originally developed to promote the African slave trade is the basis of the systemic racism that continues to harm Black people in American society today.[305] The idea of white superiority and racial hierarchies based on skin color began in the sixteenth century with the enslavement of Africans to support the plantation economy of North America. European

imperialism drove the development of the concept of skin color as the key determinant of race, and thus of a person's value and social position in society. While slavery was a pre-existing practice, slavery justified by the idea of inferiority based on skin color was an idea developed and refined by 16th century colonizers.[305,306] These ideas were vital to the early success of the economy in what is now the southern states of the US By popularizing the idea that Black people were, by virtue of their skin color, less deserving or intelligent, European colonizers were able to normalize and legitimize the slave trade even amidst America's revolution.[307]

At a biological level, there is no evidence of race as a distinct classification of the human species. There is more genetic variation within people of a specific race than between races.[308] Ethnic differences do account for some diversity in the human genome, but do not correspond to skin color or racialized social positions.[305,309] There is evidence that racism has impacted the health of populations in ways that have resulted in measurable disparities in health outcomes.[308] Two well supported theories, Weathering[310,311] and the Developmental Origins of Human Health and Disease hypotheses[312,4,313] make up part of a growing field of literature describing the negative impacts on human health of adverse exposures to stressors and toxins over the lifecourse, with Weathering explicitly referring to the exposures unique to Black women's experience of systemic racism.[119,311]

Defining Terms

The terminology surrounding race and racism has been used to mean a variety of things over time and disciplines. This study relied upon the definitions of terms described here, informed by a review of legal[136,144,145] and sociology[314] literature where these concepts were first published. Additionally, I relied upon more recent health services[315] and population health literature[126,316,317] to provide health context and guidance in choosing definitions among the

many available at this point in time. Discrimination describes the negative actions that individuals take based on social identity whereas prejudice is the negative attitudes.[318] Race-based discrimination and prejudice occur between individuals and can be perpetrated by individuals of any race towards individuals of any race. Oppression is a societal system that divides institutional and individual actors along a socially constructed division, distributing power unevenly between the dimensions, with less power going to those entities that are oppressed and more power going to privileged entities.[319] Racism is a race-based system of privilege and oppression dependent on the racialization of individuals and institutions, which in America, is done based largely on skin color but may also involve aspects of culture, religion, and language. Racism can be enacted through performance of discrimination or prejudice, as well as through institutional practices, laws and state actions, and ultimately through cultural norms and behaviors.[319,320(p16)]

Privilege can consist of either positive or negative systemic power. A positive privilege is one that is beneficial to society, and in a just society would be what McIntosh describes as an "unearned entitlement"—something that all members of society are entitled to without action on their own part. In most contexts, "unearned entitlements" are not actually available to all members of society, in this case the entitlement becomes an "unearned advantage" as the advantage of access to the entitlement creates a division between members of society that are disadvantaged and those that are advantaged. Access to LTSS is one such entitlement. The final form of privilege is "confirmed dominance," or privilege that results in unearned advantage that does not benefit society and would not be the norm in a just society.[18,321]

Confirmed dominance includes privileges such as the ability to racialize and discredit Black colleagues, or the ability to avoid court proceedings based on judicial prejudice. McIntosh

argues that confirmed dominance negatively impacts both the privileged and the oppressed parties. While people oppressed through racism are harmed at a level that is not comparable to those enacting dominance, in the same way that feminist theory has argued that normative masculinity can be harmful and dehumanizing for men, dominance resulting from White privilege can similarly dehumanize and have negative implications for White people.[321] Finally, conceptually, White members of society may lack an awareness of their privileged status because they lack social comparison information. Social comparison information comes specifically from the experience of discrimination and oppression, and may uniquely position people who have experienced oppression to question assumptions or conceive of solutions to problems of oppression.[322]

Structural racism describes the structures that arise out of the history, culture, institutions, and policies that have created and perpetuate a white supremacist environment, consistently resulting in advantages for White people and harmful outcomes for Black, Indigenous, and People of Color (BIPOC).[315] Structural racism must be enacted through mechanisms of control such as laws or standardized practices. A structural phenomenon comes about through the intersection of an ideology and sources of social control. It does not require actions or intent of any one individual. In policymaking, structural forms of oppression may be reinforced without overt policymaker actions and without intent to perpetuate race-based differences in resource allocation, health and social services or health and wellbeing outcomes of BIPOC.[117] Structural forms of racism endure for generations, are highly adaptive to new social and political environments, and have an immense impact on the distribution of health and disease within a population.[318] The disadvantages created by structural racism that persist across multiple generations are referred to as intergenerational drag.[323]

Institutional racism is a component of structural racism, that describes racism performed and perpetuated by institutions and the interactions between institutions.[30,324] Cultural racism refers to racist attitudes and assumptions embedded within a culture. Cultural racism is an important factor in perpetuating implicit bias, which has garnered media attention in the context of both the behaviors of law enforcement and teachers subconsciously taking actions that assume a person of color is less intelligent or more prone to violence without explicitly believing in racist ideas.[325]

Interpersonal racism describes the interactions between individuals that shift power to White people and enact harm to BIPOC. Interpersonal racism impacts the health of BIPOC through three primary means: denial of resources or services, psychological stress, and assault.[326] Additionally, cultural and interpersonal racism can lead to internalized racism, wherein white supremacist ideas cause BIPOC individuals to believe themselves to be inferior, either implicitly or explicitly.[326]

Systemic racism refers to the ways that the internalized, interpersonal, cultural, institutional, and structural forms of racism interact with and exponentiate one another to produce and reproduce systems of inequity. Phelan and Link (2015) identified systemic racism as a fundamental cause of inequalities in health.[317] While these many forms of racism impact the health outcomes of all BIPOC, due to the history of how race has been socially constructed, systemic racism has particularly targeted Black people since the inception of race. This is reflected in the Black-White wealth gap: as of 2016 the median Black family had less than one tenth of the wealth held by a median White family.[327]

Racism as a Cause of Racial Disparities

To investigate disparities, the World Health Organization (WHO) recommends using an explicit conceptual framework to identify sources of power and inequality.[328(pp20-23)] In the WHO's conceptual framework for action on the social determinants of health, the writers rely upon Diderichsen and Hallqvist's model of the social production of disease.[329] This model has been tested empirically, and improved over time.[328(p24)] The model identifies three primary mechanisms through which the social position moderates the relationship between social context and health outcomes for an individual: exposure, disease and injury, and consequences of illness. This model has since been built upon, but the concept persists of differences in exposure, vulnerability to disease, consequences of disease, and the impacts on social stratification.[330,331] These effects can be magnified or lessened by individual factors, but at a population level, clear differences are seen across socially stratified groups.

While this model is helpful for identifying mechanisms of stratification, it encounters the same pitfall that has recently been identified across the fields of biomedical research, public health, and health services research. Race, unlike many other categories of social position, is determined by social context.[332] Breaking out disease prevalence, incidence, risk factors, and outcomes by race is common practice across these disciplines.[309] However, there is an ongoing shift within biomedical research towards explicitly framing studies to identify racism as the causal mechanism, and race as an effect of that cause.[121,315,333,334]

Assisted Living Access

The discourse surrounding the aging of the population has constructed older adults as a homogenous group that is highly dependent and in need of care.[335] Studying ALs as an intervention for the aging population brings up conflicts of interest between the mean health of

older adults and the distribution of health inequality. Although older adults in the US as a population encompass a highly diverse range of people, AL care is provided to a largely privileged population that is more White and more economically advantaged than the older adult American population as a whole.[336] Older adults who utilize ALs are largely private pay. This necessitates higher levels of financial well-being than the average older American. Simply focusing on increasing the efficacy of care within ALs necessarily risks resulting in an increase in the overall health of the population accompanied by an increase in health inequalities.[101] In order to shift AL policy in a way that results in an increase in overall population health as well as a decrease in health inequalities, the policies targeted would be those that expand access to this form of community-based care for all.

Disparities of access to quality long-term care in NHs has long-been documented.[232] However, in the past twenty years, the nature of that disparity has shifted. White older adults have shifted out of NHs, replacing NH care with AL care. This shift has left NHs with sufficient space for Black older adults, however with the shift of White older adults into ALs the Medicaid use rate in NHs has gone up.[337] Facilities that were previously higher quality due to the capital influx from private-pay residents have decreased in quality of care and care outcomes.[198] As a result, although there has been an increase in NH care access for Black older adults, this increase in access has not closed the gap in access to quality care.[338,339]

Black and White older adults do not have equal access to ALs. Counties with higher Black populations have lower odds of having an AL. Those that do have an AL have fewer units per capita and are less likely to have memory care.[10] Black older adults are more likely than their White peers to move into NH and less likely to move into an AL.[340] Jenkins Morales and Robert (2019) found that enabling and need factors accounted for the differences between Black and

White older adults moves into NHs.[8] However, the same is not true for ALs. For ALs, the differences persisted after the enabling and need factors were added to the model; these factors included: gender, age, self-rated health, self-reported ADL assistance needs, dementia status, income, housing tenure, living arrangement, and Medicaid status.[8] The fact that the enabling and need factors do account for the Black-White differences in care transitions to NHs further suggests that access to care may be the cause of the difference in use.

Evidence of Structural Racism as a Driver of Disparities of Assisted Living Availability

The lack of a policy like the Hill-Burton Act has meant that ALs are largely reliant on the market to determine when and where facilities are constructed.[341] It is possible that this has meant that the effects of structural racism, through policies like redlining and land covenants, are heightened in ALs compared to healthcare facilities like NH. The evidence of racist housing and property valuation policies is still starkly visible in America.[342] After the end of slavery, zoning laws institutionalized racism in housing. After zoning laws banning owners based on race were overruled by the supreme court in 1917, the practice shifted towards civil and private governance. Land covenants are agreements that were created between homeowners in a neighborhood that are tied to the home deed. Covenants restrict selling the home to people of specific racial identities, usually White people. These agreements were widespread and in many cases are still tied to the deed of the home. While land covenants were ruled unconstitutional in 1947, it took many years to enforce this mandated change, and the documents themselves remain attached to many housing deeds in the US.[108]

While the enforcement of covenants was deemed illegal, the federal regulations continued practices that instilled racism into the property market in the US throughout the 1950s and most of the 1960s. The Federal Housing Administration (FHA) was created in 1934 as part

of the New Deal to oversee the housing market and ensure Americans could access necessary lending and protections to promote widespread home ownership.[110] The FHA relied upon "residential security maps," which determined which neighborhoods would be secure to invest in and which would be insecure investments. The color-coded maps commissioned by the FHA displayed cities in shades of green, blue, yellow, and red with notes that described the races of the people residing in the area, equivocating non-White residents to riskier investments. These maps were explicitly racist – downgrading the value of land based on race of residents. Neighborhoods with majority Black were outlined in red, leading to the term "redlining."[110]

While redlining was banned in 1968 with the passage of the Fair Housing Act, the lasting damage was already done to the valuations of Black-owned property. Racism in lending practices continued, with evidence of systematic overtly racist lending policies as recently as 2010.[343] Racism in housing policy translated easily to racism in commercial property. Redlining and covenants impacted the valuation of commercial properties as well as housing. This means that to this day, properties available for development in historically Black neighborhoods are worth less than those available for development in White neighborhoods.[110,344] Jacoby et al, found that areas of Philadelphia defined as low value areas by redlining in 1937 were more likely to have high levels of crime in 2013 and 2014 and grade A (green) areas of the city had the lowest levels of violence, irrespective of the current racial and economic makeup.[345] This is particularly concerning in the case of REITs, as the depreciation of a property can lead to additional tax write-offs for investors. This may incentivize investing in properties with high initial values over those that have a lower market value.[301]

Black Americans have significantly lower levels of home equity, even when compared to White older adults of a similar age and income level.[346] Racism in housing policy has resulted in

a highly unequal distribution of wealth and high valued real estate between White and Black neighborhoods. These gaps in home equity-based wealth impact both the wealth of Black communities and the value of commercial real estate within Black neighborhoods. Research has documented the impacts of low value commercial real estate on health and social service resource availability.[110] Beyer et al. further found that racial bias in lending is associated with Black-White disparities in breast cancer survival rates.[109] In sum, the high level of market influence on AL availability may make ALs more susceptible to the influences of racist lending policies and practices.

Disparate Assisted Living Quality

A complicating factor is the issue of quality in care provision. ALs that provide care to more Black resident populations have been shown to have characteristics that make them look more like a NH. Black AL residents are more likely to live in ALs with higher dual-eligible populations, which has been linked with lower quality care in NH.[111] In a study of end of life in ALs in Atlanta, Arneson et al. (2020) found that AL residents that experienced psychological distress, fatigue, or were BIPOC reported lower quality of life. However, resident acuity and ADRD were not correlated with self-reported quality of life.[348] Thus, the presence of an AL in a community may not mean the same thing from community to community and may not actually be a superior treatment to a NH.

Konetzka and Werner (2009) investigated policy initiatives and market reforms that have been used to improve quality of care in long term care (LTC) settings. Their findings, summarized in table 2.6, highlight the need for considering the impact of pay for performance and other quality improvement efforts on the availability and quality of care for low socioeconomic status (SES) and racial minority older adults.[198,232] While de-funding and closing

Table 2.6 Konetzka and Werner's Policy Initiatives to Address Disparities of Long-Term Care Quality

Initiative	Summary of Key Issues
Information Accessibility	Quality information is accessible and understandable for residents and their formal and informal care providers; Access to internet, health literacy, and mistrust of information online are important issues for low SES and racial minority populations[347]
Consumer-Directed Care	Financial incentives for consumers to manage their care decide how to spend insurer funds and expands choices of providers; Concerns raised regarding potential for exacerbating disparities if systems are difficult to navigate
Supply	Facilities should be close to home; This continues to be challenging for LTC, and in particular in AL provision
Access to Resources	Quality improvement efforts require financial investment, which may not happen in facilities that rely more on Medicaid; Public reporting leading to NH closure has exacerbated disparities;[232] Problems with improvement vs overall quality of care have been reported

Note: Key issues for addressing disparities in long-term care as described by Konetzka and Werner[198]

ALs that under-perform may eliminate the problem of low performing AL providers, it may actually result in worse outcomes for the older adults who are evicted from their homes (the AL) and displaced.[349]

Takeaway

The lack of federal investment in building residential LTSS led ALs to be more susceptible to place-based structural racism. This funding gap has been intensified by the housing and real estate system in the US which was built upon racist policy and continues to preference investment in properties in White neighborhoods over Black neighborhoods.

Racism is a complex and multi-levelled phenomenon that has created a system of oppression that impacts us all. Both historic and continued racism across many levels from structural to interpersonal impacts the continued disparities in LTSS care for Black older adults. Policy initiatives to address disparities in long-term care have focused on both expanding access to care and improving quality. Mechanisms investigated include information accessibility, consumer-directed care, and both the geographic location and financial accessibility of care.

2.7. Gap in research

In recent years, researchers have documented relationships between real estate valuation policies and health disparities.[109,350] This line of research brings to light the likely relationship between health services availability and racism enacted through governance and policies—structural racism. To dissect this possible relationship and identify policies to mute it, it is necessary to take into account the primary mechanisms through which structural racism is enacted. Network governance theories identify public, private, and civil governance as important components of governing—enacting control in a society.[100] While some urban planning publications have used a network governance perspective to analyze resource distribution influenced by structural racism,[351] there are not, to my knowledge, studies using this approach to better understand the impact of structural racism on health service access.

Recent studies have identified disparities in the availability of ALs care for counties with higher proportions of Black residents,[2] and evidence that the difference in Black and White older adult moves to AL—unlike moves to NH—cannot be accounted for by enabling and need-based factors.[3] Structural racism has been identified as a possible source of this disparity in AL availability. Unlike NHs, which had their construction largely subsidized by the Hill-Burton Act, ALs have relied on market-based developers and may be more severely impacted by policies and practices such as redlining and land covenants that continue to impact property valuation in the United States.[4(p9)]

From the perspective of the frameworks of intersectional population health and structural racism, the policies that have been put in place have created systems that produce and reproduce health inequities.[5,6] The nodal governance framework conceives of governance as the mechanisms of control in a society, enacted through public, private, and civil "nodes":

individuals or institutions that take governing action.[7] Combining these theoretical frameworks implies a potentially important, though largely undocumented, gap in knowledge regarding how private and public governance work together to reify the impacts of structural racism on systems of care, including ALs.

While there is significant, ongoing work investigating the impact of regulations in ALs as well as important investigations into the role of multiple forms of racism in ALs,[8,10,111,114] there has been little investigation into the role that either structural racism or corporate ownership structures play in this setting. To better understand the power structures that facilitate or prevent equitable access to AL services, this study investigated the relationship between structural racism, regulation and public funding, corporate ownership types, and AL availability.

2.8. Conceptual Frameworks

The study's conceptual model relies upon racism as a root cause and intersectionality analytic frameworks to combine the conceptual frameworks of population health, structural racism,[144] nodal governance,[352] and convoys of care conception of ALs.[154] Combined this model theorizes that structural racism operates through public governance—federal and state policies and regulatory actions of state agencies, and the private governance of corporate entities, to influence the geographic availability of ALs.

Racism as a Root Cause Framework

There are four principles to an RRC approach, 1) precise impact, 2) systems change, 3) long-term impact, and 4) reparations. The first principle, to be precise, refers to the need to recognize that there are vast differences in the ways that racial groups experience structural racism. The RRC implies that racism is independent of other causal factors, including governance. While governance can mitigate the role of structural racism, it cannot determine the

presence or absence of structural racism. It would be theoretically possible for policy to prevent the introduction of structural racism in the impossible case where the slate of past policies and histories of oppression were wiped clean; however, in reality, the effects of past racist policy continued to be magnified unless specifically addressed and mitigated through targeted efforts.[135]

In order to appropriately account for the historic and ongoing inequalities in access and to identify the barriers to resources and mechanisms of oppression, it is important to avoid lumping all marginalized people into one group.[135] In this study, I am specifically investigating the role of anti-Black structural racism in the context of AL care through the mechanisms of public and private governance. Theory and history support this approach due to the market-driven AL industry and the impacts of anti-Black racist policies and practices effecting real estate and land valuation. This conceptual background would be inappropriate for an investigation into the access to ALs for Hispanic older adults in America, not because they are not impacted by racism, but because the history and mechanisms of oppression are very different from those experienced by their Black peers.

To address the ongoing structural oppression of Black people, a systems approach is necessary. It is not possible to adequately document or describe the ways in which structural racism is preserved without identifying the relationally-based mechanisms that result from the relationships between nodes within the system. By identifying policy mechanisms that may have a long-term impact on the continued harm done by structural racism to the health of older adults, these policies may begin to do the work of undoing centuries of oppression. Acknowledging the structural racism inherent in the current real estate market in the US both acknowledges the long-term impact of explicitly racist policies, such as redlining, and the implicitly racist policies, like the policies that continue to uphold this gap in property value.

Takeaway

In this study, structural racism is treated as a root cause of health disparities. Functionally, this means that while governance approaches can mitigate or otherwise lessen the extent to which structural racism is enacted through governance mechanisms, no policy or governing action can negate the presence of structural racism.

Intersectionality Framework

Kimberle Crenshaw (1989) first coined the term intersectionality in her legal analysis of antidiscrimination doctrine and the intersection of feminist and antiracist political critique.[136] Generally, it refers to the concept that oppression based on various social identities is not additive, but synergistic and complex. Race, class, gender, sexuality, ethnicity, nationality, ability, and age cannot exist outside of the context of one another.[353,354] This term is now used to refer to 1) intersectionality as a field of study, 2) intersectionality as an analytic strategy, and 3) intersectionality as a critical praxis.[354] The theory work within the field of study has helped to structure intersectionality as an analytic strategy,[354] the approach this study employed.

An intersectional analytic strategy takes into account Crenshaw's concept of intersections of components of an individual's identity.[136] Using this perspective, it is impossible to address the needs of older adults without acknowledging how these needs differ based on the distribution of power within the older adult population based on wealth, class, race, ethnicity, gender, sexuality, ethnicity, nationality, and ability. This approach reveals the extent to which aging, and the accompanying needs of older adults, varies significantly based on cumulative life experiences. Both these cumulative experiences, and an older adult's current access to care are often defined by those aspects of their identity that position them as marginalized or advantaged. Crenshaw wrote that by designing law to serve the needs of the members of society experiencing

the most oppression, the laws would be better able to accommodate the needs of all people, as those with more power would be better able to advocate for their needs.[124]

Through this lens, the role of regulations may be particularly important for AL quality, as this legal approach is better able to meet the needs of residents unable to advocate for themselves. The conceptual ideas behind intersectionality should fit well with the AL ideology. ALs were designed to meet the varying needs of older adults in need of support, with the idea that while those needs may vary from person to person, all older adults deserve to maintain some control over their environment and should be involved in decision-making for their care to the extent they are able.[189] Combined with an intersectional approach, this would imply considering the needs of the most highly marginalized groups when designing ALs and AL policy, while utilizing the flexibility of the AL environment to ensure all residents have access to the type and level of care most suited to their needs.

From an intersectional perspective, social identities cannot be cleanly separated from one another, the relationship between marginalized social identities and disparate health outcomes is not additive, but complex and highly dependent on context. According to intersectionality, there is no normative identity, just those that experience more or less oppression based on the social context. Collins and Bilge (2016), identified six core ideas of intersectionality which can be used as a framework for population health study design. As an intersectional approach should include the following features: social inequality, power, relationality, social context, complexity, and social justice.[126,137]

Thus, the study incorporates each of these themes. First, acknowledging social inequality means understanding that individuals' needs vary based on their social position within society. If social inequality is acknowledged, we must anticipate that health and social interventions should

not serve everyone equally if the goal is to achieve health equity. From this perspective, the ideal distribution of ALs would meet the needs of the population, not simply correspond to the number of older adults in a community. From this perspective, communities with more older adults with a need for residential LTSS should have more ALs.

Power can come from structural, institutional, or interpersonal levels via mechanisms including both social and technical resources and abilities. Identifying and mapping sources of power within a problem space allows for a clearer articulation of the potential interventions.[124] The nodal governance framework allows for the investigation of sources of power and control in relation to one another as they impact ALs. The relationality inherent in the interactions between private and public governance is both a component of an intersectional approach, and important to understanding how these forms of governance work together. For instance, efforts that only focus on improving care quality in ALs without acknowledging the potential damage to care access, may result in ALs exiting the market due to increases in operating costs. This is an example of not accounting for relationality. To incorporate relationality is to reject that a positive change for one stakeholder will result in a positive change for all.

Social context refers to both the ongoing and historic sociopolitical environments that frame a problem.[137] In investigating AL access, taking into account the history of racism in land and property valuation policy is one example of incorporating the social context into the study design. Complex systems are systems where the interactions between elements within the system produce effects, leading to a system where knowing the inputs does not necessarily allow for knowing the output. Intersectional approaches account for complex relationships between forces and factors.[355(p18)] This study relied on comparative methods to better account for complex systems of governance. Accounting for social justice in study design requires acknowledging the

value judgements always implicit in research and making the values of advancing health equity overt. This is reflected in the study's intent to identify equitable policy solutions to enable improved distribution of residential LTSS resources.

To design a study that incorporates these ideas, I have mapped the conceptual frameworks onto the analytic framework, highlighting how each idea is addressed by one or more of these models for conceptualizing the study problem space.[125,126] This analytic framework identifies the essential components of each conceptual framework, ensuring that the study conceptual model encompasses the concepts necessary for designing a study grounded in the theories of intersectionality, as demonstrated in table 2.7.

From an intersectional perspective, while the inequality at the crux of this study is one that Black older adults are most disadvantaged by, the harm to health is neither homogenous or limited to the Black older adults experiencing the inequality. The lack of access to affordable, appropriate residential LTSS that supports older adults in living full lives is an issue that goes beyond the quality of life for the individual older adults. The accessibility of care impacts the care network of the would-be resident as well as the care networks of their caregivers. Caregiver strain is well-documented and can function as a ripple effect, impacting family members of all

Table 2.7 Conceptual Frameworks Applied to Analytic Framework

	Population Health	Structural Racism	Nodal Governance	Convoys of Care
Social Inequality	X	X		
Power	X	X		
Relationality	X		X	X
Social Context			X	X
Complexity		X	X	
Social Justice		X		X

Note: Conceptual frameworks applicable to the six components of the intersectionality analytic framework

ages. Ultimately care access impacts the health and wellbeing of communities, everyone residing in them. Just like investment in the education of children, investment in the care of older adults is an important way of supporting families. It is now well documented that structural racism negatively impacts people of all races, not just those oppressed by racism. While the negative impacts of structurally racist land valuation are far from equal in the deleterious effects on the population health of Black and White populations in America, the division, stress, and ongoing limitations in public policy, finance, and communication are felt by the entire population.

From the perspective of the frameworks of population health and structural racism, the policies that have been put in place, both now and previously, have created systems that produce and reproduce health inequities. This study investigated both the social inequalities themselves and the power and relationality implicitly involved by considering aspects of health, not just in terms of who is most positively impacted by policy, but also the potential unintended consequences of a policy on health inequalities. Nodal governance considers all potential sources of control as potential governance actors.[149] I took into account both the relationships between regulations and industry forces, but also the complex interactions that result from public funding in care spaces that are majority private pay.

Takeaway

An intersectional approach both takes into account and prioritizes the simultaneous marginalization experienced by individuals with multiple compounding oppressed identities. A study designed using intersectionality analytic framework must take into account social inequality, relationality, complexity, power, social context, and social justice. The study conceptual frameworks fit together to explain conceptually each of these aspects of intersectionality and their role in the study design.

Population Health Framework

While most health policy studies aim to improve human health, population health is a specific perspective that points to prioritizing the health of marginalized groups. Population health is, as Kindig defines it, "the health outcomes of a group of individuals, including the distribution of such outcomes within the group."[356] He described the concept that both the determinants and the health outcomes (independent and dependent variables) would need to be included in population health. Stoto describes the Institute for Healthcare Improvement model of population health as inclusive of three beliefs. First, there is a synergistic relationship between the health of individuals within a population, disallowing accurate population health measurement to be simply a sum or average of the health of individuals. Second, the inclusion of upstream factors such as the physical and socioeconomic environments is essential for both analyzing and impacting population health. Third, the government plays an essential role in population health because accountability is diffuse and similarly synergistic in quality.[357]

Therefore, without effective policy, individuals, while likely to pursue their own temporally mediated health, are unlikely to pursue behaviors that effectively impact the health of the population.[357] This approach to health system analysis is particularly relevant to ALs because it is a community living environment, likely intensifying the effects of population health impacts on individuals. Additionally, in analyzing health at the population level, it is necessary to account for and integrate the role of social services.[358] Analyzing the health systems involved in the provision of LTSS involves both the analysis of healthcare provision and the analysis of social service and housing provision. This makes the population health approach particularly fitting.

Population health provides a valuable framework for identifying appropriate policy targets. Describing health at the population level allows for a description of the many systems that affect the health outcome of interest and how those systems affect a specified population.[356] Given this frame, Benach et al. describe eight possible approaches a policy may take in attempting to address the health of a population. These eight scenarios illustrate the influence that two abstract measures may have.[129]

The first component describes how the health of the population can be maintained, improved, or worsened—reflecting whether the mean of the population health curve is maintained or experiences a shift. The second component is the measure of health inequality within a population, which may be maintained, increased, or decreased—reflected by the curve maintaining its shape, widening, or narrowing.[129] Benach et al.'s work outlines the various types of shifts in the distribution of a health outcome within a population. Specifically, Benach illustrates that the health of a population can be shifted in the positive or negative directions, or remain constant while simultaneously maintaining the spread of inequity within the population, decreasing inequity, or increasing inequity.[129]

In their 2013 paper, Benach et al. use a framework from Graham to further break down the possible options for policy interventions that range between redistributive (f) and universal (h)— a positive shift of the mean accompanied by a decrease in inequality versus a positive shift of the mean maintaining inequality.[359] This second paper uses Graham's work to categorize the policies by the target group. In the case of redistributive policies, they identify the target groups as low and mid socioeconomic groups (SEG), with more resources being distributed to low SEG. In comparison, universalist policies target all SEGs equally. Between these two extremes are

policies targeted to worst-off, proportionate universalist policies, and universal policies that have a focus on the health inequality gap.[359]

Increasing the efficacy of care within ALs necessarily risks increasing health inequalities. Because the population served by AL LTSS is the most privileged and well-off,[101] interventions focused solely on the improvement of care quality are likely to have little to no effect on average health outcomes while increasing health inequalities. To shift AL policy in a way that results in an increase in overall population health as well as a decrease in health inequalities, the policies targeted would need to be those that are found to be most influential on the care outcomes of Black residents.

Takeaway

The health of a population is can be described by looking at the health of the health outcomes of the most privileged or least privileged individuals, or investigating the mean or distribution of health outcomes according to privileged status. By conceptualizing health as a distribution across a population, we can better identify policy interventions that will allow policymakers to narrow the distribution of health outcomes. AL governance determines how ALs are or are not made accessible to various populations. By incorporating a population health framework, the impacts of AL policies on both those who are the most well-off and those who are the worst-off should be taken into account when assessing a policy change.

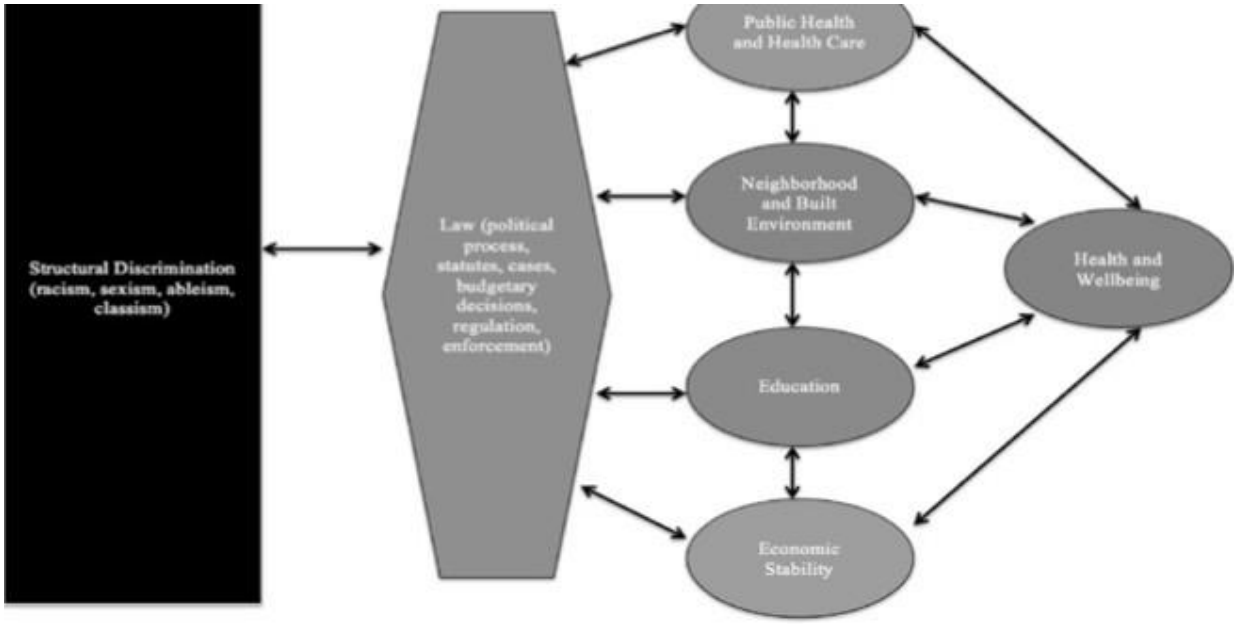
Structural Racism

Structural racism, when used as a conceptual framework, recognizes the relationship between identity, geography, and the societal structures that define opportunities and barriers for the people living within them. Where a study of the role of individual-level racism might involve interviews with staff and residents regarding racially-charged interpersonal interactions, one

investigating structural racism looks to the policy and systems-level interactions.[144] A reliance on theory is especially important to the investigation of structural racism, as questioning normative behaviors and accepted values is essential to the work of identifying structural forces that have become embedded into the fabric of society. Approaching inequalities from a structural view of racism requires a shift from the focus on individuals causing problems or being impacted by problems, to a systems view in which systems of control cause changes to social and political norms, and result in inequalities impacting individuals.[134,318]

The Social Determinants of Health (SDOH) framework was broadly adopted by the federal government starting in 2010 as a conceptual model for addressing disparities. Unlike the preceding models, SDOH identified social factors, outside of the range of control for an individual, as the most important determinants of health outcomes. While the shift to the SDOH

Figure 2.2: Yearby's Revised Social Determinants of Health Framework



Note: "Healthy people 2020" as presented in Yearby (2020)[360] used with permission of Sage Publishing ©

framework allowed for a shift towards community building work, theories of root causes of disease and structural inequalities point to a missing element of the framework.

Yearby (2020) recently put forth a revised SDOH framework that takes into account not only the idea that health is determined by social position and drivers outside an individual's field of control, but also the elements that actually cause the differences in health outcomes based on social position, see figure 2.2. This take on the SDOH model begins with the structural discrimination, then identifies the "tools" or mechanisms used to create systems. In the case of ALs, structural racism may act through both public and private governance "tools" including federal funding mechanisms and lack of oversight, state regulation, and private ownership structures.

Takeaway

The perspective of structural racism requires researchers to design studies with the concept of the racism of systems and policies at the forefront. By acknowledging structural systems of oppression as the root cause of health inequalities and policies and other forms of governance as the tools or mechanisms through which the forms of structural oppression act, it is possible to acknowledge the continued damage policies enact toward Black populations while also acknowledging the need to take into account the histories of racially charged violence and oppression. Structural racism as a phenomenon at the intersection of ideology and sources of control. This conception informs the study conceptual model, which positions structural racism as a source of disparities enacted through governance mechanisms.

Nodal Governance Framework

This study is grounded in the nodal governance framework, which identifies a need to expand the conception of regulation and governing to include practices such as regulation from

private entities and social mechanisms of control.[149] Much of health policy research is still based on the assumptions of the Westphalian model, which imagines a strong sovereign central government serving as a direct regulator of citizen behaviors.[150,151] Approaching this work from a decentered theory of governance such as nodal governance acknowledges the roles of corporate and social capital and control that have become especially influential in America's current neoliberal governing approach.[152] The nodal governance framework consists of sites—"institutions that harness ways of thinking and acting"[133(p165)]—classified as public, private, or civil governing bodies.[153] Each of which can be acknowledged for analysis and intervention.

According to the *Theory of Regulatory Compliance*, an increase in regulatory stringency may be either good or bad, as the relationship between regulatory compliance and quality is curvilinear, eventually leading to poorer outcomes.[361] The resulting over-regulation model is particularly relevant to ALs. AL as a model is based on the idea that increased older adult autonomy improves quality of life.[70] Unnecessary regulation may impede this mission, potentially creating ALs more similar to institutional care settings than was intended.[362] Additionally, over-regulation may prevent market entrance which could decrease the geographic access to ALs.

Multi-centric policymaking describes policymaking in complex governance systems that are multi-level and/or polycentric. Multi-level governance describes either horizontal or vertical distribution of governing powers, where polycentric governance describes overlapping governing powers of multiple governing centres.[221] Multi-centric governance has been described as un-democratic in the same ways that executive federalism is described. Under these conditions, a public is no longer voting for policymakers who are held accountable to their choices by elections, as is the normative model of democratic politics.[355] Both the theories of multi-centric

governance and the executive federalism point to questions of accountability. Without having a single source of political power, or legislative officials to hold accountable to executive decision making, identifying methods for evaluating democratic policymaking gain in their importance.[363]

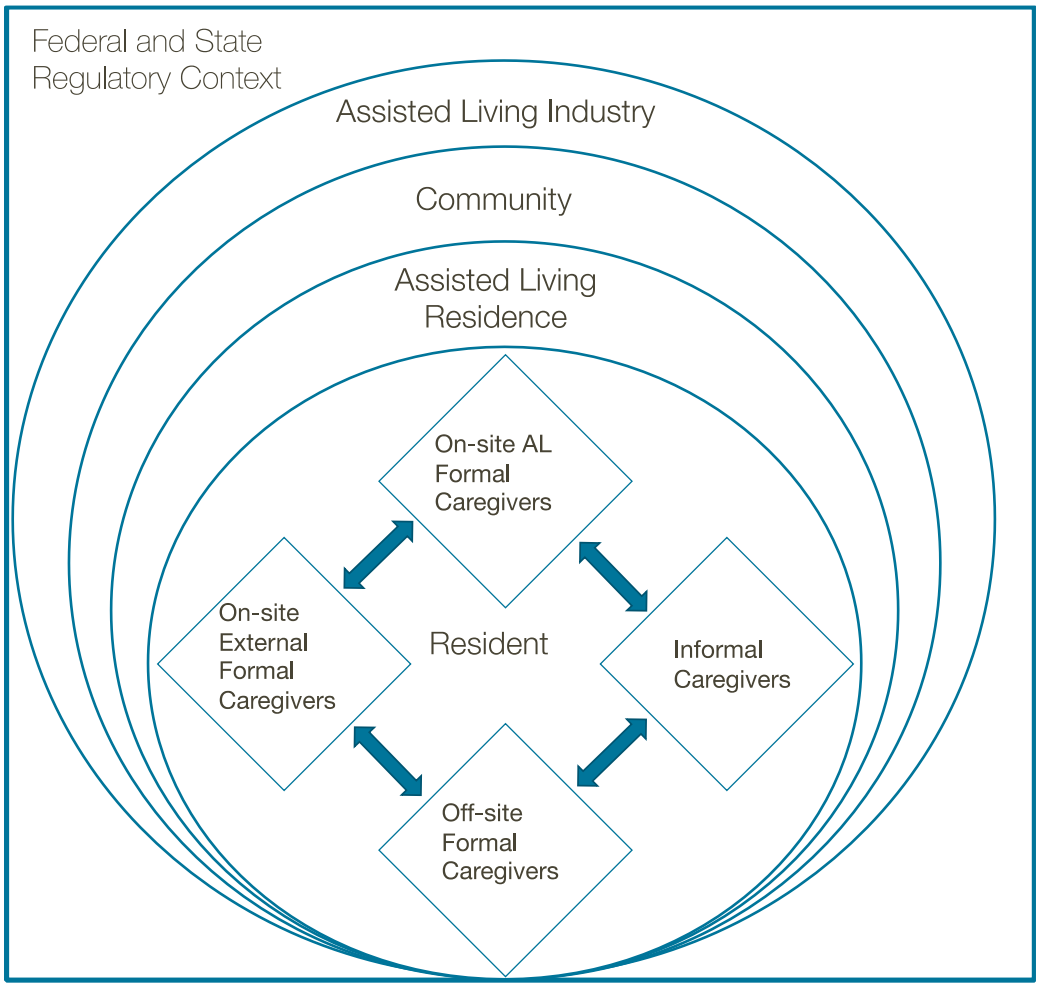
Takeaway

The nodal governance framework conceptualizes governance as a network of public, private, and civil institutions that regulate through restrictions and incentives to ensure citizen protections. Regulations, or the rules of these entities, as well as oversight, the actions taken to enforce the rules, determine the regulatory stringency of any one node. Much of the regulatory research to date in long-term care and ALs has focused solely on public governance mechanisms. This study incorporated both public governance and private governance institutions in an attempt to capture the combined impact.

Convoys of Care

The convoys of care model, as demonstrated in figure 2.3 posits that care within the AL is formally provided by AL staff and third-party providers while also informally provided by family and friends. This is particularly true of larger ALs. In contrast, small ALs are less likely to report families regularly visiting, or active within the residence. For larger ALs (25 beds or greater), family involvement is common and an essential part of care.[154] The lower levels of staffing and caregiver expertise means that many ALs rely on the families of residents more heavily to advocate for the needs of their loved one, particularly if the resident has ADRD, as due to their cognitive status the resident may be less able to advocate for themselves.[158] While family members offer important supports in terms of socialization, in ALs the role family members play in the coordination of health services for the resident is essential in most settings.[7,364]

Figure 2.3: The Convoys of Care Model



The Assisted Living Convoys of Care Model adapted from Kemp et al. (2018)[158]

Takeaway

ALs are different from NHs in their reliance on informal and third-party providers for care coordination and care provision. By conceptualizing AL as a residential LTSS setting that is heavily reliant on informal and third-party care, the importance of AL location within the older adult's community is highlighted as essential to equitable care provision.

2.9. Conceptual Model

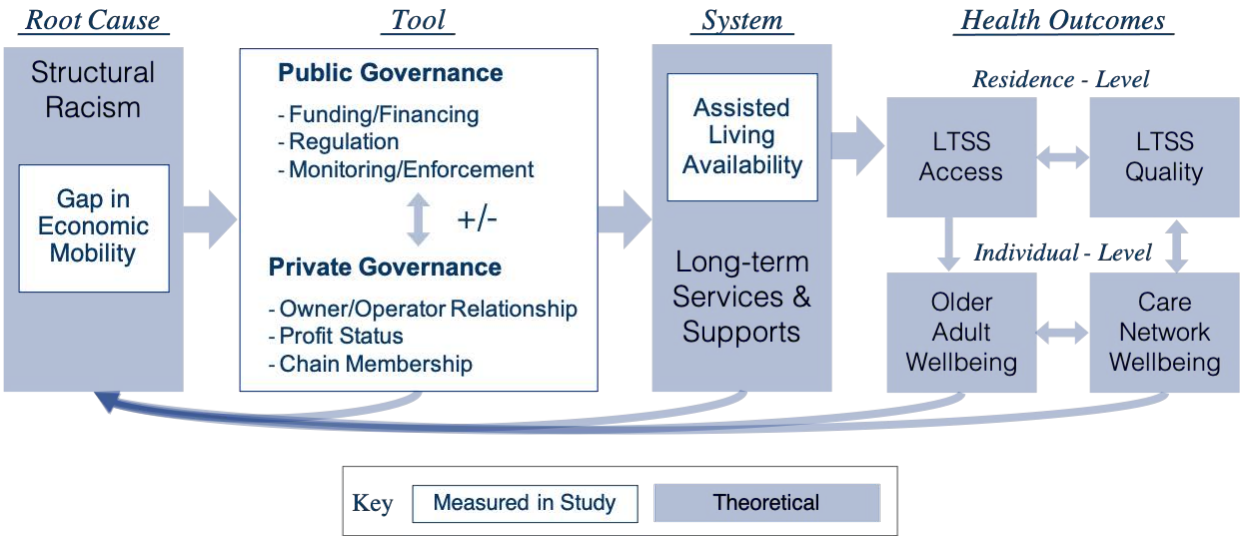
As demonstrated in figure 2.3, the study conceptual model combines Yearby's adapted model of structural racism and combines it with the nodal governance framework within the context of ALs and LTSS provision. Racism is conceptualized as the root cause of the health disparity, following the RRC framework. Then, according to the structural racism framework, the racist ideology intersects with systems and institutions that enact control. This interaction is structural racism. The systems and institutions enacting control in this model can be described using the nodal governance framework. The policies and practices of government and private institutions and norms enacted through civil governance create an environment that either mitigates or advances structural racism. The result of this interaction determines the availability of ALs, which in turn impacts LTSS access and quality as well as the wellbeing of both older adults and their formal and informal caregivers. This study investigated the potential role of structural racism as the root cause of disparities in AL access, then types of governance as possible mediating mechanisms.

Structural racism includes historic and ongoing policies and practices that structurally oppress racial minority populations. As a root cause, structural racism must be enacted through a tool (process or mechanism), in this case governance (mechanisms of control). The tool enacts the structural racism and in doing so may magnify or attenuate the impact on the system. The system under question is the LTSS system in the US AL availability is the specific attribute of the system investigated here. Though not assessed in this study, theoretically, the system and specifically AL availability, impacts how accessible a specific AL may be to the population in need. This in turn impacts the quality of care and the older adult's wellbeing, as the AL depends on geographic access as well as the other aspects of access (see section 2.2.2). Finally this impacts both the well being of older adults and their care network.

2.10. Research Question and Aims

ALs are an important long-term care option for older adults in need of assistance with ADLs and IADLs. ALs are increasingly funded through public programs; however, it is not

Figure 2.3: Study Conceptual Model



Study conceptual model, adapting Yearby's Revised Social Determinants of Health Framework

equally accessible to all older adults in America. ALs are more likely to be located in counties with a smaller Black population, and unlike NHs, the differences in availability cannot be accounted by looking to differences in older adult needs. The history of racist property valuation, such as redlining, and the AL industry's reliance on private market drivers for determining where and how AL properties are developed raises the question, to what extent does structural racism play a role in determining the accessibility of this important service setting? While it may not be possible to prove whether structural racism is or is not the root cause of this disparity, it is possible to investigate related associations and the possible roles that mediating mechanisms play. This study investigates:

What are the combinations of public and private governance approaches that limit or expand the impact of structural racism on disparities of AL availability?

Aim 1: Measure the relationship between structural racism and AL availability. To determine the extent to which a measure of structural racism accounts for race-based disparities of AL availability, I combined an existing dataset of AL locations and the racial opportunity gap (ROG) for each county, an existing measure of structural racism within a community; then created a random intercept linear probability regression model to estimate the association between the ROG as it intersects with the racial demographics of the census tract and AL availability.

Aim 2: Determine the extent to which private governance factors are associated with AL availability. To describe the private governance the relationship, I first used text mining to collect AL corporate ownership data; second, created a random intercept linear regression model to estimate the association between the private governance characteristics and AL availability; and third used the same model to analyze racial demographic-specific groups.

Aim 3: Identify combinations of public and private governance factors that differentiate AL availability, given the level of structural racism. To identify combinations of state-level policies and corporate ownership structures that strengthen or attenuate any association between structural racism and AL availability, I used Boolean description and the coincidence analysis (CNA) algorithm to compare combinations of levels of structural racism and governance factors with AL availability.

The results of this work may both directly and indirectly inform policy interventions. Directly, by providing feedback regarding public funding mechanisms and state regulations that may address disparities in AL availability. Indirectly, this study may inform research design for future policy relevant-population health and health services studies. This study relies on datasets constructed using two innovative approaches, the ROG and health services regulatory analysis.[32,96] As ROG is a novel measure of structural racism (published in 2020), few studies have applied it. Additionally, my study team recently published our approach that connects regulations to specific residences to allow for greater specificity in regulatory research. By using datasets constructed using these two innovative approaches, this study will contribute to identifying the strengths, weaknesses, and potential future applications of these novel tools.

Chapter 3 The Association between the Racial Opportunity Gap and Assisted Living Access

Abstract

Research has previously identified Black-White racial disparities in the use of assisted living, a category of community-based care where older adults can receive assistance with activities of daily living. Our study employed a multilevel random effects linear probability model to estimate the relationship between assisted living location and a measure of structural racism, based on the Black-White gap in economic mobility. We found that within counties with the largest gaps, census tracts with the greatest relative Black populations had significantly lower likelihoods of having an assisted living present than similar tracts in counties with smaller or no gap in Black-White economic mobility. These results identify a relationship between the structural racism responsible for these gaps in the US and geographic access to assisted living.

3.1. Introduction

Assisted living (AL) is a category of community-based care that serves an increasingly important role in the long-term care provision in the US. However, previous research has identified Black-White racial disparities in AL use.[111] Unlike nursing homes (NHs), Black-White disparities in moves to AL are not explained by individual factors such as personal finances and medical acuity.[8] The disparities between Black and White older adults persist after enabling and need factors are accounted for. These include: gender, age, self-rated health, self-reported ADL assistance needs, dementia status, income, housing tenure, living arrangement, and Medicaid status.[8] In contrast, the disparities in moves to NHs are explained by these factors. This further suggests that access to care may be the cause of the disparities in use.

Individual preference does not appear to account for this difference either, as when surveyed, over 20% of Black older adults preferred AL care over home care and institutional care options. While a greater proportion of White older adults reported a preference for AL care (29%), Black survey participants were significantly less likely to end up receiving care that aligned with these preferences 3 years later.[9] One potential explanatory factor is the geographic availability of AL, as these residential communities are less likely to be located in counties with higher proportions of Black residents.[10] This study explores the role that one type of structural racism may play in determining the locations of AL residences and the implications for equitable access to care.

AL is a residential long-term care setting that primarily serves older adults. Staff and third-party providers offer full-time scheduled and unscheduled supportive care and health-related services.[365] These communities were initially designed to provide older adults an environment that emphasizes autonomy and choice and provides assistance with daily living activities.[52] In contrast with NH residents, where certified nursing assistants and nurse staff provide care, AL residents receive care from paraprofessional direct care workers.[366] While historically AL has been predominantly private-pay, this varies considerably by state, and use of home and community-based services Medicaid waiver funding has increased over time. As of 2014, between 6% (New Hampshire) and 40% (New York) of AL residents in each state were dually eligible, and as of 2016, Medicaid supported 18% of all residents.[52,242] This increase in public funding for residents in this setting elicits the importance of public fiscal accountability and the possible applicability of legal access to care provisions.[367]

While older adults' need for assistance with activities of daily living as they age is not new, the AL model is.[70] The challenges to AL access are best understood through the context of

the American welfare system and previous state-subsidized forms of residential long term services and supports (LTSS), which are typically made affordable through service subsidies and/or construction and development incentives. Starting in 1946, the Hill-Burton Act infused 4.6 billion dollars into hospital and healthcare facility construction across America.[107] The federal government distributed construction funds with the intent of building healthcare infrastructure to serve the entire American population. Unfortunately, the act initially served as a form of de jure racial segregation via the specification of "separate but equal" hospitals and hospital wings that were far from equal for White and Black Americans. The subsidized construction of healthcare facilities officially reached long-term care in 1954, when legislation expanded the Hill-Burton Act to include NHs.[197] The segregation of these facilities officially ended when Title IV of the Civil Rights Act of 1964 required all public services receiving federal funds to allow equal access based on race, color, or national origin. However, disparities of care quality and access have continued.[368]

As a result of Hill-Burton and the applicability of Title IV due to Medicare and Medicaid funds, NHs followed a more similar construction and capital support trend to that of hospitals. While many studies have demonstrated continued segregation and discriminatory practices in nursing homes, the disparities in geographic access have narrowed over time, though gaps in access to quality care remain.[368,369] In contrast to NHs, AL was never eligible for Hill-Burton funds. After AL was introduced in the late 1970s, some states and nonprofits attempted to make AL more available to communities where the market has not supported investment. However, there has never been a large-scale investment in making AL available across the US. Without widespread federal funding for infrastructure, AL location has been more susceptible to market pressures.[198]

In contrast to NHs and hospitals, Medicare has almost no role in AL as AL providers do not provide Medicare-reimbursable healthcare services. Medicaid funds can make AL affordable by paying for services on behalf of low-income residents, but the use of Medicaid in AL is limited. Medicaid funds can only be disbursed to ALs if a state alters their state Medicaid plan or receives a state waiver.[113] Demand for AL services and the supply of caregivers are not the only economic drivers of the AL industry. It is also, in large part, an industry that revolves around real estate and the valuing and financing of that real estate.[70] The influence of real estate markets has opened up the door for the inequalities of the real estate industry to impact AL location. The ways that racist ideologies have influenced real estate policies is an example of structural racism.[370]

Structural racism, the systematic use of a racist ideology to structure institutions and systems of resource allocation, regulation, and governance, has been fundamental to property ownership and valuation in the US.[134] Structural racism includes the structures that arise out of the history, culture, institutions, and policies that have created and perpetuated a white supremacist environment, consistently resulting in advantages for White people and harmful outcomes for anyone racialized as non-White.[144,318] Structural racism must be enacted through mechanisms of control such as laws or standardized practices.[360] It does not require the actions or intent of any one individual. Policymakers may reinforce structural forms of oppression without overt actions or intention to perpetuate race-based differences in resource allocation, health, and social services or health and wellbeing outcomes.[117] Structural forms of racism endure for generations, are highly adaptive to new social and political environments, and have an immense impact on the distribution of health and disease within a population.[118,134,371]

AL development has been almost wholly driven by market factors, unlike hospitals and NHs which have benefitted to some extent from government investment.[198] Additionally, the AL industry has relied heavily upon real estate investment for development funds, making real estate values a highly influential factor for AL developers.[70,372] Real estate values in Black neighborhoods are lower than those in White neighborhoods in the US. This gap in value is due to both historic and ongoing racist policies like redlining, FHA-backed mortgages, and racial discrimination in lending practices.[148,373] Finally, AL markets are also driven by demand for services from older adults able to pay for the services. The minimal public funding available for AL care has meant that a majority of AL residents are private pay.[191] It follows that income inequality is an additional driving factor in AL location. In the US, racism is a root cause of income inequality.[135,360]

The compounding effects of little public investment, reliance on real estate development, and reliance on private-pay residents makes it highly likely that disparities in AL availability are at least in part a result of structural racism. While previous studies have described this disparity, none have investigated the relationship between any of the components of structural racism and AL availability. Structural racism has broad effects that reach beyond the racialization of resource distribution.[374] However, based on the essential role real-estate investment has played in AL development, we hypothesized a possible connection between racialized resource distribution and AL location. This study aims to estimate the relationship between AL location and a measure of this component of structural racism—the Racial Opportunity Gap (ROG).[32]

3.2. Study Data and Methods

Overview

We conducted a cross-sectional observational study of the association between AL location in 2019 and a component of structural racism estimated using the ROG. This study is grounded in the theoretical framework of structural racism as put forth by Powell and Yearby's conceptualization of this framework in the context of health disparities.[144,360] We employed three-level hierarchical random intercept linear probability models to estimate the relationship between AL presence in a census tract and the county ROG,[32] adjusting for known AL predictors.[10]

Data and Sample

This study relied upon secondary data sources including: a compiled database of AL locations during 2019,[159] Rural-Urban Commuting Area (RUCA) codes,[375] American Community Survey 5-year 2019 estimates, and economic mobility estimates from Opportunity Insight.[376] The name and location of each AL in the US licensed in 2019 came from an existing database compiled from state licensure records.[159] We determined the rurality of each census tract using The US Department of Agriculture's Economic Research Service provides Rural-Urban Commuting Area Code assignments for each census tract,[375] specifically, the codes as corrected in 2019 to describe the census tracts as defined in 2010.[162] Additional covariate data came from the 5-year estimates from the 2019 American Community Survey using the Social Explorer database to identify the percent of the population over 65, median income, median home value, percent with a bachelor's degree or higher, and racial demographics for each census tract. Finally, county level ROG is used as a measure of the magnitude of the local structural racism effect.[32,376]

The primary unit of analysis for this study was the US Census tract. The US Census designs census tracts to be tracked over time, delineating homogenous populations based on demographics, economic status, and living conditions. As a result, census tracts fall within US counties and have a target population of 4,000 residents, though size varies due to population density and changes over time.[377] Our model included all census tracts in counties with data available to calculate the ROG in 2015 and all census tracts with covariate data available from the 2019 5-year estimates. The ROG was only available for 59.7% of counties (K_2=1,915). However, these represent 92.4% of all census tracts (N = 67,808) across all 50 states and DC (K_1=51). Appendix C describes the counties omitted due to missing data due to either an insufficient Black population for the measure (37.4%, 1,199 counties representing 6.5%, 4,770 census tracts) or an insufficient total population (2.7%, 88 counties representing 1.1%, 748 census tracts) for calculating an ROG.

Variables

The dependent variable in our analyses was a binary value indicating the presence or absence of one or more AL communities within a census tract. The 45,798 ALs licensed by states in the US during 2019 were geocoded by address and assigned to a census tract using the 'censusxy' package in the R statistical environment, which provides API access to the US Census address database.[378,379]

The ROG aims to estimate structural racism in a community by capturing the extent to which White children have access to resources resulting in greater economic mobility than their Black peers, even when their parents make similar incomes.[32] It relies on an economic mobility measure developed by Chetty et al.[376] The measure compares a representative sample of the 2015 incomes of people born between 1978 and 1983 to their parents' incomes while they were

growing up in the 1980s and 1990s. The mobility measure comes from identifying individuals for each county that grew up at the 25th percentile and calculating their mean income percentile as of 2015. If the 2015 mean place-adjusted income for this group is significantly greater than 25, the population has achieved economic mobility.[160,376] The ROG takes this measure, and compares the economic mobility of Black and White populations for each county, subtracting the average income percentile of Black people who grew up at the 25th percentile from the average income percentile of their White peers who similarly grew up at the 25th percentile within the same county.[32]

The ROG can be calculated at many different levels of geographic analysis, including the census tract. However, a more localized measure may not reflect differences in resource access. Within a smaller geographic area, the entire population is likely to have geographic access to the same resources. As a result, such a localized measure may be more likely to capture institutional or interpersonal racism impacting non-geographic aspects of access to resources.[371] Taking this nuance into account, we chose to measure the disparities in economic mobility using a larger geographic unit than the census tract to identify census tracts that experience greater exposure to the effects of structural racism. In this way, the county-level ROG allowed us to capture differences in resource allocation across the sub-geographies (census tracts).

To account for the difference in the impact of the ROG on census tracts, we used their racial makeup to estimate the direction of the effect. The effect of exposure to structural racism is likely to depend on the racial demographics of the residents. Racist policies have been found to harm Black communities while helping White communities.[144] In the case of the ROG, it is specifically a measure that compares White outcomes to Black outcomes. High ROG counties have a White population that is experiencing an advantage and a Black population that is

experiencing a disadvantage. To identify the census tracts most likely to be disadvantaged, we grouped census tracts into linear quintiles according to percent Black. We similarly identified census tracts most likely to be advantaged by structural racism, quintiling according to percent White. The interaction between the ROG and these Black and White within-county population variables was our independent variable, estimating the structural racism effect by census tract. We constructed two models. The ROG and Black population interaction model seeks to estimate potential dampening effect of structural racism on AL presence in census tracts with the largest share of the Black population within a county. The second estimates the bolstering effects of structural racism for the presence of ALs in White census tracts, using an otherwise equivalent model where the independent variable interacts the ROG and the relative White population.

We primarily accounted for the variation of other potential causal factors across counties and states with random intercepts. Based on previous research regarding AL market trends, we included covariates associated with AL market penetration including the 2019 inflation-adjusted median income, median home value, bachelor's degree attainment, population over 65, and rural-urban status.[10] The rural-urban status was represented by a categorical variable (Metropolitan, Micropolitan, Small Town, and Rural). All other covariates were quintiled to allow for comparison of effects across factors and improve interpretation.

Statistical Analysis

We used an empty model and the interclass coefficient to identify the level of homogeneity between states, counties, and the combined effects of the two.[380] Random intercepts for nested county and state effects account for variation in AL policy across states as well as broad variation in socioeconomic and political norms. We conducted all analyses in the R statistical environment and RStudio integrated development environment.[379,381] The datasets

were combined using the 'tidyverse' package and analyses were performed using 'lme4'.[382(p4),383] Significance of effects was determined using the Satterthwaite approximation applied to a random-effects maximum likelihood-fitted model as implemented by the lmerTest package. This approach has been proven more effective than likelihood ratio tests or t-as-z strategies for avoiding Type 1 errors for linear mixed-effects models.[384,385] We interpreted the model findings using average marginal effects using Leeper's 'margins' package, as well as visualizations of effect interactions, given the estimated model.[386,387]

Sensitivity Analyses

In this analysis we used a linear probability model as the interaction term is directly interpretable, unlike the results from non-linear models.[388] Using a linear probability model with a binary dependent variable can risk inconsistent standard errors and impossible modeled probabilities (<0 or >1). To account for this, we tested the model using a logistic regression approach. We ran our primary model as logistic regression, then compared the marginal effects derived from each. An additional threat to the design is the selection bias posed by the inclusion criteria for census tracts. The primary models are limited to only the counties with a ROG. Counties lacking a ROG cannot be assumed to have similar dynamics to those with, as insufficient population or Black population was the cause of missing data. We compared descriptive statistics of the available model variables for census tracts in the study to those omitted.

Limitations

While datasets characterizing neighborhoods that experienced redlining are now available, currently, no national data source include land covenant policies or records of historical and ongoing racism in lending practices.[126] Due to the incomplete nature of this type of

empirical data at the national level, we chose to identify a proxy measure to investigate the role of structural racism at the national level.[108,389]

When measuring the role of structural racism, framing racism as a root cause means that it influences all other covariate effects. Structural racism has played a major role in determining where people live according to how they are racialized. It has also significantly influenced socioeconomics of populations as well as longevity. We included the predictors of AL presence based on the established association between these indicators and the AL market.[10] By adjusting for socioeconomic variables, our findings likely underestimate the effects of structural racism on AL location as these socioeconomic differences are likely influenced heavily by systemic racism. This underestimation is also limited to only counties with sufficient White and Black populations to measure the gap in economic mobility between the two and census tracts with enough households to calculate the ROG and covariates.

An additional challenge posed by the ROG is that it compares the economic mobility of children born between 1978 and 1983 to their parents. It does not account for the socioeconomic and health disparities resulting from structural racism that caused a greater proportion of the Black population to be at or below the 25th income percentile prior to the start of the study. As a result, it only captures the effects of structural racism due to ongoing structural racism beginning in the 1980s. While this time period coincides with the timing of the introduction and growth of the AL industry, there are still likely unmeasured effects due to this limitation. Finally, this study does not differentiate between the quality or size of ALs. While there are clear associations between this measure of structural racism and AL location, these residential facilities may vary drastically in size, quality, and cost.

3.3. Results

Table 3.1 provides a detailed comparison of census tracts that have one or more AL to those that have none. Of the 73,134 census tracts, 22,232 (30.40%) had one or more state-

Table 3.1: Descriptive Statistics for Census Tracts with and Without Assisted Living

Factor/Descriptor	*Statistic/n (% Total)*		*p value*
	No AL (n=45,718)	AL Present (n=20,366)	
Racial Opportunity Gap			< 0.001[1]
Mean	12.0221	11.3770	
SD	3.9360	3.5737	
Census tract % Black within County Quintile			< 0.001[2]
Lowest	8,222 (18.0%)	3,294 (16.2%)	
Low	8,548 (18.7%)	4,226 (20.8%)	
Mid	8,385 (18.3%)	4,127 (20.3%)	
High	12,055 (26.4%)	5,023 (24.7%)	
Highest	8,508 (18.6%)	3,696 (18.1%)	
Census tract % White within County Quintile			< 0.001[2]
Lowest	10,057 (22.0%)	3,644 (17.9%)	
Low	9,295 (20.3%)	4,266 (20.9%)	
Mid	8,182 (17.9%)	4,395 (21.6%)	
High	9,124 (20.0%)	4,614 (22.7%)	
Highest	9,060 (19.8%)	3,447 (16.9%)	
Census tract Older Adult % Quintile			< 0.001[1]
Mean	2.8183	3.2288	
SD	1.3708	1.4019	
Census tract Rural-Urban Commuting Area			< 0.001[2]
Metropolitan	39,669 (86.8%)	17,649 (86.7%)	
Micropolitan	3,867 (8.5%)	1,778 (8.7%)	
Small Town	1,313 (2.9%)	654 (3.2%)	
Rural	869 (1.9%)	285 (1.4%)	
Census tract Median Home Value Quintile			< 0.001[1]
Mean	3.0047	3.2199	
SD	1.4434	1.3301	
Census tract Median Income Quintile			< 0.001[1]
Mean	2.9912	3.2235	
SD	1.4396	1.3819	
Census tract BA Attainment % Quintile			< 0.001[1]
Mean	2.9639	3.2756	
SD	1.4483	1.3337	

1. Linear model ANOVA; 2. Pearson's Chi-squared test; AL = Assisted living

licensed AL within its borders. Of the 68,166 census tracts included in our analysis, the median percent of the population reported as Black in 2019 was 5.09% (IRQ = 1.3% - 17.24%), and the median percent of the population reported as White was 78.76% (IRQ = 57.7% - 90.54%). The median ROG was 11.62 points (IRQ = 9.57 – 14.32 points), with 71% of census tracts included in our analysis in a county with a ROG of 10 points or higher. These results suggest that, for example, if Black people in a county whose parents' income was at the 25th percentile when they were growing up had an average income ranking at the 30th percentile in 2015, a similar White population who grew up in the same county with parents at the same income ranking had an average income ranking at the 40th percentile or higher. Of census tracts in the sample, 95% had a ROG between 4 and 20.

In Table 3.1, we used ANOVA and chi-square tests, to compare census tracts with an AL present to those without any ALs. Our results demonstrate that census tracts with an AL have a lower mean ROG, a significantly lower quintile Black population than other census tracts in the county, and a higher quintile percent White. Census tracts with an AL have a higher concentration of older adults and are more likely to be in micropolitan commuting areas. Finally, echoing the results of county-level analyses,[10] census tracts with ALs have higher median home values, median incomes, and bachelor's degree attainment. Without taking into account state, county, and covariate effects, Table 3.1 illustrates a higher mean likelihood of AL presence for more White census tracts and a lower mean likelihood for Black populations. Looking at the descriptive statistics, a higher ROG (a larger gap between the economic mobility of White and Black populations) is correlated with a lower likelihood of AL presence, opposite from our hypothesis.

We began regression model construction by creating an empty model and calculating interclass correlation coefficients. These indicated that differences between counties explain 19.12% of the chance of a census tract including an AL, differences between states explain 17.83% of the chance, and 5% of the chance is explained by the difference between the nested interaction between counties and states. By using a random intercepts model, we adjusted the model to zero out this variation. The regression results are presented in Appendix A.

We identified a significant interaction effect between the county ROG and the census tract's racial demographics on the likelihood an AL will be present in the census tract. As illustrated in graph A of Figure 3.1 and detailed in Table 3.2, for census tracts with the fewest Black residents relative to other census tracts in the county (quintile 1), compared to census tracts in counties with an ROG of 0, an ROG of 10 (greater indication of structural racism) is associated with an average marginal effect of 1.33% higher likelihood that an AL will be located in the census tract. This rate remains constant between an ROG of 10 and an ROG of 20. An increase in the ROG for census tracts with a median percent of the Black population (quintile 3 from 0 to 10 is associate with a decrease in the likelihood of an AL in the census tract of 2.72%, and from 10 to 20 points, decreases 2.69%. Finally, for census tracts with the highest percent Black population of the county, at an ROG of 0, an AL is likely to be present in 35.87% of census tracts. This decreases by 6.76% to 29.11 for census tracts in counties with an ROG of 10, and additional 6.75% at an ROG of 20. Census tracts with the largest Black populations proportional to the rest of the county, being in a county at the 95th percentile for ROG (a 20-point ROG) only 3,073 of the 13,744 census tracts (22.36%) are likely to have an AL. In contrast, at an ROG of zero 4,929 census tracts (35.87%) of the same census tracts are likely to have an AL.

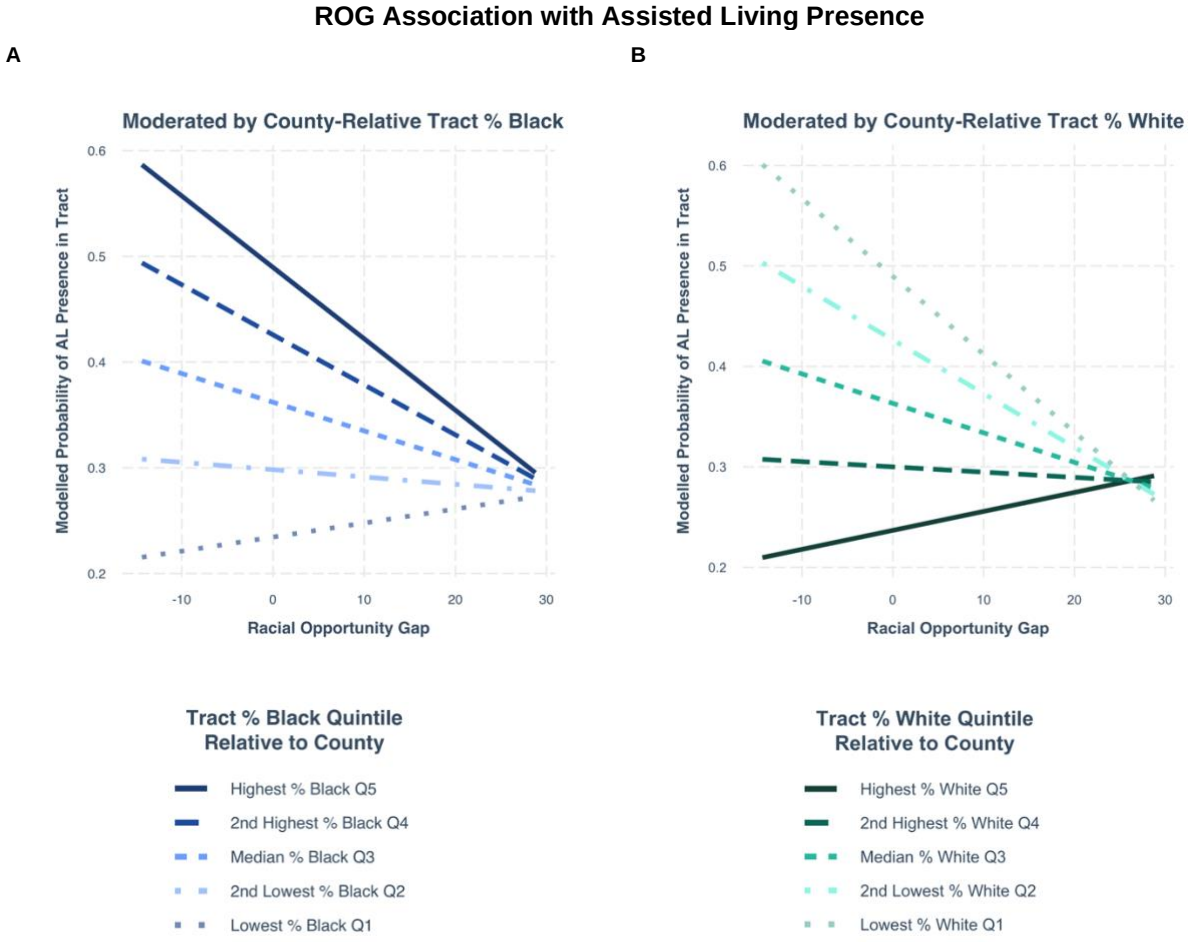
Table 3.2: Probabilities at Specified ROG Values for Primary Models

Census tract % Black residents Model					
		Census tract % Black residents, quintiled within County			*Total*
Factor	*Factor* *Census tracts* *Total Pop.* *Black Pop.*	*Quintile 1* *n = 11,527* *50.01 Mill* 0.25 Mill	*Quintile 3* *n = 13,794* *66.48 Mill* *3.87 Mill*	*Quintile 5* *n = 13,744* *58.04 Mill* *24.8 Mill*	*n = 66,084* *302.89 Mill* *39.98 Mill*
ROG AME		0.3015	0.3257	0.2748	0.3082
ROG = 0		0.2869	0.3580	0.3587	0.3433
ROG = 10		0.3002	0.3308	0.2911	0.3146
ROG = 20		0.3134	0.3039	0.2236	0.2859
Census tract % White residents Model					
		Census tract % White residents, quintiled within County			*Total*
Factor	*Factor* Census tracts Total Pop. White Pop.	*Quintile 1* n = 13,771 60.33 Mill 22.66 Mill	Quintile 3 n = 13,799 66.34 Mill 52.03 Mill	*Quintile 5* n = 13,744 47.95 Mill 45.58 Mill	*n = 66,084* *302.89 Mill* *39.98 Mill*
ROG AME		0.2791	0.3269	0.3018	0.3082
ROG = 0		0.3769	0.3617	0.2814	0.3433
ROG = 10		0.2994	0.3323	0.3003	0.3146
ROG = 20		0.2219	0.3030	0.3192	0.2859

ROG = Racial Opportunity Gap; AME = Average Marginal Effects

As illustrated in graph B of Figure 3.1 and detailed in Table 3.2, these effects are the opposite and somewhat exaggerated for the White population. In census tracts with the least and median percent White residents, proportional to other census tracts in the county, an increase from an ROG of zero to an ROG of 10 as well as an increase from an ROG of 10 to an ROG of 20 is associated with 7.75% and 2.93% respective decreased likelihoods of AL presence. In contrast, census tracts that fell in the highest quintile in the percent of the White population relative to other census tracts in the county, the same 10-point ROG increase was associated with a 1.88% average marginal effect increase in the likelihood of AL presence. For census tracts with the greatest White populations, those in a county at the 95th percentile ROG have a 3.01% higher likelihood of an AL than similar census tracts in counties at the 5th percentile.

Figure 3.1: Census tract demographic moderated associations between ROG and Assisted Living Presence



To determine whether the binary dependent variable used within the linear probability model caused inconsistent standard errors or impossible modeled probabilities, we compared our results to those using the same model and a logistic regression. An analysis of variance between the marginal effects of the logistic and linear models found that no significant differences between the two approaches. See Appendix B for a complete comparison. To estimate the difference in AL location trends between the census tracts included in the analysis and those where the ROG or one of the covariates were unavailable, we compared the descriptive statistics of our sample to those for the omitted census tracts (Appendix C). We found significant

differences between the omitted census tracts and the census tracts included in the analysis across all variables.

3.4. Discussion

We found a significant linear relationship between AL presence and the interaction between the county ROG and racial demographics of the census tract. We relied on state and county random effects to account for differences between states in policies and counties in socioeconomic and cultural norms. Our model took these effects into account as well as the census tract urbanicity, the percent of the population over 65, median home value, median income, and the percent of the people with a bachelor's degree. Outside of the differences in these socioeconomic factors previously shown to be associated with AL presence, there was still a significant effect.

Our results show a clear association between AL presence within a community and the interaction between community demographics and the aspect of structural racism measured by the ROG. While other components of structural racism are likely at play, these results do not conflict with our hypothesis that the same racist policies that made it difficult for Black families to become homeowners and build equity in both residential and commercial real estate also act as a barrier to market entry for AL providers. While the location of an AL within a neighboring census tract does not preclude Black older adults from accessing it, our model indicates that the pattern of AL location is not random. These results may not imply that AL developers are overtly aiming to locate AL solely in areas with small Black populations in high ROG counties. However, it seems likely that developers are responding to land values that reflect centuries of racist policies and a systemic devaluation of Black neighborhoods.

3.5. Conclusions

These findings point to actionable steps for federal and state policymakers. According to these results, ALs are unlikely to be located in the census tracts with the highest percent Black residents and least percent White residents within counties with the greatest gaps between average Black and White economic mobility. A program similar to the Qualified Opportunity Zone initiative could invest in those communities with development funds and incentives to build and sustain ALs within the bounds of those neighborhoods.[390] These subsidies should be large enough to account for the market-based losses a developer is likely to face in building in the area due to the harmful effects of structural racism on property values.

Future studies should explore what these findings mean for equitable access to care. Location is just one aspect of care access. It is unclear whether the trend we identified is consistent across all types of AL, including various license types, dementia-specific care, and AL size. Additionally, future work should consider variation in the cost of care, the availability of units, and the appropriateness of the care provided, as those factors may pose significant barriers to care access.

Additionally, research looking to uncover the mechanisms through which structural racism impacts care access should investigate further how the racial makeup at the census tract level interacts with disparity measures at the county level. Future studies could further isolate the effects of regional versus local distribution of Black and White as well as other racialized populations. It is possible that either county-level demographics or measures of segregation could have additional influence on the dynamics of effects at the census tract level. Finally, we used the ROG as a tool to estimate the influence of a component of structural racism for one health service—assisted living. This approach may be relevant to the investigation of access to

other health services. Future work should also seek to better understand the specific aspects of structural racism this measure captures, and how it can be combined with additional measures to better understand and address the health disparities structural racism has caused.

Chapter 4 Private Governance Characteristics Associated with Assisted Living Geographic Access

Abstract

Objectives: This study investigates the types of private governance associated with greater access to assisted living (AL) residences and how these factors vary for Black and White communities given the role of structural racism.

Design: This study applies a nodal governance framework to the issue of AL geographic access.

Setting and Participants: We associated 41,241 AL residences licensed by states in 2019 located in 2,470 counties with business databases and institutional revenue service records.

Methods: We classified ALs according to size, profit status, and operation by a large chain entity. We then compared the prevalence of these characteristics at the county level to the presence of AL within a given census tract using a multilevel linear probability model. In a secondary analysis, we estimated AL presence in the census tracts in each county most likely to be disadvantaged by structural racism and compared these to those census tracts most likely to be advantaged by structural racism, estimated using population percent Black and percent White.

Results: We found that geographic access to AL in a census tract is associated with a higher proportion of county AL capacity provided by medium and small AL residences unless they are affiliated with one of the top fifty chains. This association only holds for small for-profit residences for census tracts with the greatest proportion of the Black population. The confidence interval of the association between AL presence and small for-profit ALs is significantly greater than the association for either high percent White census tracts or the full population.

Conclusions and Implications: Our findings suggest that policymakers seeking to expand access to AL should work with small local providers irrespective of tax-exemption status, particularly if aiming to expand access for Black communities.

4.1. Introduction

Access to quality residential long-term services and supports (LTSS) is essential to the well-being of many older adults, particularly people living with dementia.[391] Assisted living (AL) is a type of care setting licensed to meet this need. Though ALs vary based on license and provider types, this flexible model of residential care has gained in popularity and now serves as an important option for older adults in need of residential-based LTSS.[52] While disparities in access to residential LTSS have long been documented, the nature of these disparities has shifted in the past twenty years. Wealthy and White older adults have shifted away from nursing homes (NHs), replacing NH care with AL care.[337] Unfortunately, this care setting is not an option for many older Americans, as race-based disparities in use and geographic access have been identified.[10]

The current AL model, introduced in the early 1990s, experienced rapid growth as the industry took off, continuing for over a decade, then plateauing until a post-recession increase in development again in the late 2010s.[102(p32)] Industry and development of AL varied greatly from state to state, especially as states have maintained sole regulatory authority for these settings. While studies of regulations and regulatory enforcement have documented the variation of public governance across states,[75,96,392] little is known about the variation in private governance. According to a nodal governance perspective, a system of governance includes mechanisms of control and management, including government entities (public), businesses (private), and social groups.[149] In ALs, the relatively low level of public funding and oversight has resulted in an

industry where private governance, enacted through the policies and norms of corporate entities, has theoretically been highly impactful.[191]

Geographic access to AL has traditionally been conceptualized similarly to the market reach of a facility, which is relatively broad, similar to NHs.[10,101] Using a county-level measure of access, previous research found that counties with a higher percent of Black residents have lower odds of having an AL.[10] However, AL is considered a community-based care setting, not an institutional setting.[52] A substantial component of the argument for community-based care is the integration with and access to community resources, including family, friends, religious services, and existing clinician relationships.[158] If AL is to genuinely serve the role of community-based care, some have argued that geographic access should be measured using a smaller unit of analysis.[78]

In addition to the evidence of county-level disparities, Black older adults are more likely than their White peers to move into NH and less likely to move into an AL.[340] Black Americans have significantly lower levels of home equity, even when compared to White adults of a similar age and income level.[346] This finding provides additional evidence that geographic access may be a significant driver behind the Black-White disparities in AL use.

Structural racism is the theoretical cause of geographic racial disparities. This includes mechanisms such as racism in housing policy includes redlining, land covenants, racism in lending, among many others. This complex array of historic and ongoing policies and practices has resulted in a highly unequal distribution of wealth and high valued real estate between White and Black neighborhoods.[346,393] These gaps in home equity-based wealth impact both the wealth of Black communities and the value of commercial real estate within Black neighborhoods. Research has documented the impacts of low value commercial real estate on health and social

service resource availability.[110] Therefore, the high level of market influence on AL availability may make ALs more susceptible to the influences of racist lending policies and practices.

To date, research studies have struggled to systematically collect data reflecting private governance characteristics in AL at a national level. However, a nodal governance perspective indicates that private governance mechanisms likely play an important role in AL geographic access.[100] The influence of private governance is theoretically uniquely strong for AL as, unlike NHs, few public policies have directly incentivized AL development.[394] Instead, market factors have driven AL construction and development. As a result, understanding whether and how private governance is associated with geographic access is an important question to investigate. Furthermore, structural racism has played a significant role in shaping the real estate market in the US through processes such as redlining, land covenants, and racism in lending. Therefore, we also investigated the differences between private governance and AL access for communities that have likely been harmed or helped by systems grounded in a racist ideology.

4.2. Methods

Study Design

We combined secondary data sources in an analytic observational analysis of cross-sectional data. Multilevel random intercept regression analyses were performed to determine the provider characteristics associated with greater geographic access to AL, as measured by the presence or absence of AL in a census tract. To explore whether the relationship between private governance and access is altered by structural racism, we additionally looked at whether these AL characteristics had different associations with access for census tracts that have a higher proportion Black residents versus higher proportion White residents.

Data Sample and Sources

For our primary analysis, the sample included all census tracts in counties with at least one AL located within the county. We found 735 counties (22.8%), home to less than 3.5% of the American population, did not have any ALs. These were omitted from our analysis. We included all AL residences licensed by one of the 50 states or the District of Columbia to provide 24-hour care to four or more residents during 2019. For our secondary analysis, we identified the census tracts within the county most likely to experience harm from structural racism by grouping census tracts into linear quintiles according to percent Black, filtering out any in which less than 10% of the population was Black. We similarly identified census tracts in each county most likely to benefit from structural racism, quintiling according to percent White.

We relied on a previously aggregated directory of all licensed ALs in the US, compiled from state agencies in 2019.[159] We then joined these licensed communities to business profiles and US Internal Revenue Service (IRS) records using a combination of address, employer identifier, AL name, and the name of the owning entity. Business profiles for the ALs in our sample were sourced from Data Axle, a business-to-business marketing database. IRS data regarding tax exemption status was sourced from the IRS website. Finally, business profiles were linked to corporate hierarchy listings in the NexisUni database for each of the largest 50 AL providers in 2019, according to Argentum, a trade organization. Additional covariate data were sourced from the Rural-Urban Commuting Areas (RUCA) codes,[375] and the American Community Survey 5-year 2019 estimates.

Outcomes

To measure AL access, our outcome of interest was the likelihood of AL presence in any given census tract within a specified county. AL presence was considered any state-licensed AL

located within the bounds of a census tract, and absence was the lack of any such business. The secondary analyses used the same outcome variable but were limited to the subset of applicable census tracts.

Table 4.1: Operator Characteristics to be Summarized at County-Level

Characteristic	Attribute Measure
Of the total AL capacity in the county, the % of capacity provided by ALs that are…	
Size	Small (4-24 residents)
	Medium (25-49 residents)
	Large (50+ residents)
Operator Type	Operated by one of the top 50 largest operators
	Non-tax-exempt and not in the top 50 largest operators
	Nonprofit tax-exempt

Key Independent Variables

We used AL licensed capacity, profit status, and participation in one of the top fifty largest operator chains as proxies to measure private governance. Our independent variables of interest were measured at the county level to describe the makeup of the AL residences across all census tracts in the area. For each county in our sample, the percent of the AL capacity provided by operators with each attribute was summarized as a percentage (0% - 100%). This measure is relative to the total AL capacity for the county, meaning that it is not weighted by total capacity, but was created to estimate the market share of these types of AL providers within the county. The size and operator type attributes and their interactions served as our key independent variables.

We defined four categories of capacity based on size categories that have been shown to be associated with differences in AL operations in previous research.[63,395] Size categories included small (4-24 residents), medium (between 25 and 50 residents), and large (50 residents or more). For the two license types that provide capacity only in units (apartments), the licensed

units count was multiplied by 1.1, following the methods of the National Survey of Residential Care Facilities.[396]

In addition to size, previous work in NHs and state-specific studies of AL have identified profit status and chain membership as potentially significant organization-level characteristics associated with differences in care access. We determined profit status according to whether the AL operator was classified as government-associated or a tax-exempt charity by the IRS. All of the top 50 largest chain operators are for-profit entities. Therefore, the mutually exclusive categories for AL operators were constructed according to whether the operator was one of the top 50 largest, neither federally tax-exempt nor part of one of the fifty largest chain operators, or a tax-exempt nonprofit entity. These size metrics were additionally interacted with the profit and chain metrics, as we anticipated different private governance approaches across size categories. Additional tract-level covariates associated with AL in-county prevalence included: percent of the population over 65, percent of the population with a bachelor's degree, median income, median home value, and the RUCA Code assignments.

Statistical Analyses

We completed all statistical analyses using the 'lme4' package in the R statistical environment.[379,382] We used county and state nested fixed effects to account for state policy differences as well as cultural norms and market variation. Our team assessed the relationship between private governance and access by evaluating the significance of coefficients for the private governance categories as compared to access for counties high in large for-profit ALs that are not affiliated with one of the top 50 chains. We compared effect estimates for the outcome variables across the primary and two sub-models to assess differences in the types of

AL providers associated with greater access within a county, greater access for the Black population within a county, and greater access for the White population within a county.

4.3. Results

The 41,241 ALs were located in 21,257 census tracts within 2,470 counties across the fifty states and Washington DC. Table 4.2 describes the prevalence and capacity of AL residences by size and type. Using our novel approach, we linked 3,908 ALs to one of the top 50 largest chain operators in 2019. Combined, these ALs provide 24.1% of the licensed AL capacity across the US. The most prevalent type of AL residence was the small (4-24 resident capacity) for-profit not affiliated with a top-50 chain. These ALs accounted for over half of all AL residences nationally, but only 16.40% of the total AL capacity. Large for-profit ALs unaffiliated with one of the top fifty chains accounted for the most capacity (41.0%), followed by large ALs affiliated with one of the top fifty chains (22.0%). Overall, large ALs made up 23.0% of residences but 70.4% of licensed resident capacity. In contrast, all small ALs makeup 66.7% of ALs but provide only 17.8% of capacity.

For our secondary analysis, we summarized the prevalence of ALs according to their private governance characteristics for the most Black and most White census tract populations for each county. A greater proportion of AL residences located in census tracts with the largest Black populations in each county were small and for-profit but unaffiliated with a chain. A significantly smaller percentage of ALs and capacity was provided by nonprofits or top 50 chains in these tracts compared to the overall population. For census tracts with the largest White populations for each county, a slightly larger proportion of ALs and capacity was provided by large chain operators, and large ALs provided a greater proportion of AL capacity.

Table 4.2: Private Governance Characteristics of Assisted Living Residences

Private Governance Type	All Residences				Q5 % Black Residents Census Tracts				Q5 % White Residents Census Tracts			
	AL Residences		Licensed capacity		AL Residences		Licensed capacity		Al Residences		Licensed capacity	
	n	Percent	n	Percent	n	Percent	n	Percent	n	Percent	n	Percent
Large	9,523	23.00%	928,725	70.40%	825	17.80%	80,314	67.30%	1,626	24.60%	165,744	73.10%
Nonprofit	963	10.11%	97,837	10.53%	85	10.30%	8,935	11.13%	179	11.01%	18	10.95%
Top-50 Chain	2,893	30.38%	290,712	31.30%	213	25.82%	20,171	25.12%	514	31.61%	53,984	32.57%
Other For-Profit	5,667	59.51%	540,176	58.16%	527	63.88%	51,207	63.76%	933	57.38%	93,617	56.48%
Medium	4,204	10.20%	155,097	11.80%	329	7.10%	12,336	10.40%	837	9.70%	23,668	10.50%
Nonprofit	557	13.25%	20,244	13.05%	36	10.94%	1,333	10.81%	79	12.40%	2,922	12.34%
Top-50 Chain	545	12.96%	21,780	14.04%	52	15.81%	2	17.15%	96	15.07%	3,853	16.27%
Other For-Profit	3,102	73.79%	113,073	72.90%	241	73.25%	8,887	72.04%	462	72.53%	17	71.40%
Small	27,514	66.70%	234,775	17.80%	3,466	75.00%	26,633	22.30%	4,331	65.70%	37,003	16.30%
Nonprofit	1,032	3.75%	12,568	5.35%	132	3.81%	1,394	5.23%	136	3.14%	2	4.25%
Top-50 Chain	470	1.71%	5	2.31%	66	1.90%	656	2.46%	60	1.39%	724	1.96%
Other For-Profit	26,012	94.54%	216,791	92.34%	4,620	94.29%	24,583	92.30%	4	95.47%	34,705	93.79%
Total	41,241		1,318,597		3,268		119,282		6,594		226,434	
Nonprofit	2,552	6.19%	130,649	9.91%	253	5.48%	11,662	9.78%	394	5.98%	22,639	10.00%
Top-50 Chain	3,908	9.48%	317,908	24.11%	331	7.16%	22,943	19.23%	670	10.16%	58,560	25.86%
Other For-Profit	34,781	84.34%	870,040	65.98%	4,036	87.36%	84,677	70.99%	5,530	83.86%	145	64.14%

In our primary analysis, we found a significant positive association between AL access and the percent of ALs in a county that are medium and small when the ALs were not operated by a top fifty chain provider. For other nonprofit and for-profits not affiliated with one of the top fifty chains, an increase in the percent of small ALs had a more significant and larger effect than more medium-sized residences. The greatest effect we observed was for small nonprofit ALs. When compared to the base category, large non-affiliated for-profit ALs, each ten-percentage point increase in the AL capacity in the county provided by small nonprofit ALs was associated with a 2.31% greater chance of an AL being located within the tracts in the county.

Our secondary analysis found this association disappeared for nonprofits in both census tracts with the highest percent Black and percent White residents within counties. For both of these subpopulations, the only private governance category we investigated associated with an increase in access was the percent of AL capacity provided by small for-profit ALs not affiliated with a large chain. Each ten-percentage point increase in the proportion of AL capacity in a county provided by this type was associated with a 2.91% and 1.40% greater chance of the presence of an AL in the county's census tracts that have the highest percent Black and percent White residents respectively (Figure 1). This effect is significantly higher for the census tracts with the highest proportion Black population, the confidence interval for the coefficient is outside of the confidence interval for the most White census tracts. For the full regression results of these three models, see Table 4.3.

Table 4.3: Random Effects Regression Models of Factors Associated with Assisted Living Presence in a Given Census Tract

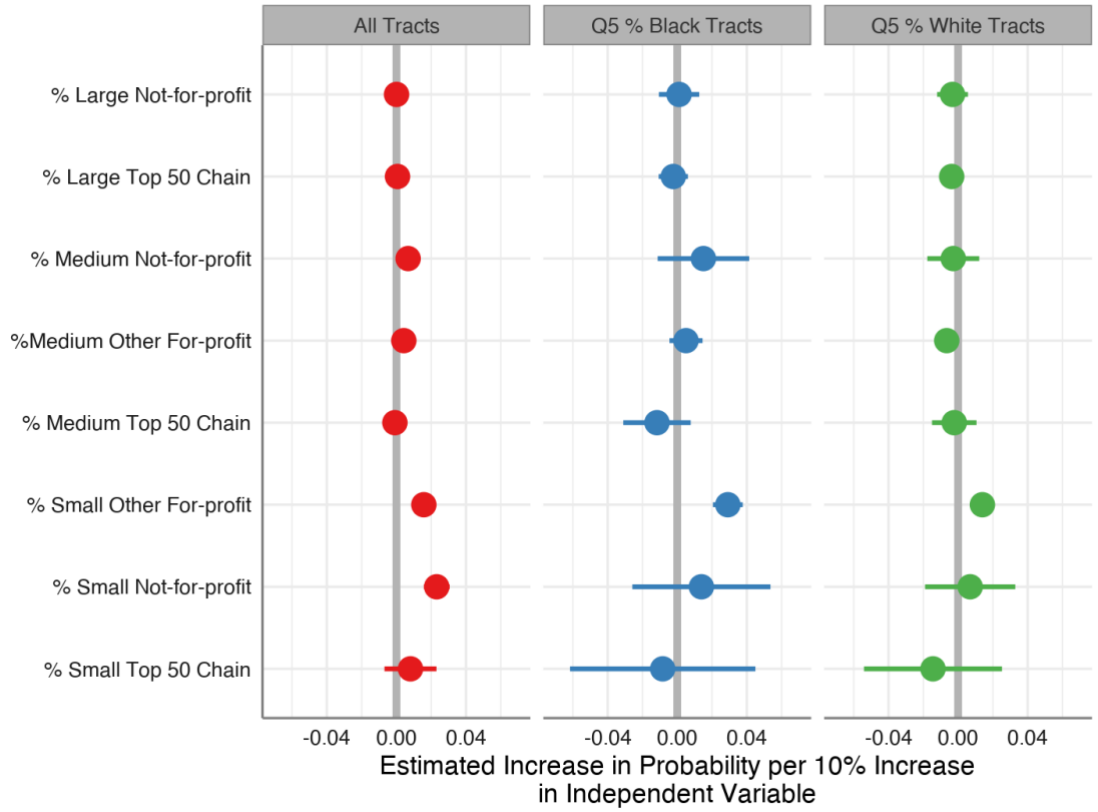
		All		% Black Residents, 5th Quintile		% White Residents, 5th Quintile	
	Coefficient	*Estimates*	*Conf. Int (95%)*	*Estimates*	*Conf. Int (95%)*	*Estimates*	*Conf. Int (95%)*
	(Intercept)	0.0797 ***	0.0423 – 0.1170	0.0365	-0.0143 – 0.0872	0.0699 **	0.0208 – 0.1189
County-Level	County AL Capacity						
	% Large Other For-Profit	-	-	-	-	-	-
	% Large Not-for-Profit	-0.0004	-0.0049 – 0.0041	-0.0007	-0.0098 – 0.0084	-0.0037	-0.0125 – 0.0051
	% Large Top-50 Chain	0.0005	-0.0029 – 0.0038	-0.0004	-0.0070 – 0.0063	-0.0039	-0.0106 – 0.0027
	% Medium Not-for-Profit	0.0064 *	0.0008 – 0.0121	0.0042	-0.0109 – 0.0193	-0.0026	-0.0175 – 0.0123
	% Medium Other For-Profit	0.0042 **	0.0013 – 0.0071	0.0045	-0.0023 – 0.0114	-0.0063	-0.0131 – 0.0005
	% Medium Top-50 Chain	-0.0012	-0.0070 – 0.0046	-0.0031	-0.0158 – 0.0095	-0.0026	-0.0153 – 0.0102
	% Small Other For-Profit	0.0111 ***	0.0079 – 0.0143	0.0151 ***	0.0071 – 0.0231	0.0066	-0.0013 – 0.0145
	% Small Not-for-Profit	0.0213 ***	0.0135 – 0.0290	0.0252	-0.0007 – 0.0510	0.0056	-0.0211 – 0.0323
	% Small Top-50 Chain	0.0062	-0.0100 – 0.0224	-0.0030	-0.0496 – 0.0436	-0.0111	-0.0575 – 0.0353
Census Tract-Level	Tract Population 65+ (in hundreds)	0.0243 ***	0.0235 – 0.0250	0.0327 ***	0.0306 – 0.0349	0.0193 ***	0.0178 – 0.0208
	Census Tract Rural-Urban Commuting Area						
	Metropolitan	-	-	-	-	-	-
	Micropolitan	0.0137 *	0.0001 – 0.0273	0.0413 **	0.0117 – 0.0708	-0.0064	-0.0363 – 0.0236
	Small Town	0.0833 ***	0.0647 – 0.1020	0.1124 ***	0.0685 – 0.1562	0.0115	-0.0366 – 0.0597
	Rural	-0.0110	-0.0317 – 0.0096	-0.0228	-0.0854 – 0.0399	-0.0395	-0.0853 – 0.0062
	Median Income, US Index	-0.0145 ***	-0.0188 – -0.0103	-0.0015	-0.0133 – 0.0103	-0.0061	-0.0146 – 0.0025
	Median Home Value, US Index	-0.0097 ***	-0.0149 – -0.0044	-0.0061	-0.0212 – 0.0089	-0.0200 ***	-0.0287 – -0.0114
Rand. Effects	σ^2	0.17		0.16		0.16	
	τ_{00}	0.00 $_{\text{county:state}}$		0.01 $_{\text{county:state}}$		0.01 $_{\text{county:state}}$	
		0.01 $_{\text{state}}$		0.02 $_{\text{state}}$		0.01 $_{\text{state}}$	
	ICC	0.10		0.12		0.10	
	N	2470 $_{\text{county}}$	51 $_{\text{state}}$	1832 $_{\text{county}}$	51 $_{\text{state}}$	1825 $_{\text{county}}$	51 $_{\text{state}}$
	Observations	68,518		12,491		12,861	
	Marginal R^2 / Conditional R^2	0.075 / 0.163		0.101 / 0.212		0.066 / 0.159	

** p<0.05 ** p<0.01 *** p<0.001*

4.4. Discussion

This study hypothesized a relationship between private governance characteristics and community access to AL care. We found that larger AL size and top 50 chain affiliation were associated with less geographic access to care. However, for our sub-analysis of census tracts with the greatest Black and White populations within counties, respectively, this association does not hold for medium or nonprofit ALs. Previous research has relied upon either state-level analyses or agency self-report to determine chain status. This study is the first to empirically examine the relationship between AL size, chain affiliation, profit status, and AL geographic

Figure 4.1: Comparison of Model Estimates of AL Presence



Note: The dots on this marginal effects graph show whether there is a significant difference in AL availability between a county where all capacity is provided by large for-profit operators not affiliated with a chain (the grey line) and a similar county, given a 10% increase in AL capacity provided by the operator type listed.

access. Our use of business data combined with a database of state AL directories allowed us to describe chain affiliation at a national level. We additionally joined our database with federal tax exemption data to identify nonprofit providers. We used a multilevel model with the resulting dataset to compare the prevalence of these categories of AL providers in a county with the modeled likelihood that an AL is present in each census tract in the county. Our results highlight the critical role that small ALs may play in expanding access to AL care, particularly within Black communities.

Relative to the percent of capacity provided by large for-profit ALs not affiliated with one of the top fifty chains, census tracts within counties where a greater proportion AL capacity was supplied by small nonprofit ALs had the highest association with greater access. We also investigated how these trends varied for the census tracts within each county that were most likely to experience different patterns of real estate and healthcare services development patterns based on the effects of structural racism. For the census tracts in the highest quintile of percent Black population for each county, the only private governance category associated with a significant increase in access was the proportion of AL capacity provided by small for-profit ALs not affiliated with one of the top fifty chains. This was also true for the most White census tracts in each county. While the direction of the effect and significance is the same among these two groups, the effect size is significantly greater for Q5 percent Black residents census tracts compared to more Q5 percent White residents census tracts.

These results may be an issue of an under-powered analysis, as our secondary analyses relied on a sample of 9,385 census tracts with high Black populations and 12,861 census tracts with high White populations, compared to the analysis of 68,518 census tracts in a county with one or more AL included in the primary analysis. However, the effect size for Q5 percent Black

residents census tracts among small for-profit ALs not affiliated with a large chain combined with the lower proportion of ALs located in these communities with tax-exempt status may also reflect the documented racism in tax exemption.

Tax-exempt nonprofit status continues to be offered to white supremacist organizations and denied for religious and social services organizations serving Black communities.[397–399] Systemic racism has meant that advocacy for racial equity is deemed political action and disallowed except in cases that qualify as community development, in which the organization also aims to "relieve poverty, […] reduce neighborhood tensions, and combat community deterioration," which ALs would not qualify under.[400] This has kept many organizations, including churches, from seeking tax-exempt status when they otherwise would be able to.[401] It's unclear whether racism in tax exemption plays a role for AL providers in Black communities. However, future research and policymaking should take the possibility into account.

We investigated the association between AL provider types and geographic access based on the nodal governance perspective, in which a system of governance includes mechanisms of control and management from governments, private entities, and social groups.[149] In A governance, the relatively low level of public funding and oversight has resulted in an industry where private governance, enacted through the actions and norms of corporate entities, has theoretically been highly impactful.[191] Previous work has documented differences between ALs run by providers managing a single AL residence and those operating a large number. It is likely that the differences in administrative capacity, access to capital, and executive involvement in day-to-day operations vary drastically across these setting types.[402,403] Our finding that smaller ALs are associated with a higher level of geographic access except in the case of providers affiliated with one of the top fifty provider chains reflects this theorized relationship.

Every AL has two economic components—the property owner and the AL operator. These two entities may be the same, but often, they are not.[102(p32)] Operators or providers are the organizations that provide the services within an AL. In this study, we looked only at the operators of the AL residences. Based on the nodal governance theory, the entities that own the properties associated with the AL may also be associated with where the AL is located and what populations it serves. Future work should consider the role that this complex relationship plays and how these sources of private governance interact with the public governance enacted through state regulations and subsidies.

Table 4.4: Comparison of Findings to Previous Research

	Study Findings	**Stearns 2007**[404]	**NCHS 2010**[405]	**NCHS 2016**[52]	**Trinkoff 2019**[395]	**June 2021**[406]	**Dobbs 2022**[407]
Nonprofit	6.2%[a]	16%	18%	19%	6.2%	8% [a]	29.3%
Chain	9.5% [b]	33%	38%	57.2%	NA	NA	NA
Sample	51 states N=41,241 ALs	4 states n=169 ALs	51 states n=3,605 ALs	51 states n=4,643 ALs	1 state N=2,689 ALs	1 state N=1,939 ALs	7 states n = 250 ALs
Source	Administrative, marketing, & industry records	Administrator Survey	Administrator Survey	Administrator Survey	State inspection records	State registration records	Administrator Survey

NCHS = National Center for Health Statistics
a. Nonprofit status includes only Federal status as a nonprofit organization, not state registration
b. Chain includes only the largest 50 chains in the US

There are limitations to the generalizability of our findings based on the definitions of our measures. Previous studies have either sampled ALs across multiple states, relying on administrator surveys, or looked at a single state's records. In comparison, we relied only on administrative, marketing, and trade organization records. When surveys are used, less narrow definitions of both nonprofit and chain affiliation are necessary, as there are limitations based on the knowledge of the survey respondent, in this case the administrator. As demonstrated in Table 4.4, findings of profit status among studies relying on administrator report vary between 16% and 29.3%, [52,404,405,407] considerably higher than findings in this study (6.2%) or the two other studies relying on state records (6.2% and 8%).[395,406] Our use of federal tax status likely under-

estimates the number of nonprofit providers, as nonprofit status is determined at the state level and may not be consistent with the way the organization files its federal taxes. However, the alignment between our findings and the studies that relied upon administrative data provide additional evidence of the validity for our use of IRS records.

For chain affiliation, previous studies are much less comparable to the measure used here. Only studies relying on administrator response have reported chain affiliation, and of those, all have looked at any chain affiliation whereas we were only able to capture the chain affiliation for the top 50 largest corporate chains. [52,404,405] Thus, it is important to refrain from generalizing our findings to smaller chain operated ALs. While a wide variety of organizational factors likely accounts for variations in private governance, we could only measure size, profit status, and affiliation with one of the top 50 chain operators. This study could not make causal inferences due to the cross-sectional nature of the data collected. Finally, this study did not look at quality or other aspects of access such as affordability or acceptability.[178]

4.5. Conclusion

AL as an intervention for the aging population brings up conflicts of interest between improving the quality of health services for a subset of older adults and narrowing health inequalities or improving the quality of care for all. Although older Americans are racially diverse, AL is provided to a largely privileged population that is more White and more economically advantaged than the older American population as a whole.[336] Older adults who utilize AL have historically been private pay, making AL only accessible for financially privileged older adults. As state and federal efforts to subsidize AL care expand, it is essential to consider how to ensure that increased subsidy and quality of care within these settings do not result in increased health disparities.[101]

While increasing funding for home and community-based services is an essential aspect of expanding access, without locally available options, these new funding streams may just expand access to care for communities that currently have geographic access to care. Based on our results, policymakers may want to consider providing additional support to providers running small ALs, whether or not they have official tax-exempt status. The largest chains are not operating in areas that expand access, so partnering with these entities may not achieve the intended results of increasing access to care. Policymakers may have more success working with smaller operators to expand services in underserved areas if they aim to expand geographic access to care.

Chapter 5 Policymaking Options to Narrow the Black-White Assisted Living Disparity

5.1. Introduction

Assisted living (AL) is a residential setting where older adults can receive assistance with activities of daily living (ADLs) and access a variable range of health services. This care setting plays an essential role in the care of older adults in the US—serving over 800,000 individuals each day.[52] Previous research has established disparities in the availability and use of AL for Black communities compared to White communities.[10,111] In previous work (chapter 3), we correlated these disparities with Black-White gaps in economic mobility—a measure of structural racism. While increasing geographic access to this resource for the care of older adults is essential, there is not currently clear evidence as to how policymakers can address the issue.

Nodal governance theories conceptualize the complexity of governance systems by describing how public policy processes interact with private sources of control and influence.[133] Unlike nursing homes (NHs), the federal government has not constructed AL facilities or regulated AL settings. There has never been a national effort like the Hill-Burton Act to increase geographic access by providing grants and loans for new construction and capital improvements for AL, and states provide regulatory oversight.[341] Where Medicaid funding from the federal government covers care in NHs, AL cannot be reimbursed through this source unless a state offers coverage through a state plan or Medicaid waiver.[161] The broad variation in policies funding and regulating AL as well as the reliance on private investment for both building the infrastructure and funding the operations of this care setting makes a nodal governance lens particularly appropriate for analysis. We used this approach to assess the wide variety of public and private governance factors likely to inform the systematic under-allocation of ALs to Black communities impacted by structural racism.

Investigating causal factors in complex systems is challenging given the variety of factors involved and how such factors may interact with one another, potentially resulting in an otherwise inconsequential variable to significantly affect the outcome. In previous work (chapter 3), we found that the relationship between the ROG and AL availability was undetectable unless the neighborhood racial demographics were considered. This makes sense, as racist policies are likely to have a negative effect on Black neighborhoods but may have a positive effect on White neighborhoods. Similarly, it's possible that a state policy providing Medicaid funds for AL residents only encourages nonprofit AL providers to expand access, not for-profit providers. An additional problem for study design in this analytic space is the high likelihood of multicollinearity. Without documenting the policy process, it is unclear whether the state policies or industry practices came first. Disentangling these forces and holding one variable accountable over another negates a key tenant of nodal governance and complex systems more generally—the interactions between public and private sources of regulation can influence an outcome.

In addition to the high likelihood of interaction effects, complex systems also have a high propensity for equifinality. Equifinality is the concept that more than one solution can produce the same result.[143] Medicaid funds could incentivize AL provider expansion into Black neighborhoods, but government-subsidized loans for for-profit providers could do the same. While a linear approach can assist with identifying the factors that are most strongly associated with an outcome, a comparative approach can identify multiple pathways made of sets of factors that are associated with an outcome. To account for these possibilities, a wide variety of methods and algorithms have been developed using Boolean algebra to analyze datasets when equifinality is present. These methods, called configurational comparative methods, include qualitative comparative analysis[408] and coincidence analysis,[409] which both identify configurations of

Boolean descriptions most likely to cause a specified outcome.[410] These approaches both begin with a commonly used approach—describing all possible combinations of factors associated with a specified outcome. This is referred to as *Boolean description*.[411] While these solutions may not be used to establish causation, they are valuable for descriptive analyses. Due to their reliance on observations of presence versus absence, instead of analysis of variance, this approach to characterizing relationships can accommodate high levels of multicollinearity between factors.

Our team hypothesized that the public and private governance factors that influence AL presence in a community will be different based on community racial demographics and the gap between White and Black populations. The public governance characteristics chosen for inclusion in this model are informed by a review of recommendations put forth by nearly 50 professional industry groups in the 2003 convening of the assisted living workgroup (ALW). In the ALW report, created through a consensus approach, regulatory barriers to market entry and operation were identified, including state certificates of need, rate-setting, mandated services, constraints for admissions, and building codes that add cost to construction and upkeep. These stakeholders supported distributive policies, including the provision of state optional supplemental security income (SSI) payments, market-rate Medicaid funding, fair market US Department of Housing and Urban Development (HUD) vouchers, and state programs.[288] We included many of these factors or proxies for them when possible.

5.2. Methods

Design

This study uses Boolean description to inductively identify patterns of public and private governance factors associated with greater access to AL for census tracts likely to be negatively

impacted by structural racism, given the ROG and racial demographics. We identified the combinations of factors using the coincidence analysis (CNA) algorithm for all census tracts as well as our sub-population of interest, census tracts with the greatest proportion of the Black population in the county.[412] Finally, we used conceptual knowledge of the factors as well as comparisons of the subpopulations to identify meaningful conditions to address our research question.

Data Sample

We used census tracts as our unit of analysis, including the full population of 73,057 US Census tracts from the 2019 American Community Survey, as applied to the geographies defined in 2010. Our outcome measure was calculated using all AL residences licensed by one of the 50 states or Washington DC to provide 24-hour supervision to four or more older adults.

We narrowed our analysis to a subpopulation for the second step of our analytic process, focusing on census tracts likely to be impacted negatively by structural racism. Based on previous work (see chapter 3), we grouped counties into five categories according to their quintiled ROG, reflecting the level of the disparity between Black and White average economic mobility compared to other counties in the US. As such, Group 1 – Lowest ROG included counties with the smallest disparity (more equality) and Group 5 – Highest ROG included counties with the greatest disparity (less equality). Within each county, census tracts were further delineated according to their racial demographics. Dividing up census tracts within the counties with the highest ROG, we identified census tracts likely to be disadvantaged by structural racism by taking the top quintile of census tracts within each county according to the percent of the population that is Black, filtering out any tracts with less than 10% Black. Then, we did the same for the proportion of the White population to identify census tracts most likely to be advantaged

census tracts. We omitted 4,834 tracts (6.7%), which were in counties with populations too small to calculate the ROG. While these tracts were not removed during the pattern recognition stage of analysis, they were not investigated for differential effects as a distinct subpopulation. The groupings are not meant to encompass all Black people or all White people but instead function as a proxy for the geographic areas in a given county most likely to be depressed by structural racism versus those most likely to have property values and access to resources bolstered.

Data Sources

We rely on both novel and existing data sources to create proxies and measures of state regulations, state and federal funding, private governance, sociodemographics, and a measure of structural racism. AL location and licensing information came from a directory constructed in a previous study, which combined state agency directories for licensed ALs for all 50 states and Washington DC.[159] We used the US Department of Agriculture's Economic Research Service provides Rural-Urban Commuting Area Code assignments to determine the rurality of each census tract.[162] We used the American Community Survey 5-year estimates for 2019 to determine Bachelor's degree attainment and the LTCfocus database to identify NH location.[413] The regulation data were collected by some of the study team members in previous work using the Health Services Regulatory Analysis process. This dataset provides the presence or absence of requirements regarding admissions, assessment, and special care requirements for each of the 350 license types in the US.[96] Both private governance and structural racism data were collected and joined to the AL directory data in studies led by study team members. The proxy for structural racism comes from the ROG, a measure created by O'Brien et al. using publicly available data from Opportunity Insight.[32,165,376] The private governance data was collected using business marketing and industry networking data sources.

Additional data sources regarding public funding for the ALs included in this study come from published and publicly available sources. Medicaid waiver or state plan type and programming by state were recorded by the Government Accountability Office and updated using the state filings on the CMS website.[161,414] These were further delineated according to whether the waiver covered care in the AL license type responsible for the majority of total capacity for each county. HUD publicly hosts information regarding all residences funded or financed through the HUD multifamily housing subsidies or Federal Housing Administration (FHA) 232/223(f) fixed-rate mortgage insurance mechanisms.[163] We used ArcGIS to identify ALs co-located with either a HUD subsidy or FHA mortgage. Finally, the National Academy for State Health Policy tracks state certificate of need (CON) programs and records the care setting types covered.[164]

Outcome

ALs in the National Directory of AL Communities licensed by states in 2019 to provide care to 4 or more older adults were geocoded and assigned to a census tract based on street address.[159] AL presence within a census tract was then measured via a binary variable indicating the presence of one or more AL residence in the tract.

Independent Variables

Table 5.1 describes all variables used in the CNA model. The independent variables in this study include a measure of structural racism, sociodemographic variables, and public and private governance factors. The measure of structural racism we use is the ROG. This measure relies upon a linked database to look at the Black-White disparities in economic mobility for people who grew up in the same county at the same income level.[32] We previously associated the interaction between this measure and the racial demographics of the census tract with AL

Table 5.1: Factors and Factor Levels by Category

Categories			Factor	Factor Description	Data Unit	Levels
Census Tract Level Measure						
Outcome			AL Presence	1+ AL present in the census tract	AL	0,1
Structural Racism Descriptors			ROG	Racial Opportunity Gap, Black-White disparity in economic mobility	Population	1,2,3,4,5
			Population Race	Indicator of high proportion of county racialized county pop.	Black, White, Other	
Community Factors			BA Attainment	% of residents with a BA	Population	1,2,3,4,5
			Nursing Home	Presence of a nursing home in the census tract	NH	0,1
			Rural Urban Commuting Area	Urban/rural status of census tract	Metro, Micro, Town, Rural	
County Level Measure						
Public Governance	Market Entrance		CON	Regulated by a Certificate of Need	License	0,1,2
			FHA	Federal Housing Admin. financing	AL	0,1,2
	Medicaid		1915(K)	License covered under a Community First Choice 1915(K) Medicaid plan	License	0,1,2
			Waiver	License covered under a Medicaid waiver	License	0,1,2
			State Plan	License covered by state Medicaid plan	License	0,1,2
	Regulation	Licensing Approach	Dementia License	licensed to provide dementia-specific care	License	0,1,2
			Differ by Residents	Licenses differ by resident characteristics	State	0,1,2
			Differ by Size	Licenses differ by allowed capacity	State	0,1,2
			Physical Plant	Licenses differ by physical plant requirements	State	0,1,2
			Mixed Use	License specifies some resident capacity in building is not AL	License	0,1,2
			Small capacity	Licensed under rules specific to small ALs	License	0,1,2
		Admission Limited by:	Behaviors	Dementia or mental illness associated behaviors	License	0,1,2
			Danger	Whether resident is a 'danger to self or others'	License	0,1,2
			Mental Health	Mental health status	License	0,1,2
		Must Assess at Admission:	Cognitive Status	Cognitive status	License	0,1,2
			Mental Health	Mental health	License	0,1,2
			Mobility	Resident mobility	License	0,1,2
		Medical Care	Skilled Nursing Allowed	May provide skilled nursing	License	0,1,2
			RN Staff Required	Must provide RN supervision a specified # of hours per week	License	0,1,2
Private Governance	Capacity of ALs:		Large	Large capacity (50+ residents)	AL	0,1,2
			Medium	Medium capacity (25-49 residents)	AL	0,1,2
			Small	Small capacity (4-24 residents)	AL	0,1,2
	Operator Type		Large Chain	Operated by top 50 largest chains	AL	0,1,2
			Nonprofit	IRS registered nonprofit	AL	0,1,2

Note: Data Unit reflects the unit of data collection for each variable represented; Levels describe the units used in the CNA analysis.
As described in text, levels 0,1,2 reflect the absence of the factor (0), presence of the factor for less than 75% of ALs in the county (1), or presence of the factor for 75% or more of the ALs in the county. Levels 1,2,3,4,5 reflect quintiles of the variable.

location. Additionally, we include education level, the rural-urban commuting area codes, which were also significantly associated with AL availability.

The private governance factors included are also informed by previous work (chapter 4), where we found that AL presence is associated with the interaction between size and provider type. Thus, we include whether the majority of the capacity in the county is provided by small (4-24 residents), medium (25-49 residents), or large (50 or more residents) as well as whether the AL residences are operated by a nonprofit or one of the top-50 largest chains, as defined by Argentum, a senior housing trade association, for 2019.

The public governance factors include the federal financing and state regulations describing admission and retention limits as well as variation in license types. These factors are summarized at the county level. FHA financing and HUD subsidies were linked to properties based on location and business name. Then, we created a variable representing the proportion of the AL capacity in the county with financial backing or grants. We similarly captured state regulations at the county level, which was necessary due to the within-state variation in AL regulation. States use up to 30 different approaches to holding AL residences to different rules based on license and certification types.[96] Using the state licensing directories, the AL regulations database we relied on specifies whether a specific provision was present or absent for each AL based on the licenses and certifications in place.[96] The presence of each provision was summarized at the county level by calculating the proportion of the capacity in the county provided by AL residences that were held to the rule.

For all public and private governance factors, we indicated whether the factor was not present (0), present for less than 75% of the AL capacity in the county (1), or present for 75% or

more of AL capacity in the county (2). Linear quintiles of the ROG were represented with levels 1, the lowest gap between Black and White average economic mobility, and 5 reflecting the highest gap in mobility. The percent of the residents in the tract that obtained a Bachelor's degree was similarly coded. Finally, the rurality of the tract was represented in four levels corresponding to the four primary rural-urban commuting area categories.

Analytic Approach

Our analytic approach consisted of four steps:

1. Algorithm-based pattern recognition for the full dataset

Once data for all factors was assembled and converted into multilevel data as described above, we employed the coincidence analysis algorithm to identify sets of minimally sufficient conditions associated with AL presence. Minimally sufficient conditions is a concept akin to prime factors—it is the least complex combination of factors associated with an outcome.[415] Thus, if the Medicaid waiver factor at a level 1 (some ALs are eligible for Medicaid according to their license, but they provide less than 75% of the capacity in the county) were associated with higher levels of access, the minimally sufficient condition would simply be Medicaid waiver = 1. This would be true whether or not large chain ALs were present in the county. We used the binary variable representing AL presence as our outcome and conducted the analysis using the 'cna' package in the R statistical environment.[379,412]

We ran the algorithm at a complexity of four, meaning we tested for combinations of up to four factors. In an analysis using CNA, two fit parameters are optimized, consistency and coverage. Consistency is the percent of census tracts with a positive outcome among all those meeting the criteria of the condition (pattern of factor levels) or combined set of conditions. Coverage is the percent of the full dataset meeting the criteria of the condition or set of

conditions.[412] In CNA analyses in implementation science, the minimum consistency and coverage are regularly set to 75% or higher, and sets of conditions are selected based on the best fit of both measures. However, in these cases, the probability of a positive outcome is 50% or higher. In this case, we specified minimum consistency at 45%, which we determined by multiplying the proportion of census tracts with AL presence (30%) by 1.5, reflecting the minimum level of AL presence a condition should return. A minimum sufficiency table produces all combinations at a set consistency for all levels of coverage. However, we considered only the conditions with at least a 0.14% coverage level, reflecting at least 100 census tracts, a significant subsample.

While this study used the CNA algorithm, it did not follow the full CNA method. A full CNA analysis would take the conditions identified by the minimal sufficiency table and identify the combination of these conditions that best accounts for the variation in the full dataset, ideally accounting for all cases. Much like determining the shape of the puzzle pieces by fitting them together, CNA identifies combinations that fit together as a solution, then further identifies which of these cases best account for all cases in the sample. By creating a solution that covers all variance in the dataset, CNA can theoretically identify causal relationships. We did not conduct a full CNA analysis as this dataset does not meet the criteria for making such a claim.

One of the assumptions necessary for the final step of a CNA analysis is that the various cases impact one another's solutions.[416] In this case, we have data corresponding to the census tract, county, and state levels. The CNA method does not currently have an approach that accommodates multilevel models. However, the multiple levels of data do have important implications for the validity of using the method for causal inference. While it's possible to present all data at the census tract level, previous multilevel models of the AL data have shown

that the way that these census tract puzzle pieces fit together are in fact, highly influenced by county and state groups. Additionally, by using some variables such as the state approach to Medicaid funding for ALs that are consistent throughout the state and unavailable as an option for the majority of tracts, we further ensure state-level grouping in the data that would invalidate a causal claim. Without a need to identify the set of conditions that best account for the full variance in the dataset, we found that focusing on the conditions themselves, instead of the disjunctive combinations of conditions, had greater utility for thematic interpretation and policy recommendations.

2. Algorithm-based pattern recognition for the sub-population of interest

Based on our research question, we used a second CNA model focused solely on the subpopulation to identify patterns of conditions specific to AL presence for tracts most likely to experience a depressed level of AL presence due to structural racism based on the criteria described above. For this subpopulation, we similarly tested for combinations of up to four factors but set the consistency to 24%, using the same calculation of 1.5 times the mean (16%). We considered conditions with at least 3.8% coverage to similarly meet the 100 tract sample criteria used in the first step. We conducted the subpopulation analysis to identify any combinations that had too low of a consistency level to be captured in the analysis of the full dataset, but a high consistency among this subset. Additionally, we aimed to identify those patterns that specifically benefit our subpopulation of interest.

3. Identify shared and unique conditions across the two models

First, we looked for conditions that included both an Q5 ROG and Q5 percent Black residents census tracts as factors. Then, we re-ran the full dataset analysis without the ROG and racial demographics included to allow for comparison between the results of the full dataset and

the results of the sub-population. We looked for co-occurring conditions in the analyses of the full and subpopulations as well as those that were unique to each.

4. Group and interpret results that benefit target subpopulations

Using this combined set of conditions, we relied upon both content knowledge, co-occurrence between analyses, and the consistency and coverage levels in the analysis of the subpopulation narrow the conditions to those less likely to reflect noise in the data. We grouped the resulting patterns thematically, following standard comparative analytic approaches which emphasize relying on content knowledge as well as factor co-occurrence to identify difference-makers and qualitatively describe the various routes to the same outcome described by the patterns.[417] Once themes across groups were identified, we further delineated conditions according to whether the full population, subpopulation, or both models identified the combination of factors.

5.3. Results

Across all 13,128 Q5 % Black residents census tracts, 28.11% had an AL present within the tract, compared to 29.70% of all tracts (N=72,131). When broken out by ROG, these prevalence rates more clearly diverge. Only 16.02% of the 2,584 Q5 % Black residents census tracts in counties with the highest ROG have an AL present, while 32.75% of Q5 % Black residents census tracts in counties with the lowest ROG have one or more ALs. The types of ALs located in these tracts similarly varied widely. Using the geolocation approach described above, we identified 1,594 ALs located in 655 counties that were financed by the FHA between fiscal years 2001 and 2020. Table 5.2 describes the prevalence of all public and private governance factors and their association with AL presence at the census tract level.

In the first step of our analytic process, we analyzed all census tracts (n=72,131) and identified 6,465 conditions (patterns of factor levels). Of these, 2,058 included the ROG, 241 included an ROG of 5 (highest inequality), 1,004 included the racial demographics variable, and 502 conditions included the percent Black residents census tract quintile variable. None of the conditions identified at a coverage rate of 0.14% or higher (reflecting at least 100 census tracts, a significant subsample) included the highest level of ROG (Q5) and the indicator for Q5 % Black residents census tracts. When run without the ROG and race variables, to allow for comparison to the sub-group analysis, we found 3,394 conditions associated with a 45% or greater AL access. These conditions included between one and four factors, and had a consistency range of 45% to 71% and a coverage ranging from 0.14% to 44%. For the second step of our process, we ran the algorithm on only the Q5 percent Black residents census tracts in counties with the highest ROG (n=2,584). For this group, we identified 281 conditions with between one and four factors, consistency between 24% and 76%, and coverage between 4.8% and 83.8%. Of this set, 13 conditions were also in the results of the first step. We reviewed these 13 as well as an additional 37 tracts in the subpopulation results that had high consistency, coverage, or were examples of contrasting patterns to those identified in conditions initially reviewed. Within these 50 conditions, we identified patterns of co-occurrence as well as five themes of conditions from these overlapping sets of conditions, a sample of these are presented in Table 5.3.

Factor Co-occurrence

In the sub-population results, 33 conditions (12%) referred only to the absence of factors, such as the absence of regulations limiting admission based on mental health or the combined absence of medium capacity ALs, absence of state plan Medicaid, and absence of licensing that

Table 5.2: Descriptive Statistics for Factors Across Models

	Primary Analysis			Secondary Analysis		
Factor	No AL (N=50707)	AL Present (N=21424)	p value	No AL (N=2170)	AL Present (N=414)	p value
ROG			< 0.001[1]			
Lowest	9374 (19.7%)	4033 (20.4%)		-	-	
Low	9118 (19.2%)	4316 (21.8%)		-	-	
Mid	8816 (18.5%)	4669 (23.6%)		-	-	
High	9584 (20.2%)	3933 (19.9%)		-	-	
Highest	10650 (22.4%)	2804 (14.2%)		2170 (100.0%)	414 (100.0%)	
Population Race Category			< 0.001[1]			
Black	9358 (18.5%)	3770 (17.6%)		2170 (100.0%)	414 (100.0%)	
White	9590 (18.9%)	3483 (16.3%)		-	-	
Other	31759 (62.6%)	14171 (66.1%)		-	-	
BA Attainment			< 0.001[1]			< 0.001[1]
Lowest	11680 (23.0%)	2717 (12.7%)		661 (30.5%)	77 (18.6%)	
Low	10267 (20.2%)	4187 (19.5%)		537 (24.7%)	101 (24.4%)	
Mid	9648 (19.0%)	4794 (22.4%)		488 (22.5%)	104 (25.1%)	
High	9327 (18.4%)	5103 (23.8%)		316 (14.6%)	70 (16.9%)	
Highest	9785 (19.3%)	4623 (21.6%)		168 (7.7%)	62 (15.0%)	
Nursing Home Presence			< 0.001[1]			< 0.001[1]
Absent	44954 (88.7%)	15039 (70.2%)		1981 (91.3%)	297 (71.7%)	
Present	5753 (11.3%)	6385 (29.8%)		189 (8.7%)	117 (28.3%)	
Rural Urban Commuting Area			< 0.001[1]			< 0.001[1]
Metropolitan	41797 (82.9%)	17269 (80.9%)		2073 (95.6%)	363 (87.9%)	
Micropolitan	4563 (9.0%)	2020 (9.5%)		59 (2.7%)	29 (7.0%)	
Small Town	2106 (4.2%)	1200 (5.6%)		33 (1.5%)	15 (3.6%)	
Rural	1974 (3.9%)	859 (4.0%)		4 (0.2%)	6 (1.5%)	
Certificate of Need			< 0.001[1]			< 0.001[1]
Most	7373 (14.5%)	1238 (5.8%)		834 (38.4%)	48 (11.6%)	
Some	192 (0.4%)	10 (0.0%)		33 (1.5%)	0 (0.0%)	
None	43142 (85.1%)	20176 (94.2%)		1303 (60.0%)	366 (88.4%)	
FHA Financing			< 0.001[1]			< 0.005[1]
Most	334 (0.7%)	79 (0.4%)		9 (0.4%)	1 (0.2%)	
Some	28442 (56.1%)	11613 (54.2%)		1681 (77.5%)	291 (70.3%)	
None	21931 (43.3%)	9732 (45.4%)		480 (22.1%)	122 (29.5%)	
Medicaid:1915(K)			< 0.001[1]			
Most	5588 (11.0%)	2928 (13.7%)		62 (2.9%)	16 (3.9%)	
Some	13 (0.0%)	3 (0.0%)		0 (0.0%)	0 (0.0%)	
None	45106 (89.0%)	18493 (86.3%)		2108 (97.1%)	398 (96.1%)	
Medicaid: Waiver			< 0.001[1]			< 0.001[1]
Most	35597 (70.2%)	18109 (84.5%)		1349 (62.2%)	379 (91.5%)	
Some	4345 (8.6%)	903 (4.2%)		458 (21.1%)	20 (4.8%)	
None	10765 (21.2%)	2412 (11.3%)		363 (16.7%)	15 (3.6%)	
Medicaid: State Plan			< 0.001[1]			< 0.001[1]
Most	11933 (23.5%)	7542 (35.2%)		556 (25.6%)	169 (40.8%)	
Some	4319 (8.5%)	734 (3.4%)		606 (27.9%)	36 (8.7%)	
None	34455 (67.9%)	13148 (61.4%)		1008 (46.5%)	209 (50.5%)	

Table 5.2: Descriptive Statistics for Factors Across Models Continued

	Primary Analysis			Secondary Analysis		
Factor	No AL (N=50707)	AL Present (N=21424)	p value	No AL (N=2170)	AL Present (N=414)	p value
License: Dementia Specific			< 0.001[1]			< 0.001[1]
Most	1928 (3.8%)	1192 (5.6%)		66 (3.0%)	43 (10.4%)	
Some	23648 (46.6%)	9472 (44.2%)		1151 (53.0%)	157 (37.9%)	
None	25131 (49.6%)	10760 (50.2%)		953 (43.9%)	214 (51.7%)	
License: Differ by Resident Type						
Most	5406 (10.7%)	4061 (19.0%)		227 (10.5%)	103 (24.9%)	
None	45301 (89.3%)	17363 (81.0%)		1943 (89.5%)	311 (75.1%)	
License: Differ by Size			< 0.001[1]			
Most	13199 (26.0%)	8013 (37.4%)		140 (6.5%)	48 (11.6%)	
Some	54 (0.1%)	23 (0.1%)		0 (0.0%)	0 (0.0%)	
None	37454 (73.9%)	13388 (62.5%)		2030 (93.5%)	366 (88.4%)	
License: Differ by Physical Plant						
Most	2879 (5.7%)	738 (3.4%)		193 (8.9%)	12 (2.9%)	
None	47828 (94.3%)	20686 (96.6%)		1977 (91.1%)	402 (97.1%)	
License: Mixed Use Facility			< 0.001[1]			
Most	20 (0.0%)	4 (0.0%)		0 (0.0%)	0 (0.0%)	
Some	4935 (9.7%)	3002 (14.0%)		471 (21.7%)	137 (33.1%)	
None	45752 (90.2%)	18418 (86.0%)		1699 (78.3%)	277 (66.9%)	
License: Small Capacity Only			< 0.001[1]			
Most	33 (0.1%)	16 (0.1%)		0 (0.0%)	0 (0.0%)	
Some	1591 (3.1%)	1413 (6.6%)		4 (0.2%)	1 (0.2%)	
None	49083 (96.8%)	19995 (93.3%)		2166 (99.8%)	413 (99.8%)	
Limit Admissions: Behaviors			< 0.001[1]			< 0.001[1]
Most	18001 (35.5%)	6277 (29.3%)		1686 (77.7%)	236 (57.0%)	
Some	2545 (5.0%)	1165 (5.4%)		39 (1.8%)	3 (0.7%)	
None	30161 (59.5%)	13982 (65.3%)		445 (20.5%)	175 (42.3%)	
Limit Admissions: Danger			< 0.001[1]			< 0.001[1]
Most	38370 (75.7%)	14474 (67.6%)		1885 (86.9%)	286 (69.1%)	
Some	4777 (9.4%)	3884 (18.1%)		39 (1.8%)	33 (8.0%)	
None	7560 (14.9%)	3066 (14.3%)		246 (11.3%)	95 (22.9%)	
Limit Admissions: Mental Health			< 0.001[1]			< 0.001[1]
Most	20309 (40.1%)	9096 (42.5%)		1530 (70.5%)	232 (56.0%)	
Some	2822 (5.6%)	1288 (6.0%)		40 (1.8%)	8 (1.9%)	
None	27576 (54.4%)	11040 (51.5%)		600 (27.6%)	174 (42.0%)	
Assess: Cognitive Status			< 0.001[1]			0.724[1]
Most	20945 (41.3%)	7610 (35.5%)		659 (30.4%)	132 (31.9%)	
Some	4900 (9.7%)	2610 (12.2%)		277 (12.8%)	48 (11.6%)	
None	24862 (49.0%)	11204 (52.3%)		1234 (56.9%)	234 (56.5%)	
Assess: Mental Health			< 0.001[1]			< 0.001[1]
Most	27723 (54.7%)	1098 (51.3%)		1515 (69.8%)	246 (59.4%)	
Some	3843 (7.6%)	2622 (12.2%)		31 (1.4%)	13 (3.1%)	
None	19141 (37.7%)	7815 (36.5%)		624 (28.8%)	155 (37.4%)	
Assess: Mobility			< 0.001[1]			< 0.001[1]
Most	18377 (36.2%)	8892 (41.5%)		791 (36.5%)	240 (58.0%)	
Some	2543 (5.0%)	1375 (6.4%)		61 (2.8%)	3 (0.7%)	
None	29787 (58.7%)	11157 (52.1%)		1318 (60.7%)	171 (41.3%)	

Table 5.2: Descriptive Statistics for Factors Across Models Continued

	Primary Analysis			Secondary Analysis		
Factor	No AL (N=50707)	AL Present (N=21424)	p value	No AL (N=2170)	AL Present (N=414)	p value
Medical Services: Allow Skilled Nursing			< 0.001[1]			< 0.001^2^
Most	38710 (76.3%)	16941 (79.1%)		966 (44.5%)	237 (57.2%)	
Some	1583 (3.1%)	366 (1.7%)		126 (5.8%)	8 (1.9%)	
None	10414 (20.5%)	4117 (19.2%)		1078 (49.7%)	169 (40.8%)	
Medical Services: Require RN Staff			< 0.001[1]			
Most	468 (0.9%)	126 (0.6%)		0 (0.0%)	0 (0.0%)	
Some	6743 (13.3%)	1341 (6.3%)		789 (36.4%)	72 (17.4%)	
None	43496 (85.8%)	19957 (93.2%)		1381 (63.6%)	342 (82.6%)	
Large Capacity ALs			< 0.001[1]			< 0.001[1]
Most	30226 (59.6%)	8791 (41.0%)		1974 (91.0%)	302 (72.9%)	
Some	14968 (29.5%)	10768 (50.3%)		152 (7.0%)	96 (23.2%)	
None	5513 (10.9%)	1865 (8.7%)		44 (2.0%)	16 (3.9%)	
Medium Capacity ALs			< 0.001[1]			< 0.001[1]
Most	1254 (2.5%)	430 (2.0%)		9 (0.4%)	7 (1.7%)	
Some	29903 (59.0%)	12465 (58.2%)		1289 (59.4%)	208 (50.2%)	
None	19550 (38.6%)	8529 (39.8%)		872 (40.2%)	199 (48.1%)	
Small Capacity ALs			< 0.001[1]			< 0.001[1]
Most	1424 (2.8%)	1241 (5.8%)		7 (0.3%)	10 (2.4%)	
Some	25801 (50.9%)	15792 (73.7%)		836 (38.5%)	315 (76.1%)	
None	23482 (46.3%)	4391 (20.5%)		1327 (61.2%)	89 (21.5%)	
Operator: Top 50 Largest Chains			< 0.001[1]			< 0.001[1]
Most	539 (1.1%)	113 (0.5l)		5 (0.2%)	1 (0.2%)	
Some	38774 (76.5%)	16536 (77.2%)		2013 (92.8%)	342 (82.6%)	
None	11394 (22.5%)	4775 (22.3%)		152 (7.0%)	71 (17.1%)	
Operator: Nonprofit			< 0.001[1]			0.030[1]
Most	567 (1.1%)	171 (0.8%)		33 (1.5%)	1 (0.2%)	
Some	29000 (57.2%)	11602 (54.2%)		1840 (84.8%)	343 (82.9%)	
None	21140 (41.7%)	9651 (45.0%)		297 (13.7%)	70 (16.9%)	
1 - Comparison of categories conducted using ANOVA						

differentiates licenses according to building specifications. In the full analysis, among the 3,394 conditions, none of them referred solely to the absence of factors.

For the sub-population, conditions that include no limitations to admission or no requirement for assessment are associated with either Medicaid funding, FHA financing, low regulation, or dementia licensing. This trend is not true of the full population. The highest consistency for our subpopulation occurred in counties where all licensed ALs are eligible for the state plan and there are no limits to admission based on mental health status, or a mental health

assessment is not required, or skilled nursing provision is allowed. However, all of these have a coverage of less than 10%. A dementia license covering some ALs in the county in combination with no cognitive assessment appears in multiple conditions with over 50% consistency for the subpopulation.

Certificate of Need

Our results included 47 conditions in the subpopulation and 357 in the full population with certificate of need (CON) as a factor. All conditions applicable to the subpopulation specified the absence of a CON, where for the full population, 97 conditions (27%) specified the presence of a certificate of need covering all ALs. For the subpopulation, the highest coverage was for the combination of high waiver availability without certificate of need, covering 84% of census tracts at a consistency of 27%. The highest consistency of those with the CON factor was also the one condition involving CON shared between datasets. The presence of a dementia license for less than 75% of ALs in the county combined with the absence of a CON and the absence of a cognitive status assessment requirement was associated with a consistency of 51% and coverage of 7% for the subpopulation and a consistency of 45% and coverage of 18% among the full population.

Licensed Capacity

We identified 89 conditions (32%) in the subpopulation and 1,388 (41%) for the full population that included the presence of a factor indicating capacity. Of these, one was common to both models. The common conditions specified the census tract bachelor's degree attainment rate to be in the fourth highest quintile, less than 75% of capacity provided by medium ALs, more than 75% of AL capacity eligible for Medicaid waiver funding, and a requirement for

Table 5.3: Condition Patterns Associated with Assisted Living Presence for Q5 ROG/Q5 % Black Residents Census Tracts

Consistency	Coverage	Public Governance																Private Governance			
		Market Entry	Medicaid		Regulation													Capacity		Operator Type	
					Licensing				Must Limit Admissions by:			Must Assess:			Medical Care:						
		CON	State Plan	Waiver	Mixed Use	Facility	Size	Dementia -Specific	Behavior	Danger	Mental Health	Mental Health	Cognitive Status	Mobility	RN Staff Required	Nursing Allowed		Large	Small	Non-profit	Top-50 Chain Operator
76%	6%		●								○										
73%	5%		●									○									
67%	6%		●													●					
59%	7%		●																	○	
53%	8%										●	●				●					
53%	7%		○								●	●									
52%	8%										●	●	●								
51%	7%	○						◒					○								
51%	7%							◒					○			●					
51%	7%							◒					○		○						
46%	8%									◒											
39%	10%							●													
39%	23%																	◒			
32%	17%																				○
31%	8%							○			●										
29%	7%		●																		
27%	76%																		◒		
27%	84%	○		●																	
27%	52%			●												●					
26%	12%						●														
25%	78%						●								○						
24%	7%			●					●				○								
24%	54%						○							●							
24%	56%			●	○	○															
24%	54%			●										●							

Note: Each row refers to one condition pattern identified with the CNA algorithm. A filled in circle refers to a condition in which the presence of the factor is necessary, where an empty circle refers to a condition where the absence is necessary. Circles that are partially filled refer to conditions identifying the factor level as "1", meaning 1-74% of ALs in the county meet this criteria, where fully filled circles refer to conditions with a factor level of "2", meaning 75-100% of ALs in the county meet this criteria.
Consistency = Among census tracts meeting the criteria of the condition, the percent with AL presence. Compare to total percent of AL presence in Q5 ROG/Q5 % Black residents census tracts at 16%.
Coverage = Among all Q5 ROG/Q5 % Black residents census tracts, the percent that meet the criteria of the condition.

limiting admission based on mental health status across all ALs. For the subpopulation this condition had a consistency of 26% and coverage of 6% versus 46% and 5% overall.

Unique to the subpopulation were three low complexity conditions, small ALs accounting for less than 75% of the capacity in the county (consistency 27%, coverage 76%), large ALs accounting for less than 75% of capacity in the county (consistency 39%, coverage 23%), and regulations that differentiate license types according to licensed capacity (consistency 26%, coverage 12%). For the full population, two low complexity conditions specific to size were also found. First, the presence of small ALs accounting for more than 75% of the capacity in the county (consistency 47%, coverage 6%), then the presence of ALs in the county licensed under a small AL specific license (consistency 47%, coverage 7%).

Medicaid Funding

Of the 50 states and Washington DC, 43 had 1915(c) or 1115 waivers that allowed for reimbursement of AL services in one or more type of AL license, 11 states could use state plan funding through the 1905a or 1915(i) options, and 4 through a community first choice 1915(K) plan. We identified 119 conditions associated with one of these options in the subpopulation and 1,152 in the full population, with five conditions found in both. Unique to the full population were solutions referencing the 1915(K) plan. The 33 solutions that included the presence of a 1915(K) had consistencies between 45% and 62% and coverage rates of between 0.2% and 6%. Across these conditions, the 1915(K) was combined with other factors including rurality and no medium ALs, some large chain ALs and no medium ALs, FHA funding and no medium ALs, and the presence of cognitive status assessment requirements.

In the subpopulation, most solutions specified the presence of a state plan or waiver in combination with other factors including the absence of nonprofit ALs, the absence of mental

health assessment, and the absence of medium ALs in addition to the presence of FHA financing. The absence of a state plan was also a part of 32 conditions for the subpopulation and 160 conditions for the full population. In the subpopulation these included a condition with high coverage, the presence of a waiver and absence of a state plan (consistency 24%, coverage 47%), as well as one with high consistency, the absence of a state plan with the presence of mental health limitations and assessment at admission (consistency 53%, coverage 7%).

Dementia License

For the subpopulation, 20 conditions included the presence of a dementia license as a factor and 101 included the absence of a dementia license. Among the full population 386 included the presence of a dementia license and 203 included the absence. Four co-occurring conditions included a dementia license, three a dementia license accounting for less than 75% of the capacity in the county in combination with the absence of cognitive status assessment requirements and another factor. Specific to the subpopulation was a low complexity condition, dementia licensed ALs accounting for over 75% of the capacity in the county (consistency 39%, coverage 10%).

5.4. Discussion

In this study, we used a comparative analytic approach to identifying combinations of public and private governance factors associated with greater geographic access to AL, particularly for those areas most likely to have less access due to structural racism. We found that higher levels of AL availability occurred where either factors associated with higher costs were absent or when they were present in combination with a factor associated with increased revenue. Additionally, small and large ALs and the absence of CON policies were consistently associated with greater access. These findings are congruent with previous research that has

called for an end to CON in HCBS,[418] as well as findings that a greater proportion of residents in both small and large ALs are non-White.[63]

Factors identified that may influence cost and were either absent or present in combination with a factor associated with revenue include: skilled nursing services allowed without limitations to admissions, not limiting admission based on cognitive, mental health, or mobility status, higher staffing requirements, and medium size. Factors that may influence revenue that occurred with cost-factors include: opportunities to charge higher rates via a memory care license, absence of limitations to allowed services, state reimbursement for care via Medicaid state plan, waiver, or 1915(K) plan, and access to affordable financing.

The policies and practices that led to the disparities of access may be those investigated here, such as Medicaid funding strategies, but may also be policies such as redlining and the denial of home loans to Black home buyers, which led to the devaluation of real estate properties in Black neighborhoods. While it was not our intent to identify strategies for combating structural racism itself, by addressing the harms these forces have done to the health services infrastructure at the community level, we aim to identify possible strategies for policymakers interested in taking steps towards equitable access to care.

Based on the nodal governance framework, we theorized that public and private governance interactions create and maintain the current disparities in AL care availability. For the subpopulation we identified most likely to have the AL market depressed by structurally racist policies and practices, we did not find clear evidence of these interactions. We found that the absence of ALs operated by one of the top fifty largest chain providers on its own is associated with greater AL availability within Q5 percent Black residents census tracts in high ROG counties, a relationship that is reversed by the presence of medium capacity ALs and

census tracts with relatively low Bachelor's degree attainment. While this difference in the effect of chain operated ALs introduces many additional questions regarding what these additional factors change, these are not public governance factors. We did identify instances in the full population model where the private governance factors (size and chain operation) appear to alter the directionality of a policy effect. For instance, the combination of no chain operators and dementia licensed AL appears to be associated with greater access where neither on its own is.

Certificate of Need

CON programs were first implemented under a federal requirement passed in 1974 which aimed to control Medicaid costs by limiting capital projects for hospitals and skilled nursing facilities. While inclusion of AL residences was never required, and the requirement for CON programs was ended in 1986, many states continued to use certificate of need programs to limit Medicaid expenditures. In 2004, Harrington et al. published findings that 9 states had CON programs for residential care, and 7 for assisted living. At that time, they pointed out the conflict between AL access and these policies. They also acknowledged the financial incentives for states to keep these programs in place as long as they have state plans that cover AL care.[418]

We found that five states had CON applicable to one or more types of licensed AL as of 2019: Arkansas, Indiana, Missouri, New Jersey, and New York. In line with previous findings, we identified the absence of CON policies as associated with the presence of AL in a greater proportion of census tracts for Q5 percent Black residents census tracts in high ROG counties. Similar findings regarding CON policies and disparities of access as well as quality have recently been published regarding home health and radiation oncology facilities.[419,420] This raises continued concerns regarding those states that apply these policies to AL. It's possible that restrictions on the entrance into the AL market exacerbates disparities in access.

Dementia License

Cornell et al. found that the disparity for ALs in counties that are more Black is even more exaggerated when looking solely at dementia-licensed AL even though Black older adults are twice as likely to develop dementia compared to White older adults.[10] This finding is echoed here. In the subpopulation, the presence of dementia licensed ALs that account for 75% or more of capacity is associated with a 38% consistency and 12% coverage. It seems likely that expanding access to dementia-specific care in these communities is a key aspect of providing access to AL that meets the needs of the population. Dementia-licensed AL are not simply a regulatory formality, these ALs are held to higher standards of care, and have been associated with fewer hospitalizations and long-term NH stay admissions. The dearth of dementia-licensed AL residences in Black geographies is an issue worthy of investigation in its own right. Future research should explore policy mechanisms specific to expanding dementia-specific care. One possible explanation is a shift towards tiers of quality in AL, a phenomenon previously documented in NH care.[421]

Capacity

In previous work (chapter 4), we associated small-capacity ALs not associated with a large chain with greater geographic access. Our findings here mirror those findings. Small capacity ALs are associated with greater access to AL, particularly for our subpopulation of interest, Q5 percent Black residents census tracts in high ROG counties. This follows previous work which found that there were greater proportions of Black residents in both small and large capacity ALs, but that medium capacity ALs had a greater proportion of White residents. This finding does raise issues for both quality and regulation. It is not currently clear how size impacts quality in AL, however there are differences in what services can be provided and the

qualifications of staff likely to work in smaller settings.[422] Additionally, the disburse nature of smaller ALs may pose challenges or increase the costs of regular regulatory surveillance.[423] Further research is necessary to better understand the trade-offs for relying on small capacity ALs to expand access to AL, however given current evidence it appears to be a promising route to explore.

In addition to an association between the presence of small ALs in the county and expanded access, we also identified an association between AL access and the presence of ALs licensed under a small capacity-specific license. This association was not only true for counties with ALs licensed under a small-capacity license type, but also for the state-level presence of a policy that differentiates AL license types based on size. This finding is congruent with recent work detailing the challenges faced by small AL providers in implementing and upholding standards imposed by federal regulations for Medicaid reimbursement in Oregon,[424] as well as previous work detailing the differential needs and regulatory risks associated with care provision in small settings.[423]

Medicaid

Under the Medicare and Medicaid Act of 1965, which amended the Social Security Act, states must cover NH care under Medicaid. Additionally, some home health benefits are covered by Medicare and others are optional for states to implement in their Medicaid state plan. States are not required to cover the costs of assistance with ADLs or LTSS provided at home or in the community.[201] Prior to the introduction of home and community-based services (HCBS) waivers in 1981 the federal government provided no matching funds for any services funded by states.[253]

Personal care services are an optional component of Medicaid that may be offered through Medicaid state plans without a waiver, funded by both state Medicaid and federal

matching funds. These services are provided to people with disabilities who need assistance with ADLs and instrumental activities of daily living (IADLs).[254] Personal care services may also be administered through 1915(i) component of the state plan, however 1915(i) allows states to offer services only to a specific population subgroup.[215] For both state plans and waivers, all solutions where these mechanisms expanded access among the tracts in the subpopulation included waivers or state plans that covered 75% or more of licensed capacity in the county. In many states, the Medicaid plan or waiver does not cover all license types. This raises the issue of either expanding access to Medicaid funding to other license types, or finding additional ways to supplement the cost of care in settings where care may not be considered 'medical.'

The Affordable Care Act (ACA) created a new option for the state plan not previously available, the Community First Choice (CFC) or 1915(K). These plans provide states with quite different options from their predecessors.[215] They require states to provide HCBS to individuals at or below 150% of the poverty level who would otherwise functionally qualify for care under the existing state plan for LTSS.[263] This means that the functional need requirements are necessarily higher than the (i), as individuals must be unable to manage their ADLs without access to nursing care. States are required to provide funded services, including AL care, to anyone who qualifies both functionally and financially.[215] This option for states is unique in that it mandates that all care paid for via CFC is self-directed in nature and inclusive of families in decision making. It is also accompanied by a mandate for the funding of staff training and development.[87]The 1915(K) removes the state option to waive "state-wideness" while increasing state fiscal autonomy.[264] We found that both Medicaid waivers that cover all AL residences in a county and state plans implemented under the Community First Choice 1915(K) are associated with increases in access for the full dataset, but did not occur in the subpopulation. Since only

four states had adopted this option for assisted living as of 2019, our sample for reflecting on this approach is limited.

Limitations

Factors likely to influence location that we were unable to take into consideration include construction and zoning regulations as well as land development costs. These factors are likely of particular influence in urban areas and are important to consider in measures of access that investigate the AL capacity available. Our focus on presence within a census tract was appropriate for answering our research question, which focused on AL location. But this does limit the extent to which our findings are aligned with realized disparities in access to AL. We did not look at resident demographic data. While the geographic component of availability is important, AL capacity as well as the additional dimensions of access – approachability, acceptability, affordability, appropriateness, and awareness – should be investigated in future research. All data sources for this study are cross-sectional, so some noise in the data may be a result of relying on data from different years. Finally, comparative analytic approaches can identify factors associated with an outcome but cannot be used to reject potential causes.[410]

5.5. Conclusion

Nearly two decades ago, Mor et al. provided clear evidence that NH care had been "driven to tiers," wherein higher-quality NHs served higher-income and White residents, whereas lower-quality NHs served lower-income and Black residents. In the interim, the AL industry has grown exponentially. In 2007, Smith et al. suggested that while access to NHs had increased for Black older adults, the shift of private pay residents to AL settings posed a growing problem in the tiered quality of long-term care. In 2018, Fabius and Thomas first identified Black-White disparities in the percent of dual eligibles served by AL, as well as disparities in the

relative presence of Black older adults in the AL setting and their medical acuity. Two years later, Jenkins-Morales and Robert found that after adjusting for age, housing tenure, annual income, Medicaid eligibility, ADL and IADL limitations, physical capacity, self-rated health, and dementia status, disparities in Black-White moves to NHs disappeared, whereas these factors failed to account for the disparity in moves to assisted living. Furthermore, Cornell et al. found that AL residences, particularly those with a dementia-specific license, are less likely to be located in counties with larger Black populations.

This work builds upon the existing evidence and provides potential avenues for both future research and policy intervention. First, it seems likely that the same tiers that came into existence in NH quality are similarly occurring within the AL sector. This raises real concerns regarding how states use various levels and types of licensure to regulate AL. Expanding access to only the less-regulated, lower-quality AL settings that may not have sufficient access to health services to accommodate aging in place may produce less disparate statistics regarding AL access for Black and White older adults, but by grouping these care settings together, we lose the true story—that Black communities still have less access to quality long-term services and supports that provide access to necessary health services.

CNA can be a powerful tool, however, in previous analyses subpopulations have not been broken out from the full population analysis. This analysis both demonstrates an approach to using CNA for studying health disparities and highlights how different the results may be for specific sub-populations. This raises the issue of being purposeful and using clear theoretical reasoning for choosing the population included in the analysis.

Our findings strongly suggest that states should either stop applying CON policies to AL care settings or only do so in combination with financial investment in constructing AL

residences in Black communities. Additionally, states may consider covering AL care through state plan mechanisms, including the CFC funding, which is consistently associated with greater access to AL. While the association between the state plan options and AL presence is more consistent, states that utilize HCBS waivers may want to consider covering all license types of AL services with the waiver or supplementing the cost of care through other means.

Chapter 6 Conclusion

6.1. Study Purpose and Findings

This dissertation study investigated the relationship between structural racism, assisted living (AL) location, and public and private governance. Previous work has demonstrated that counties with relatively larger Black populations have significantly less access to AL.[10] Private investment has driven the development of ALs in the US, possibly leaving them more vulnerable to historic redlining and land covenants than nursing homes, which were constructed under federal subsidy programming.[198] Based on this history, the 'racism as a root cause' framework and theories of structural racism inform the study conceptual model,[135,144,314] wherein structural racism causes disparities in access to AL, but public and private governance factors moderate this effect. This study focusses on factors impacting the potential geographic access to AL, the proximal location of health services resources has been established as one important component of expanding access.[425] The empirical relationships put forth by this model were assessed using an observational, cross-sectional approach, relying on linear and comparative analytic methods.

Aim 1 used a random-effects linear probability model to estimate the relationship between AL location and the racial opportunity gap (ROG; measure of structural racism),[32] adjusting for known factors associated with AL presence in a county.[10] I found that the effect of exposure to a high ROG is dependent on the racial demographics of the population. Racist policies have been found to harm Black communities while advantaging White communities.[134] Thus, the model estimated the probability of AL presence within a census tract given the interaction effect between the quintiled percent of the census tract population that is Black and the ROG for the county. The results show a significant linear relationship between AL presence and the interaction between the county ROG and racial demographics of the census tract.

The second aim of the paper set out to determine the extent to which private governance factors are associated with AL availability, particularly for the census tracts with lower AL access identified in the first aim. I determined which ALs were part of a large chain by combining business to business listings with the list of the top 50 largest corporate chain operators for 2019, according to a senior housing trade organization. Using a similar multilevel random intercept model to that used in the first aim, I compared AL presence in a given census tract to the prevalence of private governance characteristics at the county level, including AL size, nonprofit status, and whether it was operated by a large chain. I found that across all census tracts, compared to large non-affiliated for-profit ALs, each ten-percentage point increase in the AL capacity in the county provided by small nonprofit ALs was significantly associated with a 2.31% greater chance of an AL being located within the tracts in the county. Among the census tracts with the highest proportion of Black residents in the county, small nonprofit ALs were not significantly associated with greater access, but for every 10% increase in the percent of capacity in the county provided by small for-profit ALs that are not operated by a large corporate chain, the likelihood that an AL was in a given census tract increased by 2.91%. While this relationship was also significant for the full population, the coefficient was significantly lower, at only 1.57%. These results demonstrate a relationship between private governance approaches and AL availability that is different for the full population of census tracts compared to Q5 % Black residents census tracts.

Aim 3 uses Boolean descriptive analysis to inductively identify patterns of public and private governance factors associated with greater access to AL for two groups—the full population and a sub-population of census tracts with low levels of AL geographic access associated with a measure of structural racism.[409] We identified the top quintile of counties

according to their ROG,[32] then within each county, the top quintile of census tracts according to the percent of the population that is Black. I employed the coincidence analysis algorithm to identify minimally sufficient conditions associated with AL presence. The identified patterns of factors are classified according to consistency—what percent of census tracts with a given pattern have an AL, and coverage—what percent of all census tracts analyzed have the pattern. Results of the aim 3 analysis indicate that certificate of need (CON) policies reduce the availability of AL for the full population, but do so at a greater rate for the subgroup of census tracts most likely to experience harm from structural racism, as measured by the ROG. Additionally, smaller ALs, Medicaid funding and dementia licensing were associated with greater access for both populations investigated.

The compounding effects of limited public investment, reliance on real estate development, and the nature of payment for AL (primarily private pay) make it highly likely that Black-White disparities in AL geographic access result from structural racism.[8,78,191] In aim one, I hypothesized a relationship between structural racism and AL location, and found that there is an association between a measure of structural racism and AL geographic access. It has previously been unclear how private governance factors may influence or counteract policy initiatives aimed at expanding geographic access. I hypothesized that private governance played a significant role in AL location. In aim two, I found that combinations of size, profit-status, and operation by a large corporate chain are associated with significantly different likelihoods of AL presence within a given census tract. Small and medium capacity ALs that are not operated by a large chain are associated with greater access and small non-chain for-profit ALs are associated with greater access for Q5 percent Black residents census tracts. Finally, it has been unclear how public governance mechanisms, such as state regulation and public funding, interact with the

levels of structural racism and corporate chain prevalence. By identifying the combinations of public and private governance factors associated with greater access to AL, policymakers can take a more deliberate approach. The results of aim three suggest that policymakers should begin by taking a closer look at existing certificate of need programs, as well as trade-offs between the level and stability of both revenue and costs.

6.2. Synthesis of Findings

The research question driving this research was:

> What are the combinations of public and private governance approaches that limit or expand the impact of structural racism on disparities of geographic access AL ?

To answer this question, it was necessary to first establish the presence of a relationship between structural racism and potential assisted living geographic access. The first aim of this work identified a clear correlation between the Black-White gap in economic mobility and AL presence in a census tract, establishing the basis for the assumptions regarding the relationship between the two in the following aims. The second aim found a relationship between the type of operator (i.e., profit-status and large chain operation), capacity of the AL, and presence of AL within census tracts, and that this relationship differs for the census tracts in each county with the highest percent Black population compared to either all tracts or tracts with a predominately White population. Each of these findings informed the construction of the final model wherein the patterns of governance associated with greater access to AL differed for the full population compared to the census tracts with larger populations of Black people experiencing less economic mobility than their White peers growing up at the same income levels.

While previous research has established disparities in use and move-ins to AL,[8,111] the evidence for geographic disparities in access were only available at the county level.[10] While

ALs were previously documented to be less prevalent in counties with a higher percent Black population, this high-level geographic analysis left the connection between geographic access and use unclear. The analysis of presence at the census tract level, while maintaining the context of the county through the use of multilevel modeling, allows for the documentation of racist geographic trends in a way that county-level analysis erases. Racist policies and practices do not impact all residents equally,[134] and my use of multilevel models allows me to account for this difference in how an effect is experienced.[426] The findings in aim one demonstrate this concept, while also clarifying the relationship between racial demographics and AL presence. The addition of a measure of structural racism to this equation accounts for more of the variance, clearly illustrating the importance of including both of these factors in analyses.

Taken together, the findings from this dissertation paint a clearer picture of the Black-White disparities in AL geographic access. There are policy factors that alone act to both worsen and alleviate these disparities. Findings in the third aim provide compelling evidence that certificate of need policies exacerbate disparities in AL access, particularly for Q5 percent Black residents census tracts experiencing the worst ROG. However, other findings are less clear cut. The other patterns of conditions associated with an increase geographic access for these communities all involve combinations of factors that influence either the levels or stability of revenue or costs. Higher levels of access occurred where either factors increasing costs were not present, or they were present in combination with a factor associated with increases in revenue. Factors that may influence revenue include: opportunities to charge higher rates such as a memory care license, fewer limitations to services not allowed, state reimbursement for care, and access to affordable refinancing. Factors that may influence cost include: higher acuity residents, more residents living with dementia or mental illness, higher staffing requirements, and funding,

level-of-care required, and services allowed. Funding may occur at the level of loans and financing or via reimbursement through Medicaid waivers or plans. Level-of-care requirements add cost to the operation of an AL, by expanding the scope of liability for the AL provider as well as the number of services they must offer.[427] In contrast, expanding the types of services allowed enables a provider to offer additional higher profit services, such as dementia care, or to allow third party service providers to offer care—expanding the scope of care available without taking on significant additional costs.[428]

The findings in both aims two and three appear to point to a difference between how nonprofits and providers operated by one of the top fifty corporate chain operators balance these tradeoffs. The finding in the third aim that the absence of large chain operators is associated with greater AL access for Q5 percent Black residents census tracts in counties with a high ROG is consistent with the second aim. There, I found that both small and medium-sized ALs are associated with greater access for Q5 percent Black residents census tracts when they are not operated by large chains. While there is not clear evidence from this work as to why this relationship exists, it seems possible that the margin of trade-offs that must be balanced to make a profit for these ALs is simply narrower.

6.3. Limitations

This study was limited based on the availability of data. In the first aim, the availability of the ROG measure limited which census tracts and counties I could include in the analysis. In the second aim, I initially looked at both owners and operators of the AL residence and the relationship between these two entities. Due to data availability and time constraints of this dissertation study, I found it necessary to focus only on the operators and specifically on determining which AL residences were operated by one of the top 50 largest chains and those

with a nonprofit affiliation. While these two indicators have proven to be valuable in the beginning to understand the landscape of private governance in AL, it is clear that there are much more nuance to what it is that differentiates one type of AL provider from another. Finally, in aim three, I was limited by the availability of public governance data. First, I could not include information about all types of government subsidies available to ALs. Supplemental Social Security benefits and funding specific to state programming may also play a role in AL availability. The policies included omitted local ordinances and variation in approaches to implementing and enforcing regulations due to data availability.

This study is also limited by the types of measurement that I could use. Structural racism is an incredibly complex phenomenon, and there is not one single measure that accounts for all aspects of structural racism.[134] Given this, I was most interested in the effects of real estate-based structural racism. That is, racist policies and practices that impact the real estate system in the US have been developed that result in lower-value homes and real estate for Black communities and higher-value homes and real estate for White communities.[393] The ongoing barriers to access for home loans, business loans, and other development funds and the overt racism in practices like redlining have made it difficult for Black communities to build and sustain the value within the real estate market. I hypothesized that this phenomenon would mean that AL would not be available in areas most harmed by these practices and policies. While the ideal measure for establishing this would be based on the racist policies and practices utilized to create such a system, this data is far from complete. Some of the data regarding redlining practices have become available; however, much of the racist policy and practices that led to the current disparities in real estate values were tied to homeowners' associations, business practices, loan agency practices, and land covenants.[108,109] This data is unavailable and has not been fully

documented to allow for comparative analysis. Instead, I used the ROG as a proxy measure. I acknowledge that the ROG is limited. It looks at the difference in economic mobility between people whose parents were at the same income level in the 80s and 90s and their incomes as adults in 2014.[32,376] This means that the ROG does not capture the effects of racist policies that resulted in people's incomes in the 80s and 90s. This measure only captures the effects of a divide between Black and White outcomes that was exacerbated during this time. However, given the aim of this work and the development of the AL industry in the 80s and 90s,[70] I argued that the ROG was an appropriate proxy measure for the questions posed here.

While the way I measured AL availability allowed me to identify Black-White disparities and identifying mechanisms for addressing these disparities, it is limited in several ways. First, I looked only at whether or not a census tract has AL. I did not look at the capacity of those AL residences and whether or not that capacity is likely to meet the needs given the size of the older adult population. I acknowledge that capacity per thousand older adults is an essential metric for measuring the availability of AL; however, in this study, I was focused first on establishing whether or not there was any access within a given community. This focus likely did produce a bias towards a preference for smaller communities of AL. Given my conceptual frame relying on AL's convoys of care model, prioritizing having some access to AL within one's specific census tract level community is an appropriate outcome. Based on the convoys of care model, it is essential for family members to have easy access to the AL.[158] The reliance on informal caregiving in combination with formal caregiving is an essential component of the success of community-based care. Thus, I argue that while limited, the presence of AL in a census tract as a measure of access is a valuable first step to improving our understanding of racial disparities of access to AL.

6.4. Implications For Policy

Based on the findings of this study, there are multiple pathways forward for policymakers. Given the current policymaking environment wherein there is an effort to expand funding for home and community-based services,[429] prioritizing a more inclusive approach to AL funding, and removing barriers to entry should be a priority for state policymakers. While expanding the funding for home and community-based services has the potential to improve the lives of older adults and their families significantly, it also has the potential to expand health disparities. Enabling and need factors accounted for the differences between Black and White older moves into NHs. However, the same is not true for ALs. For ALs, the differences persisted after accounting for factors including: gender, age, self-rated health, self-reported ADL assistance needs, dementia status, income, housing tenure, living arrangement, and Medicaid status.[8] The fact that the enabling and need factors do account for the Black-White differences in care transitions to NHs, but do not for ALs further suggests that access to care may be the cause of the difference in use. Without also expanding access to home and community-based services settings, expanding funding could improve the health outcomes of people in communities that are already more privileged as they are in proximity to the care settings receiving the influx of funding. Acknowledging this disparity and including plans for addressing this unequal access to care should be an essential component of any plan to expand home and community-based care funding.

Based on findings in aim three, eliminating or reconfiguring certificate of need requirements for AL could be an important first step for the five states that have them—Arkansas, Indiana, Missouri, New Jersey, and New York. Previous research has indicated that these policies were designed for limiting the construction of healthcare services the federal

government subsidized.[418] However, the federal government has never invested in AL in the way it did NHs or hospitals.[368] There is no threat with hospitals that too many ALs will enter a market, placing an undue burden on consumers. Instead, these policies primarily allow the states to control Medicaid spending for the license types that qualify for Medicaid state plans.[430] By limiting the number of AL residences that can operate within a market, results indicate that states end up limiting AL construction instead of encouraging it in areas in need. While it is reasonable for states to be interested in limiting the amount they spend on AL services, using certificate of need policies to achieve that goal appears to have the effect of prioritizing White communities' care over Black communities.

In addition to reconsidering barriers to market entry, it is also essential that policymakers consider how to support ALs in balancing the costs of care (i.e., required services, higher acuity residents, staffing requirements) with potential sources of revenue (i.e., increased or guaranteed Medicaid reimbursement, specialty care associated with higher rates, property financing). An important factor to take into account is the differences in the effects of adjusting any of these factors for large chain operators, smaller for-profits, and nonprofit ALs.

6.5. Implications for future research

The findings from this study have implications for designing research that addresses health disparities and future work in assisted living and long-term services and supports. In the first aim, my use of the county-level ROG in combination with the racial demographics of the census tract is an approach that could be helpful for others looking to document the relationship between a measure of structural racism and the location of a health service resource. The finding that neither the racial demographics nor the ROG alone accounted for the disparities in access

reflects the previously documented need to take into account both the source of oppression and the population impacted when investigating structural phenomena.[431]

The third aim additionally provides guidance for future health disparities study design. While Ragin and Amoroso identified comparative analytic approaches as an avenue with great potential for "diversity" research, there is a gap in the comparative configurational methods literature regarding how to best apply these approaches to health disparities research.[417] In the standard application of coincidence analysis, both the consistency and coverage are maximized. However, I found that if coverage was maximized in the full population, patterns specific to marginalized groups, such as the subpopulation investigated, did not emerge due to their low coverage level. While lowering the coverage to less than one percent is not a feasible solution for any studies using the full coincidence analysis method, conducting an additional analysis with only the most marginalized subpopulation may be worth consideration. Designing interventions that meet the needs of the most marginalized group can be an effective strategy for narrowing inequities, a prime tenant of intersectionality theory.[125] Additional research is needed to further explore and methodologically refine approaches that take these findings into consideration.

This study also provides learnings for AL researchers. In aim one, my findings point to the importance of considering AL location at a more localized level rather than using larger, somewhat arbitrary units like the county. More work is needed to better define and distinguish geographic units of analysis for studying disparities of access. Future research should consider how best to define the spatial relationship between resident or informal caregiver location before move-in, likely reflected in measurements of market reach. It would be additionally useful for studying disparities of access to define a unit of analysis that better encompasses the proximity to informal caregivers necessary to ensure quality of care in AL settings.[158] Additionally, these

findings reinforce previous findings that the percent of the population with a Bachelor's degree is a strong determinant of AL presence across subpopulations. While previously documented, more research is necessary to fully understand why college degree attainment is such a powerful indicator compared to other factors such as income or home value.

Aim two identifies the importance of private governance and the types of businesses operating the AL to location. Future research should explore what other correlates of these AL operators may be. Specifically, here I only investigate location, however resident composition and indicators of quality may also vary across these provider types. In terms of provider types, aim three points to very different patterns that similarly lead to AL presence. Future research is needed to better understand whether the types of ALs present are actually comparable to one another. For instance, it is possible that while small ALs are associated with greater access in some states, they are also unable to provide specific healthcare services, limiting the ability of these ALs to meet the needs of their local communities.

This points to an additional avenue for future research, the presence of an AL in a community does not mean that it provides accessible care for everyone who may need it in the community. This study investigates potential geographic access to AL care. Potential access is different from realized access, as it refers to the coexistence in space and time of willing and able health service providers and a population in need of care. This is in contrast to realized access, which refers to actualized care access wherein all barriers to care access are addressed.[425] Geographic or spatial access, also described as availability, is just one component of access to care. Additional research is also needed to achieve realized equitable access to AL, including all types of access—approachability, acceptability, affordability, appropriateness, and awareness.[178–

[180] As a part of this research, an emphasis on quality as defined by older adults and their care partners is essential.

Policy implementation and enforcement is an area of research necessary for improving models like the one used in the third aim of the study. While recent work provides a basis for conceptualizing the differences across states, there is a gap in evidence regarding how enforcement and monitoring practices interact with scope and specificity of regulations in place. All three components are necessary to take into account when aiming to understand the effect of regulations on care provision. With an improved conceptual and data model, future research could better contextualize the findings presented in aim three.

Finally, this study did not investigate the role that workforce may play in the location of ALs. It is possible that some providers develop ALs in areas that best accommodate potential staff. It is unclear whether this impacts the extent to which an AL is actually available to provide services to the census tract population within-which it resides. Improving our understanding of this confluence of factors may assist with both improving our conceptualization of disparities in access and the potential for AL location to impact the wellbeing of the caregiver staff. There is a need for AL settings that are supportive workplaces with living wages and environments where older adults can receive assistance with activities of daily living and the healthcare necessary to age in place. However, this ideal is still far from accessible for most communities. By better defining the existing disparities and identifying the potential factors to address them, I hope this line of research can help shift towards such a reality.

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Appendices

Appendix 3.A: Regression Estimates

Census tract % Black Residents Model			
	Census tract AL Presence		
Predictors	*Estimates*	*CI*	*p*
(Intercept)	-0.1501	-0.2093 – -0.0909	**<0.001**
Census tract Older Adult % Quintile	0.0611	0.0585 – 0.0637	**<0.001**
Census tract Rural-Urban Commuting Area			
Metropolitan	-	-	**-**
Micropolitan	0.0153	0.0006 – 0.0299	**0.041**
Small Town	0.0402	0.0191 – 0.0614	**<0.001**
Rural	-0.0770	-0.1031 – -0.0509	**<0.001**
Census tract Median HomeValue Quintile	0.0212	0.0161 – 0.0263	**<0.001**
Census tract Median IncomeQuintile	0.0072	0.0033 – 0.0111	**<0.001**
Census tract BA Attainment% Quintile	0.0176	0.0139 – 0.0213	**<0.001**
Racial Opportunity Gap	0.0033	0.0011 – 0.0056	**0.004**
Census tract % Black Residents within County Quintile	0.0638	0.0548 – 0.0728	**<0.001**
ROG : Census tract % Black Residents within County Quintile	-0.0020	-0.0027 – -0.0013	**<0.001**
Random Effects			
σ^2	0.17		
τ_{00}	0.01	county:state	
	0.03	state	
ICC	0.19		
N	1,915	county	
	51	state	
Observations	66,084		
Marginal R^2 / Conditional R^2	0.045 / 0.224		

Appendix 3.A: Regression Estimates Continued

Census tract % White Residents Model			
	Census tract AL Presence		
Predictors	*Estimates*	*CI*	*p*
(Intercept)	0.2338	0.1718 – 0.2959	**<0.001**
Census tract Older Adult%Quintile	0.0622	0.0595 – 0.0649	**<0.001**
Census tract Rural-Urban Commuting Area			
Metropolitan	-	-	**-**
Micropolitan	0.0140	-0.0007– 0.0286	0.062
Small Town	0.0365	0.0153 – 0.0577	**0.001**
Rural	-0.0846	-0.1107 – -0.0584	**<0.001**
Census tract Median Home Value Quintile	0.0182	0.0131 – 0.0233	**<0.001**
Census tract Median Income Quintile	0.0064	0.0024– 0.0103	**0.001**
Census tract BA Attainment% Quintile	0.0197	0.0160 – 0.0234	**<0.001**
Racial Opportunity Gap	-0.0102	-0.0133 – -0.0071	**<0.001**
Census tract %White Residents within County Quintile	-0.0632	-0.0723 – -0.0541	**<0.001**
ROG : Census tract %White Residents within County Quintile	0.0024	0.0017 – 0.0031	**<0.001**
Random Effects			
σ^2	0.17		
τ_{00}	0.01	county:state	
	0.03	state	
ICC	0.18		
N	1,915	county	
	51	state	
Observations	66,084		
Marginal R^2 / Conditional R^2	0.043 / 0.212		

Appendix 3.B Marginal Effects of Logistic and Linear Probability Models

	Logistic Probabilities			Linear Probabilities		
Factor	*AME*	*SE*	*p*	*AME*	*SE*	*p*
Census tract % Black Residents Model						
Racial Opportunity Gap	-0.0031	0.0009	< 0.001	-0.0029	0.0009	< 0.001
Tract % Black Residents, County Quintile	0.0410	0.0022	< 0.001	0.0399	0.0015	< 0.001
Tract BA Attainment %, US Quintile	0.0182	0.0020	< 0.001	0.0176	0.0019	< 0.001
Tract Median Home Value, US Quintile	0.0185	0.0027	< 0.001	0.0212	0.0026	< 0.001
Tract Median Income, US Quintile	0.0098	0.0021	< 0.001	0.0072	0.0020	< 0.001
Tract Older Adult %, US Quintile	0.0602	0.0026	< 0.001	0.0611	0.0013	< 0.001
Rural/Urban: Metropolitan	-	-	-	-	-	-
Rural/Urban: Micropolitan	0.0179	0.0075	0.0172	0.0153	0.0075	0.0407
Rural/Urban: Rural	-0.0748	0.0126	< 0.001	-0.0770	0.0133	< 0.001
Rural/Urban: Small Town	0.0435	0.0112	< 0.001	0.0402	0.0108	< 0.001
Census tract % White Residents Model						
Racial Opportunity Gap	-0.0036	0.0009	< 0.001	-0.0031	0.0009	< 0.001
Tract % White Residents, County Quintile	-0.0355	0.0020	< 0.001	-0.0347	0.0016	< 0.001
Tract BA Attainment %, US Quintile	0.0203	0.0021	< 0.001	0.0197	0.0019	< 0.001
Tract Median Home Value, US Quintile	0.0155	0.0027	< 0.001	0.0182	0.0026	< 0.001
Tract Median Income, US Quintile	0.0085	0.0021	< 0.001	0.0064	0.0020	< 0.001
Tract Older Adult %, US Quintile	0.0615	0.0026	< 0.001	0.0622	0.0014	< 0.001
Rural/Urban: Metropolitan	-	-	-	-	-	-
Rural/Urban: Micropolitan	0.0165	0.0075	0.0283	0.0140	0.0075	0.0622
Rural/Urban: Rural	-0.0808	0.0125	< 0.001	-0.0846	0.0133	< 0.001
Rural/Urban: Small Town	0.0388	0.0112	< 0.001	0.0365	0.0108	< 0.001

Appendix 3.C Descriptive Statistics for Omitted Census tracts

Factor	*Statistic/n (% Total)*		*p value*
	Omitted Census tracts (N=7,050)	No Missing Values (N=66,084)	
Presence of Assisted Living			< 0.001[1]
No AL	5,106 (73.2%)	45,718 (69.2%)	
AL Present	1,866 (26.8%)	20,366 (30.8%)	
Racial Opportunity Gap			0.008[1]
Mean	12.05	11.82	
SD	4.09	3.84	
N-Missing	4,968	0	
Census tract % Black Residents within County Quintile			< 0.001[1]
Mean	2.08	3.08	
SD	1.34	1.39	
N-Missing	724	0	
Census tract % White Residents within County Quintile			< 0.001[1]
Mean	3.76	2.92	
SD	1.46	1.39	
N-Missing	724	0	
Census tract Older Adult Quintile			< 0.001[1]
Mean	3.57	2.94	
SD	1.50	1.39	
N-Missing	628	0	
Census tract Rural-Urban Commuting Area			< 0.001[2]
Metropolitan	2,059 (32.4%)	57,318 (86.7%)	
Micropolitan	964 (15.2%)	5,645 (8.5%)	
Small Town	1,358 (21.4%)	1,967 (3.0%)	
Rural	1,973 (31.1%)	1,154 (1.7%)	
Census tract Median Home Value Quintile			< 0.001[1]
Mean	2.06	3.07	
SD	1.05	1.41	
N-Missing	2,056	0	
Census tract Median Income Quintile			< 0.001[1]
Mean	2.30	3.06	
SD	1.05	1.43	
N-Missing	1,102	0	
Census tract BA Attainment % Quintile			< 0.001[1]
Mean	2.37	3.06	
SD	1.17	1.42	
N-Missing	742	0	

1. Linear model ANOVA; 2. Pearson's Chi-squared test; AL = Assisted living