



# **Racial and Ethnic Disparities in Access to Home and Community-Based Services Among Individuals Dually Eligible for Medicare and Medicaid:**

An Environmental Scan of the Literature

Submitted to Arnold Ventures

May 2, 2022



## EXECUTIVE SUMMARY

Currently, over one-third of individuals who are dually-eligible for Medicare and Medicaid rely on home and community-based services (HCBS) to remain in their communities and avoid having to move to institutional settings in order to address their functional or cognitive care needs. Care at home and in the community is the preferred setting for those who need it and their family caregivers. With a growing and diverse aging population, the need for HCBS will only increase, making the need for an inclusive, culturally competent HCBS system that is responsive to the needs of people of color critically important.

Data shows that the American aging population is growing and becoming increasingly diverse. According to statistics from the Administration for Community Living (ACL), the number of African American, American Indian and Alaska Native, Asian, and Hispanic older adults is expected to grow by 115% by 2040 (2021). People from all backgrounds are living longer and experiencing the need for long-term services and supports (LTSS) and it is important that our care systems be prepared to meet the needs of this increasingly diverse population now and in the future.

In this environmental scan, we review the recent academic and grey literature to identify the nature and extent of racial and ethnic disparities in access to these services. Specifically, we reviewed 34 articles from the academic (peer-reviewed) literature and 19 papers from materials and research produced by organizations outside of the traditional commercial or academic, focusing on more recent publications (from 1998 to 2022). Nearly one-third of the peer-reviewed articles were published within the last two years. While the review focused largely on articles specifically studying populations that are dually enrolled for both Medicaid and Medicare, we also expanded our review to include closely-related populations — eligible for only Medicaid or only Medicare — in order to have a more expansive body of literature to review.

While some of the studies were based on surveys not routinely available in existing databases, most relied exclusively on analysis of information from one or more national datasets. None of the studies relied upon a qualitative study approach. This reinforces the need for studies that rely on mixed methods,

including focus group and key informant interviews. Such approaches enable a better understanding of provider and person-focused variables that influence how barriers identified through quantitative analyses might be modified to ensure greater equity in access to HCBS among populations from traditionally underserved communities.

The literature was definitive in highlighting the presence of racial and ethnic disparities in access to HCBS. Compared to other populations of individuals who are dually eligible (or other Medicaid-only or Medicare-only populations), people of color are more likely to have:

- Unmet needs for HCBS and other services,
- More limited access to a wide variety of HCBS and other types of care,
- Poorer health outcomes, which are postulated to be related to unmet needs, and
- Disparities with regard to HCBS utilization and expenditures – in general and with regard to specific services.

In short, the literature highlighted disparities in spending, access, and outcomes.

There are a number of limitations across the literature that are important to note. First, there are not a large number of recent peer-reviewed articles that specifically focus on people who are dually eligible as the study population, even though this population has complex needs and disproportionately includes people of color. Moreover, dually eligible people themselves are not a homogeneous group. There are full duals, partial duals, and variations within those categories with respect to whether or not coverage includes prescription drugs, and other plan and coverage type variables. There are also significant variations within and across states in terms of Medicaid LTSS service, provider and HCBS program characteristics that influence disparities.

Several articles highlight data limitations, which encumber a more extensive understanding of the issue. Specifically, data collection on HCBS is inconsistent and limited, which makes measuring and tracking racial and ethnic disparities very challenging. The grey literature also provides a detailed look at the inadequacies of data collection. Moreover, even data that are collected are limited in scope and

not standardized, making it difficult to identify and compare racial and ethnic disparities within and across programs and geographic boundaries.

Even so, certain key themes emerge from the literature. While certain disparities can be traced back to structural issues associated with state-specific uptake of HCBS as an optional Medicaid benefit, many cannot be fully explained by structural issues alone. Some articles cite the fundamental lack of cultural competency as a factor that makes HCBS less accessible to communities of color. Other drivers that contribute to disparities in access, use, and outcomes include the following:

- **Inequities in the supply of resources in communities of color.**
- **Limited access to managed care.** One hypothesis from the literature is that communities of color (for a variety of reasons to be determined) may have more limited access to care management or managed care plans. As a result, this could disadvantage their access to better quality, more appropriate and more timely care to meet their needs.
- **Some studies suggest that inherent racial bias/systemic racism play a role in creating inequities in access and quality.** This may derive from provider bias – e.g., providers not wanting to offer in-home care in low-income/poverty or ethnic communities unfamiliar to them, or inherent racism that might impact policies and protocols with regard to Medicaid programs, provider reimbursement, and HCBS expenditures.
- **Differences in Medicaid policy and programs across states are likely an important factor.** Low Medicaid reimbursement rates inherently affect dual eligibles with lower incomes and/or less family support who may be unable to supplement the care needs they cannot meet in other ways.
- **Other factors that likely play a role in creating or exacerbating inequities are differences in underlying co-morbidities, where a greater health burden or complexity could worsen outcomes or compromise access to the proper package of specific HCBS support.** Additionally, having limited

caregiver supports or caregivers with more limited access to information and training can also confound the access to care (e.g., transportation) and the outcomes (e.g., medication compliance support) experienced by people of color.

- **Community variables are also important.** Lack of transportation, other community variables such as limited internet for telehealth for obtaining information about providers, limited provider supply, and other community factors can also affect communities of color differently.

What are the policy levers and program changes that can be implemented to address these inequities? While there is more research needed to untangle some of the key drivers of access and outcome inequities, based on existing evidence, the following recommendations to address racial disparities mentioned in the literature include:

- Increase Medicare/Medicaid reimbursement rates for providers who serve Medicaid-eligible people of color and other vulnerable older adults;
- Develop and report health equity measures in outcomes of care for dually eligible people of color;
- Expand access to Medicaid-waivered HCBS;
- Adopt culturally-appropriate HCBS and offer better support for family caregivers of color and/or family caregivers caring for a person of color;
- Increase integrated HCBS programs for communities of color; and,
- Expand the use of proven effective care models, and/or incorporate elements from those models into programs serving dual eligible populations of color such as PACE and CAPABLE programs, which have been cited in the literature.

Despite knowing that racial and ethnic disparities exist, there are limited policy and practice change efforts that directly engage LTSS users of color about their experiences with HCBS services and how they can be improved. For policy and practice solutions to address these disparities and improve the experiences of these enrollees, more research and better data are needed, and their lived experiences must be centered in the discussion of solutions.

## INTRODUCTION

Across all population groups, the preferred setting of care for those who need functional or cognitive care support is to remain at home or within the community wherever feasible. However, access to desired home and community-based services (HCBS) is not always possible. Financial, logistical, and other barriers can limit access to HCBS services. Additionally, significant racial and ethnic disparities leave communities of color<sup>1</sup> more vulnerable to limited access to HCBS and other preferred sites of care. We report on the literature over the past decade that has attempted to identify and analyze racial and ethnic disparities in access to care and the outcomes associated with access issues. Specifically, we summarize the populations studied, the data and methodologies used and key findings and limitations in the existing literature.

## Research Objectives

Currently, over one-third of individuals who are dually eligible for Medicare and Medicaid rely on home and community-based services (HCBS) for care – enabling them to avoid moving to an institutional care setting. However, the literature suggests that significant racial and ethnic disparities in access to HCBS exist, which in turn affect the health and well-being outcomes of those populations.

A disproportionate number of individuals who are dually eligible are from racial and ethnic minority<sup>2</sup> populations. While dually eligible individuals represent a small share of the Medicare-Medicaid population, they account for a significantly higher share of expenditures; similarly, they have greater functional and cognitive impairments than either population separately. There is a greater proportion of Black and Hispanic persons among the duals cohort (21% and 17% respectively)

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<sup>1</sup> We use the terms “people of color” and “communities of color” throughout the scan to encompass the racial and ethnic diversity of the duals population. This term is inclusive of Black, Indigenous, Asian American and Pacific Islanders, Latino, and multiracial people.

<sup>2</sup> We use this term because of its prevalence in the research as a generalization for the specific study populations that will be explored. Additionally, where we use the terms Black, Hispanic, White, White/Non-Hispanic, we use the terms as they appear and are defined within the article being cited. As noted, different definitions and classifications are used throughout the literature, depending on the database that is used for the research.



than among a non-duals cohort (9% and 6% respectively). Dually eligible individuals who are age 65 and older are more likely to be Hispanic than those who are under age 65 (20% vs 12%). Looking at those under age 65, dually eligible individuals are more likely to be Black (25% vs. 19%). More “full benefit” duals are Hispanic (18% vs. 15%) or live in an urban area (81% vs. 75% (MACPAC and MEDPAC Databook, 2022)).

We analyzed the academic and grey literature to address the following questions:

- What disparities in access to HCBS exist for dually-eligible beneficiaries of color?
- What factors, if any, are identified in the literature as associated with or possibly cited as causal variables for access barriers?
- Does the literature provide insights into any policy levers that can be used to mitigate these access disparities?
- Does the literature provide fruitful areas for further inquiry as we develop our interview and focus group protocols for the qualitative study component?

## **About the Literature**

The research team reviewed a total of 34 articles from the academic (peer-reviewed) literature and 19 papers from materials and research produced by organizations outside of the traditional commercial or academic publishing (commonly referred to as “grey literature”) ranging in date from 1998 to 2022. Nearly one-third of the peer-reviewed articles were published from 2000 to 2022.

Articles were accessed using a broad internet search and a search of the Healey Library, UMass Boston on-line search function. We also identified relevant articles from the bibliographies and literature reviews of relevant articles. Additionally, we reached out for grey literature on the websites of organizations known to do research in this field such as MACPAC, AARP, National Council on Aging (NCOA), and more. Among the search terms used were: racial and ethnic disparities in access to HCBS; dual-eligibles; health outcomes and racial/ethnic disparities; disparities in LTSS access/outcomes; and more. We also explored specific

journals in their entirety for recent relevant articles such as the Journal of Racial and Ethnic Health Disparities and the Disability and Health Journal.

*Populations Studied.* Due to the focus of our research on individuals who are dually eligible for both Medicare and Medicaid, we begin our literature search on studies specific to that population. However, we also included research that focused on racial and ethnic disparities in health care, access and outcomes more broadly, and particularly long-term care (LTC), so that we might reveal some underlying factors relevant to include in the qualitative component. Some of the research summarized here may have included a Medicare-only or Medicaid-only population. Specifically:

- Eleven (11) of the published articles used dual eligibles as the study population;
- Three (3) examined racial biases in LTC use among Medicare and/or 65+ adults;
- Eight (8) of the articles used a Medicaid population as the study group;
- Others used a specific type of disease or service setting as the basis for the analysis (e.g., adults with cerebral palsy, autism, Alzheimer's disease and related dementia, and others.)

*Method and Data Sources.* The most typically used methods and data sources are the following:

- Medicare Beneficiary Summary File
- The Outcome and Assessment Information Set (OASIS), providing patient-specific, standardized assessment information on Medicare home health care.
- [NIH Health Disparities Framework](#)
- Medicaid Analytic eXtract (MAX files)
- Medicare Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey
- National Health and Aging Trends Study (NHATS)
- National Study of Caregiving
- Medicare Provider and Analysis Review data
- Medicare Chronic Condition Warehouse
- [Harvard Implicit Association Test](#) to measure racial bias



- Nursing Home Minimum Data
- Minimum Data Set 2.0 and Medicare data
- Medical Expenditure Panel Survey (MEPS)
- 1987 National Medical Expenditure Survey (NMES)
- Survey data or measurements created specifically for the individual study

## Definitions

In order to precisely frame the differences in experiences of people of color using HCBS versus their white peers, we need to provide working definitions of the following terms:

- Disparity
- Equity

These working definitions are not meant to be binding, but rather to bring about a shared understanding of the core research goals of the project. While these are frequently used terms in health policy and advocacy spaces, they are often not precisely defined, making it more difficult to compare data and reach a detailed understanding of the experiences of HCBS users. As one group of researchers tasked with defining health equity have stated:

*“The words we use can matter. Definitions can matter. While some differences in definitions may reflect only stylistic preferences, others convey values and beliefs that can be used explicitly or implicitly to justify and promote particular views, policies, and practices.”* (Braverman, 2017)

By sharing our understanding of these terms, we hope to bring both transparency and precision to our discussion of the literature.

## Disparity

Health differences are not synonymous with health disparities. The difference between a simple health difference and a health disparity is that concerns for social justice are at the root of a health disparity. A health disparity is a difference that negatively affects socially and economically disadvantaged groups

(Braverman, 2014). A concise yet effective definition of disparity that is widely used in other countries is as follows:

*...Disparities are “health differences that are avoidable, unnecessary, and unjust.”* (Braverman, 2014)

While it is important to take the quantitative metrics of the difference into consideration, equal consideration must be put into the social positionality of the individual or group of people experiencing a health difference. This is because many disparities go unreported because they are not detected by statistical models; therefore, a more contextual definition of disparities would make it more difficult for differences that could be rooted in racial inequality to be explained away with other variables.

We found that the U.S. Institute of Medicine’s definition of “disparity” best encompasses the specific dimensions of this research. It allows for appropriate context regarding the lived experience of people using HCBS. Instead of shifting blame on individual behaviors, this definition allows researchers to appropriately probe systemic barriers such as lack of access or implicit bias. That definition is as follows:

*“A difference in access or treatment provided to members of different racial or ethnic groups that is not justified by the underlying health conditions or treatment preferences of patients.”* (IOM 2003)

This definition allows for appropriate context regarding the lived experience of people using HCBS and is the one that will be used in this paper.

## **Equity**

The federal government currently defines equity as the following:

*“The term “equity” means the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer*

*(LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.”(Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, 2021)*

This definition is important to note because of both its widespread use in the current administration, and for its direct citation of what specific groups experience marginalization in the United States. Often people with disabilities are not identified as a group experiencing marginalization, and it is important to name disability status in addition to racial and ethnic identity in this work. It is important to note that, prior to the CMS Framework for Health Equity, there was no shared language within the federal government on the use of these terms. It is important that we now have moved closer to alignment in this area.

An important addition to this definition is the idea of intersectionality. Many individuals, including dually eligible individuals of color profiled in this study, belong to multiple categories within this definition; those intersections may impact their experience as they interact with systems such as HCBS. Another note is that “consistent and fair” must and will look different for each community included in this definition. All approaches to advancing equity must take the lived experiences of each of these communities into consideration. A “one size fits all” approach to equity has the potential to exacerbate existing inequalities and disparities, and the language of our research needs to reflect these considerations.

The Robert Wood Johnson Foundation provides the following definition:

*“Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care. For the purposes of measurement, health equity means reducing and ultimately eliminating disparities in health and its determinants that adversely affect excluded or marginalized groups.”(Braverman et al. 2017)*

This definition is important to cite because of its direct call for accountability that speaks to the relationship between health disparities and health equity. This

definition informs this research's direct identification of solutions and recommendations for policymaker action on identified disparities.

## FINDINGS

In the sections that follow, we summarize the literature with regard to research on the nature and extent of disparities between duals of color and other populations of dual eligibles (and others) in terms of the following:

- Unmet needs for HCBS and other services,
- More limited access to care,
- Poorer health outcomes,
- Disparities with regard to HCBS utilization and expenditures – in general and with regard to specific services, and
- Other findings of disparities in spending, access, and outcomes.

### Unmet Needs

Several articles identify disparities in unmet needs associated with racial differences. In this section, we cite the literature that focuses on any number of types of unmet needs. They run the gamut from studies measuring individuals who need help with activities of daily living, instrumental activities of daily living, housing safety, basic health or medical care needs, supervision for a cognitive loss, medical transportation, or other needs. The term “unmet need” will be used differently in this report, varying as used in the research cited.

One report found that non-White people were more likely than White people to have certain types of unmet needs, and non-Hispanic White HCBS users were more likely to have all of the needs examined in this study adequately met, compared with people of other racial and ethnic groups (Gardiner, 2021). Specifically, 67.4% of White people reported no unmet needs, compared to 13.9% of their Black peers, 8.3% of their Hispanic peers, and 5.8% for other races (Chong et al., 2021). In this study, the unmet needs examined included a variety of measures of health and personal care use and community living outcomes such as: help with personal care and access to transportation, assistive technology,

and home modification. In terms of outcomes, individuals with unmet needs were more likely to have an emergency room (ER) visit and less likely to have social and community interactions and/or to report that they felt control or satisfaction in their life.

A 2005 study (Komisar et al.) examined elderly dual eligibles in six states (Florida, Iowa, Massachusetts, New Jersey, Washington and Wisconsin) – chosen to reflect variation in terms of the type of Medicaid home and community-based care and Medicaid programs in general. Overall, the variation was designed to reflect national variations. Individuals were surveyed to identify the how access to HCBS interacts with the extent of unmet personal care need and how access to HCBS interacts with that. The study found that 58% of dual eligibles needing LTSS reported unmet needs. This study looked at the type of adverse consequences associated with unmet HCBS needs, such as the following: those having any unmet ADL need reported a fall (28%), being wet or soiled (15%), or being unable to bathe or shower (33%). Overall, 56% of those with any unmet need cited at least one adverse consequence associated with the need. Individuals in the study were receiving a mix of paid care, some with additional unpaid care, with the majority receiving only unpaid family care. Some received no care at all.

The authors cite shortcomings in the Medicaid/Medicare programs, stating while “...some unmet needs are probably inevitable, [but] the high level of unmet needs and the fact that 46% of those with needs receive no paid care indicate that the Medicaid and Medicare programs are falling short of adequate service for a large number of people.” On the positive side, their study does suggest that receiving paid care does significantly reduce the level of unmet need, all else equal, finding that “the proportion reporting unmet need is one-fifth lower among those receiving paid care than among those who do not receive paid care (p. 178).” This pattern holds true across the states analyzed in the study. The survey found that there are lower levels of unmet need where the proportion of people getting paid care help at home is higher (relative to other states). Their conclusion – “paid care matters” when it comes to addressing unmet needs and that if paid care is less likely to be received by certain sub-groups in the population, they are more likely to have adverse consequences. This raises an important dilemma in that access to paid care is constrained, both as a result of socio-economic barriers for those lacking financial and housing accommodations to support in-home paid care, and



also even for those with adequate financial resources, given the dramatic shortages among the paid direct care workforce.

## **HCBS Access and Outcomes**

A number of studies focused on challenges faced in gaining access to HCBS, in particular among people of color. The literature looks both at access to care literally and in terms of the type of care to which individuals have access. Quality of care or equity of care was defined as the “type” of service mix available to communities of color.

Another study (Fashaw-Walters et al. 2022) found that while Black and Hispanic patients lived in neighborhoods with a higher number of home health agencies (HHA) per 1,000 older adults, the authors found that a smaller percent of the agencies were high quality agencies (with “quality” being determined using the star-rankings on [www.homecarecompare.gov](http://www.homecarecompare.gov)). Among individuals using services from a HHA, Black and Hispanic individuals had lower rates of use of from the HHAs with the higher “star quality ratings” than did their White and higher income counterparts. Differences existed even when controlling for important health and sociodemographic factors. Findings suggest that “racial, ethnic, and socioeconomic inequities... are robust and pervasive, and they put high-quality home health agency services ‘out of reach’ for the most vulnerable Medicare...patients...” (pp. 251-52). This study identified, but could not isolate, patient versus provider driven factors. For example, perhaps the authors question whether home health aides do not feel safe in some neighborhoods; or perhaps HHA quality ratings are less well articulated or less accessible to patients of color, or perhaps institutional racism/discrimination and providers' bias about patient adherence to medical advice are in play. Regardless of the potential explanation for this disparity in access, this important research demonstrates that it exists.

Another study (Fabius et al., 2019) looked at how the type and amount of HCBS used and how that varied by race/ethnicity and the impact on the use of other service settings. Postulating that lack of access to HCBS might lead to greater reliance on hospital care, the study found that dual eligibles who were Black had the highest hospitalization rates (44%) compared with White duals (36%), Hispanic duals (37%) and Asian duals (28%). Black people used less hospice care

than White people (8% vs 15%) and less residential care (2% vs 6%). An analysis of Medicaid HCBS use among persons with multiple sclerosis (MS) (Fabius, et. al., 2018) found that Black HCBS users were disadvantaged in care access in the following ways:

- They were less likely to receive care management,
- Less likely to have access to equipment and technology, and
- Less likely to receive home modification or to access nursing services at home.

These differences are critical as the Black community is disproportionately impacted by MS, so limited access to these important components of HCBS can greatly disadvantage their care outcomes and support.

Chong et al. (2022) found that unmet needs for ADL support and related LTSS and community care needs were associated with a variety of adverse outcomes. Additionally, unmet needs were more prevalent among non-White people with all other factors equal. Further, having unmet need was associated with a greater likelihood of an emergency room visit and/or a hospital stay, a reduced likelihood of receiving preventative care and a lower likelihood of experiencing favorable community outcomes such as feeling in control of one's life and having social engagement.

## **HCBS Utilization**

The differences in HCBS utilization provide important clues for where barriers to access exist for people of color. A 2018 study of beneficiaries with dementia found that Black beneficiaries were 64% less likely to use case management, 31% less likely to use equipment, technology, and modification services, and 48% less likely to use nursing services than their white peers (Fabius et al., 2018). The study found these disparities even after controlling for age, sex, comorbidities, state, and months of eligibility for Medicaid HCBS. A California-specific study of people with intellectual and developmental disabilities (IDD) (Harrington & Kang, 2016) found that a higher percentage of people who did not receive services were in racial or ethnic minority groups. The same study also found that even when controlling for need, four minority groups (Asians/Pacific Islanders, African

Americans, Hispanic people, and other races) were less likely to receive services. It found that in 2013, 82% of White people with IDD received services, which was higher than Black (78%), Asian/PI (75%), and Hispanic peers (70.4%).

## **Adult Day Services Utilization and Quality**

When breaking down HCBS services by type, certain kinds of services and supports were more common among people of color than others. In particular, the racial and ethnic demographics of adult day service centers stand out. CDC data from 2019 identifies adult day centers as the most racially and diverse sector of HCBS, with only 42% of participants identified as non-Hispanic White, 15.4% non-Hispanic Black and 22.7% Hispanic.<sup>3</sup> The most racially diverse adult day centers were also found to be disproportionately for-profit. On average, these centers were more likely to be for-profit and receive more of their funding from Medicaid (Lendon et al., 2020). Interestingly, another study found that more racially and ethnically diverse centers had comparable or lower percentages of participants with IDD, Alzheimer's disease or other dementias, and severe mental illness compared to less diverse centers (Harrington & Kang, 2016). This racial and ethnic diversity points to adult day centers as an important type of HCBS to investigate further, as they could provide valuable lessons for how to reach duals of color more effectively.

## **Respite Care Utilization**

Another significant type of HCBS with clear racial and ethnic utilization differences is respite care. In a 2020 study, researchers found that among caregivers of people with dementia, Black caregivers were 69% less likely to use respite compared to their White peers (Parker & Fabius, 2020). The exact reason for this difference is not fully understood, but other research has pointed to Black caregivers being less likely to use formal care generally, as well as a lack of culturally appropriate services. This data and the ambiguity of the causation points to a high need for additional research that directly engages Black duals

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<sup>3</sup> CDC data – need to confirm





about their needs and in particular their views on the engagement with formal paid care services.

## **Home Care Utilization and Quality**

The literature identified multiple racial disparities in access to home care and to the quality of care provided. One study found that while Black patients had a similar likelihood of referral to home health care at hospital discharge as did white patients, discharge to home health care was less common for AAPI (OR 0.91, 95% CI 0.88–0.95), Hispanic (OR 0.81, 95% CI 0.79–0.83), and American Indian/Alaska Native patients (OR 0.79, 95% CI 0.74–0.85) (Smith et al., 2021). As indicated, even when there is access to home health care, there are disparities in access to a high-quality home care agency (as measured based on the star-rating system). Research on Medicare home health agency use also found that Black home health patients had a 2.2% lower probability of high-quality agency use compared to their white counterparts in the same neighborhoods, while Hispanic patients were 2.5% less likely to use an agency with a high-quality ranking (Fashaw-Walters et al., 2022). This research adjusted for health status and care needs, as well as neighborhood characteristics, and still found a statistically significant disparity. As home care is a critical service designed in part to keep dually eligible individuals in the community, the racial gap in quality care points to a need for further understanding into the experiences of duals of color as they seek out home care.

## **HCBS Spending**

HCBS spending patterns reveal disparities by race as well. A recent study found a spending difference between white and Black HCBS users with Alzheimer's disease and other related dementias – while the average yearly spend for white users was \$5,913, the yearly spend for Black users was \$5,111 (Yan et al., 2021). Another study (Fabius et al., 2018) found that even when adjusting for other variables, white men had the highest total Medicaid HCBS expenditures at roughly \$70,000, while the spends for white women, Black women, and Black men were significantly lower (\$59,783, \$56,335, and \$56,088). This research shows that

while HCBS spending improves outcomes for people, spending on those benefits tends to be lower for racial and ethnic minorities.

There is evidence this HCBS spending disparity also extends to overall health spending for duals. In a study of dually eligible people diagnosed with Alzheimer's disease, researchers found a disparity in medical care spending between racial and ethnic minority duals and White duals. A report by Latinos Against Alzheimer's (2016) found lower medical care spending for Latinos with Alzheimer's disease compared to non-Latinos with the disease (\$7,496 per person per year compared to non-Latino White people at \$14,821 and African-American at \$10,559). In addition, Latinos with AD relied more on unpaid informal care than non-Latino White people with the disease. These findings suggest that significant barriers may exist for Latinos in accessing timely, quality care.

HCBS spending also intersects with geography. A 2018 study (Leitner et al., 2018) looked at the correlation between a given state's implicit and explicit bias and HCBS spending. It found that for every one standard deviation (SD) increase in implicit bias, Medicaid disability spending decreased 21% in states with low White income (but increased 4% in states with high White income) and decreased 20% in states with high Black income (but increased 2% in states with low Black income). Median household income was assessed by compiling data from the 2009–2013 5-year estimate from the American Community Survey. For explicit bias, it found that for every one-SD increase in explicit bias, Medicaid disability spending decreased 26% in states where White people had low income (but increased 1% in states where White people had high income) and decreased 24% in states where Black people had high income (but decreased 2% in states where Black people had low income). Another study (Gorges & Konetzka, 2019) observes higher Medicaid HCBS spending for White people than non-White people, and also raises the concern about the possible adverse outcomes that could result from the racial and ethnic disparities in access to HCBS that underlie disparities in resource allocation.

## HCBS Spending by Geography

Due to the fact HCBS is not a mandatory benefit and how it is funded varies greatly across states, many racial and ethnic disparities in HCBS are rooted in geography. This may come down to whether beneficiaries live in states and counties that allocate resources to HCBS. Some disparities may exist or be exacerbated merely by whether or not beneficiaries live in states and counties with sufficient HCBS resources, or by the relationship between HCBS resources and the economic and racial/ethnic mix of communities. A 2021 study (Yan et al.) found that Black HCBS users have a higher likelihood of living in counties with lower HCBS spending per person (under \$800 a month) compared to their White peers (46.5% vs. 44.5%). The same study found that Black HCBS users were less likely to live in counties with high HCBS spending (over \$1,000 per month) than their White peers (31.8% vs. 33.2%). A recent Justice in Aging report (2021) points to this same nationwide trend, citing Wayne County, Michigan as an example. Half of Michigan's population lives in 10 counties, yet those counties only receive one third of the state's total waiver slots. This means there is only one waiver slot for every 58 eligible individuals in those counties, compared to one slot for every 20 eligible individuals in the rest of the state. For a county like Wayne County, where 40% of older adults are not White, that means Michigan's communities of color are disproportionately impacted by these geographic limitations (Christ & Huyenh-Cho).

Other studies point to the geographic nature of many disparities, down to the neighborhood level. The study about home health care quality cited previously (Fashaw-Walters et al, 2022) found that 40 to 77% of the disparities identified in the study were attributable to neighborhood-level factors. A 2020 study by UsAgainstAlzheimer's found that counties with a higher prevalence of Black and Latino people with Alzheimer's disease had worse social determinants of health than found in counties with a lower incidence of Alzheimer's disease. As the report concludes, "Systemic barriers in equitable access to health services and research participation, including persistent racial discrimination, are limiting opportunities for brain health among communities of color. In many cases, brain health is inextricably linked to "place" – the geographic location where one is born, lives, works, and ages." (2020, p. 6)

## **Nursing Home Utilization and Quality**

In order to fully understand the racial and ethnic disparities in HCBS, it is also important to examine nursing homes, as people with significant care needs can be forced into these settings when community-based options are inaccessible to them. The literature has identified a racialized trend in nursing home use. In 2000, the Black population's use of nursing homes was 14% higher than White use, with the largest relative Black use of nursing homes occurring in the southern and western regions of the country. In that analysis, Black rates of use were higher than White rates in 33 of the 39 states analyzed (Smith et al., 2008). This trend continued in the next decade. From 1999 to 2008, the overall nursing home population decreased by 6.7%. However, while white nursing home populations decreased by 10.2%, the total number of Hispanic and Asian residents grew by 54.9% and 54.1%, respectively (Feng et al., 2011). Knowing that the preference of many people with complex needs, particularly duals, is to remain in community, this data could point to a lack of community-based options for people of color.

Another study looked at disparities in staffing resources – specifically, the number of RN and LPN hours per day – in facilities with high vs. low concentrations of minority residents. They found that disparities remained even after a period when staffing levels increased overall across facilities. When Medicaid rates were increased, disparities mitigated to some extent, but the use of case-mix adjusted payments exacerbated disparities (Li et al., 2015).

State HCBS spending has a direct impact on nursing home admission and also has identifiable racial disparities. A 2021 study (Yan et al.) found that higher HCBS spending was associated with a lower probability of high impairment levels at the time of nursing home admission among Black individuals, but this did not hold true for their White counterparts. It found that inadequate levels of existing HCBS spending correlated to higher levels of cognitive and physical impairment for Black individuals. In particular, the average ADL impairment scores for White and Black individuals were 17.6 and 19.1 respectively ( $p < .01$ ), and 9.8% of White individuals versus 13.7% of Black individuals had severe cognitive function impairment at the time of nursing home admission ( $p < .01$ ). This disparity points to the likelihood of greater unmet needs and lack of support for Black individuals prior to nursing home admission, but more investigation is needed to understand the experience of Black duals who have sought HCBS to remain in the community.

Curiously, the same study found that while HCBS spending positively impacted physical and cognitive impairment levels, it did not impact nursing home admissions in the same way across race. The authors found a 0.35 percentage points ( $p < .01$ ) decrease in the likelihood of nursing home placement among White people, but a 0.25 percentage points ( $p < 0.01$ ) increase in the likelihood of nursing home placement for the Black population. Since one of the main functions of HCBS spending is to divert nursing home admissions, understanding the relationship between spending on HCBS and its related impact on utilization of nursing home care across racial and ethnic lines is particularly important.

## **Assisted Living Utilization**

Depending on the level of LTSS needs, the receipt of care in an Assisted Living Facility (ALF) setting can be a viable alternative to nursing facility care when the services and supports for maintaining care at home are not available. This does not mean, however, that there are fewer inequities in access to ALFs. In fact, the literature finds inequities in access to and the quality of care provided in ALFs for dual eligible of color. While nearly half of ALFs are Medicaid certified, they are less often found in counties where people with lower education or incomes reside; as a result, dually eligible people living in those counties have limited access to ALF care. Also, because Medicaid pay rates are lower than private pay rates, ALFs may have an incentive to limit the number of dually eligible individuals they accept. One analysis shows that duals represented 18% of ALF residents in the cohort and were more likely to be younger, people of color, and disabled, with higher rates of chronic conditions and cognitive impairment (Fabius, 2022). The study also found great variability across states, with higher rates of utilization for dually eligible people in ALF care where the state had a state plan or a waiver program. This is an important option for expanding access to non-institutional care, although for some less desirable than accessing HCBS.

## Caregiver Support

There is also research on disparities in access to caregiver supports among individuals caring for minority populations. Black dementia caregivers were 69% less likely to use respite compared to White caregivers. Other factors found to be associated with rates of respite utilization (along with race) were education, having caregiver help, the type of care being provided, and to whom it was being provided (e.g., providing care for more self-care/mobility tasks or providing care to a Medicaid-enrollee (Parker & Fabius, 2020).

Family caregiving is a challenging undertaking. Caregivers take on a broad range of personal care and supervisory tasks on a nearly “round the clock” basis. For the most part this work is done in the absence of financial compensation or training. For example, in nearly all cases, caregivers of persons aged 50 have to provide assistance in at least one Instrumental Activity of Daily Living (IADL) such as shopping, balancing a checkbook, getting to places outdoors, or doing laundry. On average, caregivers of aging African Americans handle nearly five IADLs. These caregivers also take on more “advocacy” duties such as monitoring conditions, communicating with healthcare professionals, and representing their clients in business matters (NCBA, 2021).

In addition, Latinos with Alzheimer’s disease rely more on unpaid family care than do non-Latino White people. Findings suggest that significant barriers may exist for Latinos in accessing timely, high quality care for their disease (LatinosAgainstAlzheimer’s, 2020). Compared to caregivers of other races, African American and Hispanic caregivers were more likely to be single or never married, and more likely to have incomes less than \$50,000 per year. These demographic factors may limit their ability to get support in their caregiving role from other family members or to be able to afford to purchase needed care-related supports.

## **Racial and Ethnic Disparities in Medical Care Use**

Racial disparities in the use of preventive and health maintenance care were observed in adults with congenital disabilities such as spina bifida and cerebral palsy (Mahmoudi, 2021). Compared with White people, Hispanic people had lower odds of annual wellness visit but higher odds of diabetes screening. Black people had lower odds of bone density screening and annual wellness visit (MACPAC 2022).

In a four-state study in California, Florida, New York, and North Carolina (Horvitz-Lennon et al., 2015), a quality-of-care index was created to measure treatment for Medicaid beneficiaries with schizophrenia and showed lower quality care for Black beneficiaries compared with White beneficiaries. Hispanic care recipients had lower scores in all states except North Carolina. Variations were also observed between counties. All four states had variations in race and ethnicity-stratified quality of care by county.

Another study found racial differences in end-of-life care. Comparing dually eligible decedents enrolled in Medicare FFS plans, they found higher rates of hospitalization for end-of-life care for Black people (43%) vs. White people (32%) (Cai et al., 2016).

## DISCUSSION

### Limitations in the Existing Literature

It is important to identify the limitations and complexities inherent in the literature exploring this topic. As noted, there are not many recent peer-reviewed articles that specifically study the dually eligible population. Insights reported here have been drawn from analyses using populations that include some but not all of the characteristics found in the dually eligible population (e.g., older adults; Medicaid-only or Medicare-only populations). Additionally, dually eligible people are not a homogeneous group. There are full duals, partial duals, and variations within those categories with respect to whether or not coverage includes prescription drugs, and other plan and coverage type variables. There are also significant variations within and across states in terms of Medicaid LTSS service, providers, and HCBS program characteristics that may be difficult to untangle from other variables at play.

There are always going to be gaps in the data available to fully analyze access and outcome issues. Factors such as the availability of in-home supports, housing quality, and a wide range of personal and socio-demographic variables that are rarely captured in a single source. Some studies do combine survey data collection with the use of existing datasets for analysis to expand the variables available, or use additional data sources or methodologies, but there will always be exogenous variables that are difficult or impossible to control. The literature duly identifies limitations in terms of being able to fully explain what drives the clear disparities that have been identified. Specifically, the lack of qualitative information or additional data elements to provide a more complete picture of the dynamics at play. Of course, most of the analyses identify associations between unmet needs, poor outcomes, or access disadvantages and racial/ethnic identity, but the analytic methods cannot definitively prove causality.

We also note that there are few qualitative studies that allow for a greater depth of analysis into the “how” and “why” some of the trends identified in the quantitative analyses occur. That is, there is a paucity of literature focused on uncovering the underlying dynamics that are integral to understanding the



interactions among the care recipient, family dynamics, and provider and community settings.

## Data Limitations

Several articles specifically identify limitations with regard to the data available for studying these critical topics. HCBS data collection is inconsistent and limited which makes tracking racial and ethnic disparities within the existing data very challenging. The grey literature also provides a detailed look at the inadequacies of data collection. The review indicated that not only is HCBS demographic data inconsistently collected, even the data that are collected are limited in scope and not standardized, making it difficult to identify racial and ethnic disparities. This includes data pertaining to intersections beyond race and ethnicity (e.g., sex at birth and gender inclusion/identity). There is little accountability for states to collect HCBS data consistently and accurately, so it is not surprising that they do not do so.

Specific illustrations of these data and information limitations include the following:

- Current national surveys provide little detail on adults under age 65 with disabilities, the nature of their disabilities, the level of their LTSS need, or on their service utilization (James et al., 2021).
- Despite a new CMS regulation requiring it, few states have actually articulated a meaningful health equity plan in recently updated quality strategies for Medicaid managed care. CMS has rolled out a new state data reporting system, the transformed Medicaid Statistical Information System (T-MSIS), but its promise remains largely aspirational due to issues with quality, completeness and timeliness of certain data categories (Machledt, 2021).
- Many health programs do not have complete and accurate race and ethnicity data because of a lack of a clear and sufficient federal standard. For example, within the U.S. Department of Health and Human Services (HHS), two standards are used (James et al. 2021).
- There are also misconceptions about limitations on collecting racial and ethnic information with some noting a belief that there are legal restrictions

on collecting race and ethnicity data. However, there are no federal limitations on doing so. Also, only a few states limit data collection in certain circumstances (James et al. 2021).

- For a variety of reasons, individuals may be unwilling to self-identify and providers and staff may be reluctant to ask (James et al., 2021).
- The collection of demographic data for analysis is inconsistent across programs and data collection protocols (e.g., time period and service categories) differ across states. There is no single repository for all state HCBS data hosted on a website, for example (Machledt, 2021; Christ & Huyenh-Cho 2021; James et al. 2021).
- The variability in service availability, enrollment caps, waitlists, and eligibility criteria makes it difficult to make comparisons across states and draw conclusions about why there may be inequities in access to HCBS. The lack of a consistent, standardized assessment tool opens up opportunities for implicit bias (Machledt, 2021 and James et al., 2021).

## Conclusions and Concerns Identified in the Literature

This broad review of the academic and grey literature analyzing racial and ethnic disparities in access to HCBS, care outcomes, and issues in the use of care suggests clear barriers to access for dual eligibles of color. In addition, care outcomes often differ based on race and ethnicity even when other variables are accounted for. Some racial and ethnic disparities can be traced back to structural issue of state-specific uptake of HCBS as an optional Medicaid benefit, but many cannot be fully explained by structural issues alone. Some articles cite the fundamental lack of cultural competency as a factor that makes HCBS less accessible to communities of color.

Some of the other drivers identified in the literature that contribute to these disparities include the following:

- **Inequities in the supply of resources in communities where people of color reside.** For example, consider the study that found that home health

care agencies with lower quality ratings are more prevalent in neighborhoods with predominately residents of color.

- **Limited access to managed care.** Another hypothesis from the literature is that communities of color (for a variety of reasons to be determined) may have more limited access to care management or managed care plans. As a result, this could disadvantage their access to better quality, more appropriate and more timely care to meet their needs.
- **Not surprisingly, some studies find that there is an inherent racial bias/systemic racism that plays a role in creating inequities in access to care and to the quality of care provided.** This may derive from provider-bias – e.g., providers not wanting to offer in-home care in low-income/poverty or ethnic communities unfamiliar to them, or inherent racism that might impact policies and protocols with regard to Medicaid programs, provider reimbursement, HCBS expenditures, and program structure.
- **Differences in Medicaid policy and programs across states are likely an important factor in understanding HCBS disparities.** Low Medicaid reimbursement rates inherently impact dual eligibles with lower income and/or less family support who may be unable to supplement the care needs they cannot meet in other ways.
- **Other factors that likely play a role in creating or exacerbating inequities are differences in underlying co-morbidities, where a greater health burden or complexity could worsen outcomes or compromise access to the proper HCBS.** Additionally, having limited caregiver supports or caregivers with more limited access to information and training can also confound the access to care (e.g., transportation) and the outcomes (e.g., medication compliance support) experienced by people of color. In one study, American Indian, Alaskan Native and Native Hawaiian populations indicated reluctance to access programs because the offerings are not always considered culturally appropriate (NCOA, 2021).
- **Community variables are also important.** Lack of transportation and other community variables such as limited internet for telehealth or for obtaining information about providers, limited provider supply, and other community factors can also impact communities of color differently.

- **Financial access and stigma.** A study of American Indians and Alaskan Natives observed that they experience lower enrollment rates in Medicare and Medicaid because of “costs associated with premiums, their lack of awareness or knowledge, their mistrust of federal and state programs... a perceived “welfare stigma” ... and language or literacy barriers.” (Goins et al., 2015, p. 14)

## Policy Interventions

There are a number of solutions or policy initiatives that emerge from the literature as options for addressing racial and ethnic inequities in access to HCBS and the impact this may have on health outcomes. Based on existing evidence, some of the recommendations include:

- Increasing Medicare/Medicaid reimbursement rates especially for providers who serve Medicaid-eligible people of color and other vulnerable older adults;
- Developing and reporting health equity measures in outcomes of care for people of color;
- Expanding overall access to Medicaid-waiver HCBS and developing policies to assure a more geographically dispersed set of HCBS, with particular emphasis on placing them in communities of color;
- Adopting culturally-appropriate HCBS and offer better support for family caregivers of color and/or family caregivers caring for a person of color; and
- Increasing integrated HCBS programs for dually eligible individuals of color; and
- Expanding the use of proven effective care models, and/or incorporating elements from those models into programs serving dual eligible populations of color.

The literature identifies programs such as [PACE](#) and [CAPABLE](#) as models that illustrate successful ways to provide care to older adults of color.

It is important to note that CAPABLE addresses the safety of the in-home environment which is a critical intervention likely missing from other Medicaid



HCBS waiver programs for duals, but one which may be especially important for higher-risk or lower-income populations.

In closing, we find there has been little qualitative research on this topic. We are hoping to use the subsequent phases of this project, most especially the focus groups to help identify some of the provider-driver and socio-cultural and family dynamics that may be important variables not captured in the data available for studying access barriers using quantitative methods.



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