Community
Catalyst

Improving the Access and Outcomes of Home and Community-Based Services (HCBS) Use Among Older Adults of Color Enrolled in Both the Medicare and Medicaid Program:

A Summary of Findings and Policy & Practice Recommendations

Acknowledgements

Table of Contents

Executive Summary

Demographic trends forecast greater racial and ethnic diversity among America's growing older adult population (ACL, 2021). America's older adults are also living longer, making them more likely to need long-term services and supports (LTSS). Within LTSS, the essential services that help people age in place by delivering care in people's homes and communities are commonly known as home and community-based services (HCBS). Generally, people with LTSS needs prefer HCBS over care delivered in institutional settings.

With support from Arnold Ventures this project set out to explore whether the HCBS system is prepared to meet the needs of this growing and increasingly diverse aging population. More specifically, whether the system is prepared to meet the needs of an aging dually eligible population from communities of color. A population who are most impacted by poverty, have greater levels of unmet needs and often the most complex health statuses. Our project was guided by two research questions:

- What disparities in access to home and community-based services (HCBS) exist for dually eligible beneficiaries of color?

- How can we mitigate the disparities through policy change?

In order to answer these questions we used multiple study methods including: a comprehensive literature review; quantitative data analysis of Health and Retirement Study (HRS); key informant interviews; and focus groups with older adults of color who are dually eligible for Medicare and Medicaid.

Key findings across this research include:

- Demonstrated disparities with respect to HCBS spending, access, and outcomes among communities of color. These disparities include increased unmet LTSS needs; a lack of help from either unpaid care sources (i.e., family or friends) or from HCBS; limited access to HCBS; poorer health outcomes; and lower HCBS utilization and expenditures.

- Limited access to culturally and linguistically appropriate HCBS services.

- Limited access to information, training, and support for caregivers and care recipients

- Ongoing impacts of systemic and interpersonal racism including inequities in the supply of community level resources and provider bias.

- Usual source of care as a key element in reducing racial and ethnic disparities in HCBS utilization and reported unmet need, but limited access to managed care among communities of color.

Using these findings, we developed policy recommendations which we believe will help address racial and ethnic disparities within HCBS services by enhancing a combination of: (1) access; (2) quality of care delivery; (3) cultural responsiveness; (4) workforce quality, and (5) data practice.

Our top policy priorities include:

- **Connect beneficiaries with a usual source of care:** A usual source of care, as operationalized by the HRS, is a medical provider or health care location (such as a doctor's office, clinic or health center) that an individual will usually go to if they are sick or in need of guidance related to their health.

- **Strengthen the HCBS workforce**: A robust workforce that is high-quality, culturally and linguistically competent, and equipped to meet beneficiaries' needs is essential to reducing disparities in care.

- **Engage Beneficiaries, Family, and Caregivers:** Engagement should be a key ingredient in all phases of policy creation and service provision including design, dissemination, and implementation.

The policy section of the report includes recommendations on how to advance each of the above policy priorities, as well as targeted approaches to improve access, quality of care delivery, cultural responsiveness, workforce quality, and data practices within HCBS services. Additionally, the report provides a high-level summary of the research that informed our policy recommendations.

Introduction

Individuals with LTSS needs generally prefer to receive care at home or in the community, a preference that is also true for the families that care for them. Currently, over one-third of individuals with LTSS needs who are dually eligible for Medicare and Medicaid rely on home and community-based services (HCBS) to have their LTSS needs met. Policymakers championing this issue have spent decades trying to "rebalance" systems of care away from institutional settings.

Demographic trends among America's growing older adult population forecast much greater racial and ethnic diversity (ACL, 2021). In fact, the Administration for Community Living (ACL) projects that the number of older adults who identify as African American, American Indian and Alaska Native, Asian, and Hispanic is expected to grow by 115% by 2040 (2021). Because people are living longer, it is more likely that they will experience the need for LTSS. The service system must adapt to the needs of this growing and more diverse population – a population already experiencing the impacts of ongoing unmet needs (Chong et al., 2021; Gardiner, 2021). Many of these older adults are served by both Medicare and Medicaid and as the latter program has expanded access to home and community-based care (HCBS), a question arises: is the system currently meeting their needs and is it robust enough to address growing future needs? The research presented here suggests that it is not.

Research Focus

In order to begin to assess the current system's performance, we conducted a series of qualitative and quantitative analyses focused on determining whether there are disparities in the access to and utilization of HCBS among dually-eligible persons of color with LTSS needs. We also explored the extent to which there may be differences across racial and ethnic groups in the use of family care to address needs, care outcomes and unmet needs. Both efforts were informed

by a comprehensive literature review. This report summarizes the key policy recommendations that have emerged from our research on this topic – research that relied on a mixed-methods approach to define and measure the nature and scope of the disparities this population experiences, to understand what matters most to them, and to query experts in the field to identify viable policy recommendations to create a more equitable HCBS service system.

Key Findings and Policy Implications

Findings from our research and literature review demonstrate racial and ethnic disparities with respect to HCBS spending, access, and outcomes. Specifically, the studies we reviewed showed people of color are more likely to have: unmet LTSS needs; a lack of help from either unpaid care sources (i.e., family or friends) or from HCBS; limited access to HCBS; poorer health outcomes; and lower HCBS utilization and expenditures. Limited access to care likely contributes to lower expenditures and utilization rates and plays a part in poorer health outcomes. These issues are, of course, interrelated and likely driven by underlying inequities.

While many factors influence the use of HCBS, our research shows that "a usual source of care" is a key element in reducing racial and ethnic disparities in HCBS utilization and reported unmet needs. Beneficiaries who switched from Medicare fee-for-service to managed care had a significant increase in HCBS utilization.

Our research and the literature also identified factors experienced by communities of color that contribute to racial and ethnic disparities in HCBS access and utilization. While this list is not exhaustive, it includes:

- Ongoing systemic and historical racism, such as redlining and segregation, resulting in inequities in the supply of community-level resources.

- Greater underlying co-morbidities and health burdens, often caused by commercial, political, and social determinants of health.

- Limited access to information, training, and support for caregivers and care recipients

- Limited access to culturally and linguistically appropriate services.

- Increased structural barriers to accessing HCBS including limited transportation options, long waiting lists and fragmented systems of care.

- Limited access to managed care plans and a usual source of care.

- Individual provider bias, including interpersonal racism and providers choosing not work in certain communities.

- Disproportionate experiences of poverty and unmet care needs.

No single policy prescription can address these many challenges; the work requires a multi-pronged approach that focuses on strategies designed to enhance: (1) access; (2) quality of care delivery; (3) cultural responsiveness; (4) workforce quality, and; (5) data practice.

Our top policy priorities, identified by distilling learnings from this study and analyzing their potential to move the needle forward across multiple factors discussed above, are:

- Connect beneficiaries of color with a usual source of care.

- Strengthen the HCBS workforce.

- Advance efforts to engage beneficiaries, families, and caregivers.

For each of these major areas of investment, we provide concrete policy recommendations designed to help reduce the disparities in HCBS services noted in our qualitative and quantitative analyses. In addition, we provide targeted policy recommendations designed to advance the five domains pertaining to HCBS listed above.

Methods

This summary draws upon five sources of information and analysis including:

- A Literature Review which led to a report entitled "Racial and Ethnic Disparities in Access to Home and Community-Based Services among Medicare and Medicaid Dual Eligible Populations: An Environmental Scan of the Literature."

- A Data Analysis of the Health and Retirement Study (HRS) which resulted in a report summarizing findings entitled "Understanding the Utilization and Impacts of Home and Community-Based Care among Racial and Ethnic Dually-Eligible Populations Using Home and Community-Based Services: Analyses of National Longitudinal Datasets."

- A series of HCBS Key Informant Interviews with stakeholders and experts at both the HCBS policy and service delivery levels, which led to an analysis memo summarizing key themes.

- Focus group findings derived from a series of meetings with beneficiaries of home and community-based services that led to the development of a summary report entitled "Understanding the Impact and Utilization of Home and Community-Based Services (HCBS) among Medicare-Medicaid Enrollees of Color: Report on Findings from Focus Groups."

- A Community Listening Session that was used to share, refine, and validate the conclusions and themes drawn from the focus groups.

We briefly highlight our approach to obtaining the information from each of the primary sources listed above. Because our focus in this report is on policy recommendations, we provide links to the other documents, which offer greater detail on methods and findings.

Literature Review

The literature review included recent academic and grey literature to identify the nature and extent of racial and ethnic disparities in access to HCBS. Specifically, it included 34 articles from academic (peer-reviewed) literature and 19 papers from materials and research produced by organizations outside of the traditional commercial or academic spheres. The analysis focused on more recent publications from 1998 to 2022, with nearly one-third of the peer-reviewed articles having been published within the last two years. While the review focused largely on articles specifically studying populations enrolled in both the Medicaid and Medicare programs, in some cases, we examine the experience of closely related populations, specifically those who may be eligible only for Medicaid or only for

Medicare. We do this in part because there are relatively few recent peer-reviewed articles focused exclusively on the dually eligible population using HCBS.

Data Analyses of the Health and Retirement Study (HRS)

To provide new and updated information on the profile and utilization of HCBS among older adults age 50 and over with LTSS needs, we conduct quantitative analyses using data from the 2010 to 2018 waves of the HRS.[1] This nationally representative longitudinal survey of individuals age 50 and over enables us to generalize results to the U.S. population. Our analysis enables us to identify whether and in what magnitude disparities exist in access to HCBS for dually eligible beneficiaries of color[2], whether patterns have changed over time, if there are differences by region or urban/rural residence status, and whether individuals of color have similar or different experiences compared to white beneficiaries. We also uncover factors associated with differences in utilization and experience. One of the important features of the HRS is that to achieve a representative sample. It oversamples African American and Hispanic older adults, which enables more in-depth analysis of these two population sub-groups. The most recent 2018 HRS sample of community-dwelling dually eligible beneficiaries was analyzed with a focus on racial and ethnic disparities pertaining to HCBS services. The 2010 through 2018 waves of HRS were analyzed to further explore the longitudinal nature of any observed racial and ethnic disparities relating to HCBS services and how they are changing over time, as well as identify factors that may moderate these disparities.

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[1] We focused on data from 2010 forward because of the passage of the Patient Protection and Affordable Care Act (ACA) in 2010 which significantly changed the health care landscape and utilization trends since its implementation, in part by significantly expanding Medicaid coverage.

[2] At baseline, HRS respondents are asked whether they consider themselves to be White, Black or African American, American Indian, Alaska native, Asian, Native Hawaiian, Pacific Island, or something else as well as Hispanic or non-Hispanic. Race and ethnicity are considered together and respondents were not able to identify as multi-racial.

HCBS Key Informant Interviews

We interviewed seven key informants and asked them to put forward their thoughts on policy changes that could lead to a reduction in disparities in access and utilization of HCBS for dually-eligible beneficiaries of color. Stakeholders included thought leaders in HCBS, provider organizations, researchers, federal officials and advocates. The results of these interviews were aggregated and analyzed to draw out common themes related to promising practices and recommendations.

Focus Groups

We conducted eight focus groups of dually-enrolled Medicare-Medicaid beneficiaries from communities of color to better understand the nuances and complexities of their experiences with the utilization of and access to HCBS. Two groups each were conducted in Arizona, Pennsylvania, and Michigan; and one each in Alabama and Tennessee. These states were chosen not only to provide geographic diversity and variety in service system characteristics, but also because relationships with local community organizations enabled a streamlined recruitment process. Our focus was on persons of color enrolled in Medicare and Medicaid with current or prior experience using HCBS. Roughly 70% of focus group participants identified as Black/African Americans and most focus group participants (75%) were between the ages of 50 to 69 years. Thus, this represented a somewhat younger group of beneficiaries than what is typical of dually eligible beneficiaries.

A Community Listening Session to Share, Refine, and Validate Qualitative Findings

A post-focus group listening session was convened to share back key findings and themes and to gain additional feedback that allowed us to refine the findings from the focus groups. All 52 participants across the various focus groups were invited to participate and a total of 17 attended the 2-hour zoom session. The listening session commenced with participants receiving a summary presentation on key themes from the focus groups. Participants then were divided into breakout rooms and participated in a facilitated, World Cafe-style 3-part conversation[3] focusing on three primary themes that emerged from the focus groups: quality and decision-making, family versus professional care considerations, and race and racism.

[3] The World Café methodology is a simple, effective, and flexible format for hosting large group dialogue. Each element of the method has a specific purpose and corresponds to one or more design principles.

Findings

Findings from the Literature Review

The literature was definitive in highlighting the presence of racial and ethnic disparities with respect to HCBS in spending, access, and outcomes.

Compared to other populations of older adults who are receiving HCBS, people of color are more likely to have:

- LTSS needs and no informal care and/or HCBS (Chong et al., 2021; Gardiner, 2021)

- More limited access to a wide variety of HCBS (Fabius et al., 2018; 2019)

- Poorer health outcomes, which are postulated to be related to not having needs met through family or HCBS (Chong et al., 2022)

- Lower HCBS utilization and expenditures both overall and regarding specific services (Christ & Huyenh-Cho, 2021; Yan et al., 2021)

The literature offers some theories for what factors might be driving these disparities. While certain differences 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 these issues alone. Some articles cite the fundamental lack of cultural competency as a factor that makes HCBS less accessible to communities of color. In other words, providers do not represent and/or adequately respect the cultures or languages of the people they are serving, which makes beneficiaries less likely to engage with the system.

Other drivers identified by the literature contributing to disparities 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 may have more limited access to care management or managed care plans. As a result, this may disadvantage their access to more appropriate, timely, and higher quality care.

- **Individual bias and systemic racism likely play a role in creating inequities in access and quality.** Broadly classified, these can be both systemic and individual. Systemic inequities include both past and ongoing policies like redlining and systemic disinvestment which create segregated and underserved neighborhoods; policies that result in a lack of transportation, internet access, and accessibility of information about services which create disparities in access and quality of HCBS services; and policies and protocols regarding Medicaid programs, provider reimbursement, and HCBS allocations. Individual behaviors on the part of providers can include not wanting to offer in–home care in low–income and/ or ethnic communities, or biased decisions being made about eligibility or need.

- **Other factors that likely play a role in creating or exacerbating disparities have to do with underlying health conditions of various populations.** For example, HCBS beneficiaries of color are more likely to have complex and acute health needs, but less likely to have access to the quality and type of care required to meet those needs. Additionally, having limited caregiver supports or caregivers with less access to information and training can also increase difficulties with obtaining care (e.g., transportation) and achieving positive outcomes (e.g., medication compliance support) experienced by people of color.

Findings from the Focus Groups and Listening Session

The following key themes emerged from the analysis of focus group discussions:

- Both family caregivers and professional caregivers have important roles to play in meeting the HCBS needs of individuals, and people seldom rely only on professionals. Focus group participants expressed that caregivers are high-quality when they are: trustworthy (meaning they will not try to take advantage of people's vulnerability), reliable (they can be trusted to show up and do the work) and caring. Participants also placed high importance on mutual respect between care recipients and caregivers, and good communication between caregivers and the people they support.

- Focus group participants generally choose providers based on practical considerations, such as a provider's willingness and appropriateness to provide care, recommendations from their family and friends and program eligibility requirements to enroll with different HCBS programs. However, participants also mentioned that it is difficult to find willing and appropriate caregivers who can anticipate clients' needs and provide care free of disability-related stigmatism ("how would you know anything") that they often resort to recommendations they receive from their social circle.

- Focus group participants described both subtle and overt experiences of racist interactions with their HCBS caregivers and care managers; various participants shared perceptions that some providers are less willing to serve people of color.

- Focus group participants were very aware of structural and historical racism and how it negatively affects them. Some participants made an association between historical racism and feelings of vulnerability and mistrust, pointing out that even if current providers were wonderful, past experiences made them more likely to feel vulnerable.

Findings from Analysis of Health and Retirement Study (HRS)

The analysis of data from the Health and Retirement Surveys revealed that the racial/ethnic composition of dually eligible beneficiaries has been shifting over the last decade towards an increasingly diverse and somewhat younger population, leading to a decline in the prevalence of LTSS needs among the dually eligible population. There are significant differences across racial and ethnic groups regarding whether and how LTSS needs are met. Hispanic beneficiaries stand out in their much higher reliance on family care to meet their LTSS needs rather than on HCBS. They are only half as likely to report unmet LTSS needs, despite relying much more heavily on family care.

Other important findings include the following:

- As the dually eligible population's use of HCBS has declined, the reported level of unmet LTSS needs has increased – suggesting that when services are used less, there are greater unmet needs. However, people who have higher levels of LTSS needs, are more likely to report that their LTSS needs being met. Meaning that as people's LTSS needs increase, it is more likely those needs will be met by services – either informal (family) and/or paid HCBS.

- While many factors influence the use of HCBS, having a "usual source of care" is a key element of reducing racial/ethnic disparities in HCBS utilization and in reducing reported unmet LTSS need. This is particularly true for people of color, who often avoid using health care services due to issues of [distrust](#), misinformation, and low expectations regarding outcomes.

- Beneficiaries who switched from Medicare fee-for-service to managed care had a significant increase in HCBS utilization. Enrollment in managed care facilitates the procurement of and helps maintain a usual source of care for

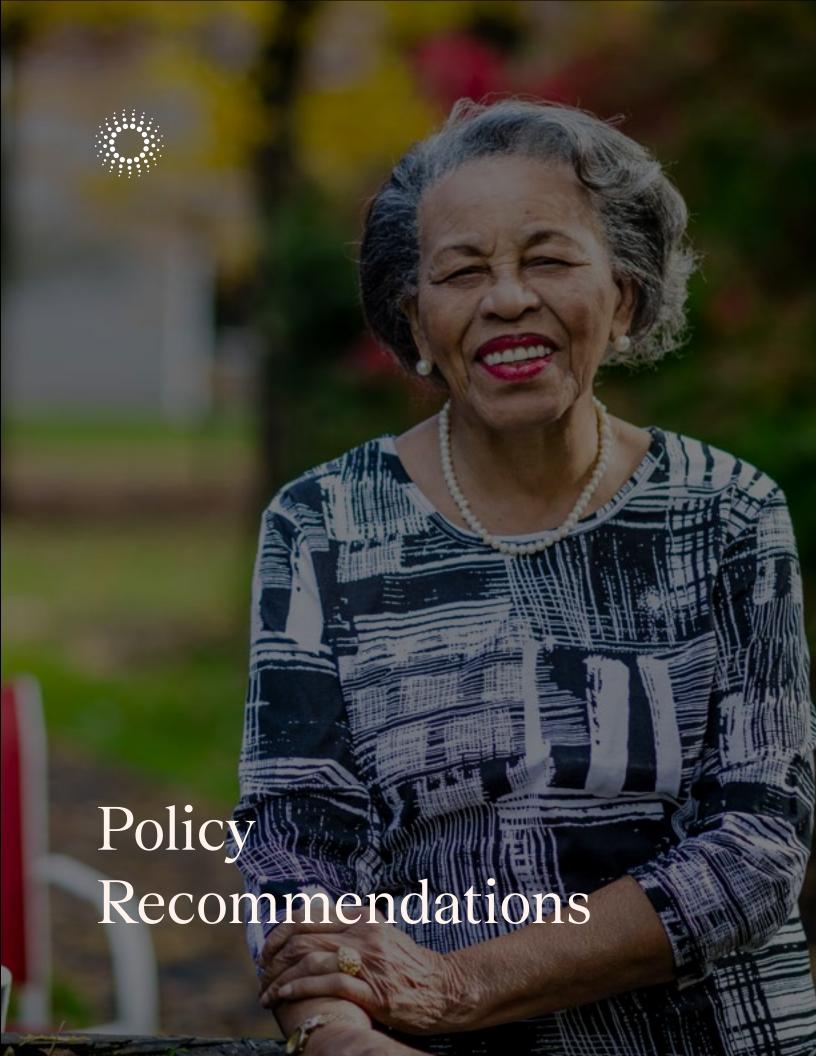beneficiaries. Having a usual source of care also emerges as a significant factor in addressing unmet needs.

- The groups that fare the best in managed care plans that successfully provide a usual source of care are beneficiaries who are non–Hispanic Black/African American or Hispanic. Thus, managed care may provide a particularly important point of leverage for reducing racial and ethnic disparities in HCBS utilization among dually eligible beneficiaries.

- Changes in dually eligible beneficiaries' use of HCBS over time vary by race, but are dependent on changes in "usual source of care". The analysis shows that from 2010–2018 when non–Hispanic Black/African American beneficiaries acquired a usual source of care, they had a greater increase in HCBS utilization than non–Hispanic White beneficiaries. Further, non–Hispanic Black/African American beneficiaries who lost a usual source of care over that time span, had greater decreases in HCBS than their non–Hispanic White counterparts. Additionally, dually eligible beneficiaries in managed care plans are significantly more likely to have a usual source of care than those in fee for service plans. This suggests that structural changes in how care is delivered – specifically by enabling and encouraging enrolling in managed care and ensuring more individuals are provided with a usual source of care – may mitigate racial and ethnic disparities in access and utilization of HCBS services.

Findings from the Key Informant Interviews

The discussion topics with key informants covered a broad range of topics related to care access and quality, measurement and data challenges about disparities, culturally appropriate care, and other factors affecting access and utilization of care. Many of the important observations shared by key informants were consistent with findings in the literature and include:

- Information on HCBS – availability and location of services – is often not available to potential recipients in an accessible way, that is, materials do not consider health literacy levels, language needs, and/or cultural issues.

- There are issues of discrimination, concerns about immigration status, and a lack of language accessibility that can deter racial and ethnic minorities from using services.

- Structural barriers to HCBS include long waiting lists, a fragmented delivery system, and limited transportation to service locations.

- Evaluating and addressing disparities without adequate equity–focused data and measurement tools makes it challenging to develop policy and practice responses.

- Lower–income areas often have fewer services available and people who have higher medical needs, resulting in unmet needs. In addition, providers in these areas often struggle to provide culturally appropriate care, resulting in poorer quality of services.

- False stereotypes can also perpetuate inequities in access to care – for example, the assumption that Hispanic and Latinx communities have a cultural preference for family care over paid care, despite the lack of objective data supporting this.

- Historical legacy of racism including redlining and segregation has led to fewer resources available in communities with a disproportionate share of older people of color along with a preference of some providers not to serve such neighborhoods.

Policy Recommendations

While the challenges associated with addressing identified disparities in both access and quality are varied, there are several policy and program changes that could be implemented to reduce disparities. No single policy prescription can do the job on its own – the work requires a multi–pronged approach that focuses on strategies designed to enhance: (1) access; (2) quality of care delivery; (3) cultural responsiveness; (4) workforce quality, and; (5) data practice.

Through synthesizing our learnings, we have made several priority policy recommendations which span multiple issue areas.

Connect Beneficiaries with a Usual Source of Care

The HRS defines a usual source of care as the place you go when you are sick or need advice about your health – 95% of people within the HRS report that place to be doctor's office or clinic. As illustrated in the quantitative analysis, having a usual source of care is a key element of reducing racial and ethnic disparities in HCBS utilization and in reducing unmet LTSS needs.

> **66** I always call my primary care doctor. I've had her over 10 years. She's always in. I usually leave her a message or she usually calls me back if it's something because we've been working kind of hand in hand a lot since 2020. So, when I call, she usually gets right back to me or I leave the message or whatever I think it may be. She's very good with that.
>
> **Focus Group Participant**

Focus group participants emphasized the importance of having consistent, respectful, and high–quality providers that they trust. This sentiment resonates with our learnings on navigating enrollment decisions – maintaining care with trusted providers is often a core component of navigating dual–eligibility enrollment options.

Facilitating or increasing the connections with usual sources of care is a complex undertaking, but can have a major impact on influencing both access and quality of care. Several potential policy directions for advancing this objective are listed below:

- **States and Health Plans can provide incentives that encourage dually–eligible beneficiaries to enroll in managed care programs.** Our research findings show that participation in managed care has a positive impact on reducing racial and ethnic disparities in HCBS utilization among older adults of color, in large part by facilitating access to a usual source of care.

- **Provide incentives to both managed care and traditional Medicare to connect beneficiaries to a usual source of care.** For managed care plans, this can be done by giving a disproportionately higher weighting in the STAR ratings calculation for plans that are more successful in achieving this. In traditional Medicare, consider higher reimbursement or bonus payments to physicians that establish long–term relationships with dually eligible individuals.

- **Implement policies that encourage managed care arrangements which improve access and quality such as the Program for All Inclusive Care for the Elderly (PACE) and the Community Aging in Place – Advancing CAPABLE programs.** These improvements are particularly noticeable among populations with the most complex needs, often disproportionately older persons of color.

However, while encouraging participation in managed care plans can be helpful, this must be done with caution, as concerns have been raised regarding managed care arrangements. It is important that any design and implementation of the policies above be attuned to health advocates' feedback and desires around managed care. Some methods for helping ensure this safeguard include encouraging meaningful engagement and collaboration with advocacy and beneficiary organizations around the design and implementation of managed care programs and incentives. One possible vehicle for engagement is Enrollment Advisory Committees (EAC's) which Dual Eligible Special Needs Plans (D-SNPs) are required to have under the 2023 Medicare Advantage and Part D final rule. EAC's provide an avenue for direct feedback between enrollees and managed care plans. Resources for Integrated care recently released tip sheets on forming an EAC and incorporating EAC feedback. In general, policies should ensure that beneficiary choice is maintained and people are provided access to a range of provider options. Accountability should also be built in through clear standards for managed care and performance measure requirements to measure the quality of care. Finally, pilot programs can be used to test different approaches in select regions or states in order to better understand the impact they have on dually-eligible beneficiaries.

Strengthen the HCBS Workforce

In addition to a usual source of care, high-quality staffing is needed. Recent experiences with HCBS ARPA spending plans, has demonstrated that increasing wages, benefits, and career opportunities for direct care workers is critical to maintaining access to home and community-based care. Moreover, there is new evidence that increasing the compensation of workers has significant economic benefits including reducing turnover and staff shortages, enhancing the quality

of care, reducing expenditures on public assistance, and infusing new dollars into local communities to support economic growth. [This guide](#) developed by the HCBS Learning Collaborative provides a number of concrete steps that can be taken at federal, state, and local levels to strengthen and diversify the HCBS workforce and ensure there are providers for the most underserved communities.

> **❝** Childcare issues or transportation issues or whatever their issues are because they're not paid, I think that we can all agree that that's... [...] part of the process, is the fact that the people can't fully continue those services because they get tired over time...
>
> **Focus Group Participant**

A prominent finding from our focus groups was that low wages also lead to strains on relationships between caregivers and patients. Caregivers struggling to afford childcare, transportation, and other costs of living impacts their ability to be consistent, reliable, and remain in a low-paying field. In turn, these issues have both access and quality for care recipients, as this can lead both to disengage from each other and encourage turnover among paid caregivers and a sense of churn among care recipients.

"If they pay more, then we would get the quality of workers that we need to come out and assist us with our needs."

Focus Group Participant

Given the under-investment in communities predominately made up of older adults of color, increasing the wages of HCBS workers would likely have a disproportionate and positive impact on these communities. Data also shows that the direct care workforce is predominately comprised of Black/African American, and Latina/Hispanic women.

> 66 We need more healthcare providers that have different characteristics, and I think in that way, they are going to provide more diverse help to people that need them. We need therapists that are Black.
>
> We need nurses or even therapists, or social workers, or pediatricians, that are in the [Inaudible] general spectrum or that they're Black. We need those that are disabled too... The people that have those specific needs will feel comfortable, and encouraged that they have someone that they can talk to, that they share characteristic with, yes.
>
> **Focus Group Participant**

High-quality care is culturally and linguistically appropriate. As highlighted by a focus group member above, a diverse provider population that reflects beneficiary populations is essential. However, without livable and sustainable wages or career mobility recruiting and retaining the target workforce is near impossible.

Policy mechanisms that can be used to strengthen an equitable and high-quality workforce include:

- **States can implement requirements that promote livable minimum wages for direct care workers.** States can use waivers, such as the 1915c waiver, and state plan amendments to design innovative policies for long term care services – including setting standards for livable wages for direct care workers. States can also require high percentages of Medicaid service payments for HCBS services to pass through directly as wages to the lowest-paid sectors of the HCBS workforce, or by directly mandating livable minimum wages for direct care workers. Further CMS can assist by providing guidance and technical assistance to states on how to use the above levers, as well as provide incentives and promote collaboration with all stakeholders. While many of the recommendations below also hinge upon providing livable wages, trends suggest this is an area that is gaining momentum and while in transition the below suggested practices can still be implemented in parallel.

- **States and Localities Can Build Career Pathways and Fund Targeted Recruitment.** One of the most important ways to recruit and retain HCBS workers is to build career ladders and pathways. HCBS workers often have some level of general training but not knowledge on specific disabilities. Improved training focusing on enhancing skills, training for advanced roles, and specialty training (e.g., for conditions such as dementia and cardiovascular disease) will help to professionalize the HCBS workforce and improve quality of care. It is worth noting that some community programs recruit high school students for certified nursing assistant training, preparing them to work for HCBS providers by the time they graduate. Another example is state level cross agency initiatives, such as the Health Professional Equity Initiative in Rhode Island, which removes barriers

to career advancement for paraprofessionals supporting underserved communities. States can also partner with anchor institutions and consider innovative collaboration with community colleges, Historically Black Colleges and Universities (HCBU's), and Latinx serving institutions to create pathways to careers. These pathways could include mentorships, internships, scholarships, and specialized training.

- **Hire Representative Staff.** Providers can prioritize culturally appropriate and responsive services to care recipients by recruiting and hiring staff that have cultural, ethnic, racial, and linguistic concordance to the people they support. This practice is especially important for supervisory, management, and leadership roles where decisions about care delivery are often made. To successfully implement this best practice, it must be done in unison with livable wages and targeting skill building so that people have what they need to thrive in these roles in a sustainable manner.

- **CMS and States can implement differential provider payment rates.** Increasing public program reimbursement rates for providers who serve dually-eligible older people of color or serve communities or geographic areas that do not have adequate HCBS infrastructure in place can help overcome supply-barriers to access.

- **Compensate and train family caregivers.** Not only are older people of color less likely to use paid services and more likely to rely on family, but many also report unmet needs. Financial support for family caregivers could help address both access and quality disparities among older people of color. Regardless of workforce advancements, family caregivers will always play an essential role in HCBS. Policy advancements to bolster the HCBS workforce should be done in conjunction with providing caregivers the resources they need. For example, the nationwide Guiding an Improved Dementia Experience (GUIDE) model through CMMI seeks specifically to

provide 24/7 supports to caregivers including training and education in order to reduce disparities and reduce caregiver strain. A thriving, person–centered and flexible system of HCBS care is one where paid workers support people in unison with family caregivers. Compensation and skill–building is necessary – it benefits the care recipient, family caregiver, and paid HCBS worker when family caregivers receive training, oversight, and compensation for the work they do supporting family members. Currently, a select number of states allow this and there is a growing consensus that the benefits of doing so justify the investment. Such a policy approach would have a particularly significant impact on certain groups of older adults, as demonstrated by HRS data Hispanic groups, rely most heavily on family care when compared to other racial and ethnic populations. In addition to standardizing the ability to be compensated and opportunities for learning for family caregivers, supporting the RAISE Act National Strategy, and the expansion and implementation of the CARE Act across all states are meaningful policy steps forward.

Engage Beneficiaries, Families, and Caregivers

Engagement builds trust between health systems and communities, and providers and care recipients – which is critically important to obtaining positive outcomes. Meaningful engagement also ensures that community voices and experiences inform discussions around policy and practice. Engagement should be a key ingredient in all phases of policy creation and service provision including design, dissemination, and implementation. To advance engagement within the HCBS system:

- **States, health plans, and health systems can create beneficiary/family advisory committees.** State level community advisory groups, requirements that HCBS provider leadership and boards of directors include HCBS

beneficiaries, and local advisory boards are all ways to ensure HCBS beneficiary voices are meaningfully heard.

- **Health systems and providers can promote active engagement in care planning.** Many families want to be involved in their family member's care, to make sure that the needs and preferences of their family member are heard and considered. This is important because it has [been shown](#) that by doing so, perceived quality of care and care outcomes improve

- **Providers can engage HCBS users and family caregivers as managers and bosses:** Many people receiving HCBS and their close family already manage both family and paid caregivers to ensure that their needs are met. This challenging work is under-appreciated, under-invested in, and uncompensated under current systems. We recommend an investment in empowering people in these roles and providing skill building opportunities so that self-directed care is a viable option. This should involve recognizing and building appreciation for this management work, working together with people doing the work to develop systems and tools to support them in this work, and building in compensation for the work. Particular attention should be given to rural communities where self-directed care is a more challenging and burdensome endeavor given provider shortages, making it a less feasible option.

In addition to these broader recommendations, we also believe targeted policy interventions pertaining to each of the domains discussed above will lead to reductions in disparities and improved access and outcomes for older adults of color with LTSS needs.

Targeted Policy Recommendations by HCBS Issue Area

A. Access

Policies designed to reduce and better manage HCBS waiting lists. A frequently cited policy recommendation is to find ways to both eliminate and/or prioritize wait lists for HCBS. Because HCBS remains an optional benefit in many states, and is subject to funding constraints, many people are on waiting lists to receive services. Receipt of service and placement on a waiting list is often only a function of when someone applies for benefits. However, policymakers should consider a system that prioritizes individuals with the greatest care needs, those who live in underserved communities, or individuals who have been on the waitlist for more than a specific amount of time. Given that needs are often greater among older adults of color, such criteria could then help to amend some of the inequities in access.

A policy that would benefit all HCBS eligible individuals would be to **make the benefit mandatory** under the Medicaid program. For example, federal legislation such as the HCBS Access Act would make HCBS a mandatory, not optional, benefit and create national, minimum requirements for HCBS. Finally, federal legislation based on policies underlying the Better Care Better Jobs Act would enhance Medicaid funding for home care, which would help the over 650,000 people on HCBS waiting lists nationally receive care.

Reducing Medicaid institutional bias. Despite the overall shift in Medicaid funding toward community-based settings and recent regulations such as the HCBS settings rule, an institutional bias remains against community-based care options. Even for states that do not make HCBS a mandatory benefit, there are a number of steps that can be taken to reduce this bias such as making permanent and

investing in community integration demonstration programs like Money Follows the Person or the Balancing Initiative Program. The former can have an important impact in reducing access disparities, since beneficiaries have much greater flexibility in finding and hiring care support workers. This includes ensuring those who utilize HCBS have the opportunity and supports to participate in programs for self-directed care. Liberalizing spousal impoverishment protections has been shown to have a relatively small financial impact on the system, but could enable individuals to remain in the community and access HCBS.

Enable retroactive HCBS coverage. Currently, retroactive Medicaid coverage is available to those admitted to nursing homes or other institutionalized care, but not to individuals in need of HCBS services. This discrepancy has a specific impact on older adults of color, who may be forced into nursing facilities due to a lack of resources, a lack of knowledge about and access to HCBS alternatives.

Use presumptive eligibility to better streamline Medicaid enrollment. To address some of the information challenges faced by older adults of color, a strategy of presumptive eligibility for Medicaid enrollment could reduce an access barrier. Presumptive eligibility is currently available to adults in a limited amount of states. Presumptive eligibility allows beneficiaries to access HCBS more quickly and it would help close the gap between those who are eligible for Medicaid coverage and those who use it – a particularly acute problem for older adults of color. Presumptive eligibility for HCBS would disproportionately help older adults of color.

Increasing support for respite services. Respite is a highly desired and needed care resource, especially where consumers are receiving care from family (in whole or in part) either because of shortages, preferences, or access barriers. Hispanic older adults would benefit disproportionately from such investments, given their higher-than-average reliance on family caregivers. Strategies include

funding for the National Family Caregiver Support Program, which provides grants to states to provide respite care, as well as working to ensure that both respite and adult day care are covered benefits under Medicaid and Medicare individually and specifically available within the HCBS program for dually-eligible beneficiaries. Funding for respite could come from a variety of sources, an example being to increase funding for the Older Americans Act. The Older Americans Act currently facilitates meal delivery, transportation, legal assistance, housing and home-based care but is limited in reach due to its funding limitations.

Disseminate Information on HCBS. Increase the availability of HCBS information in inpatient settings, such as at hospital discharge, in senior housing and community centers, and in faith-based institutions. Information should be developed in multiple languages and be tested prior to widespread distribution to assure it is culturally sensitive and accessible. Another approach is to develop caregiver registries, something being piloted in several states. This approach promotes engagement in one's care and allows beneficiaries to select providers based on quality indicators that are important to them, including cultural fit. Finally, another option is using school-based campaigns to advertise the availability of services; families often trust and respond to school-provided information more than information from other sources.

> " I talked to so many families – even now as a researcher – that have no idea where to even start in terms of finding services, whether they'll be eligible, misunderstandings about Medicaid eligibility...and oftentimes, that uncertainty is universal.
>
> **Academic Researcher from Key Informant Interviews**

Improve Wi-Fi access. A large amount of information is now provided via the internet. There are major gaps in broadband coverage throughout the country, and in particular, in rural communities. Investing in community hotspots and broadband to ensure internet access, will enable individuals to more effectively locate and make informed choices about HCBS services. Of course, this must be accompanied with efforts to ensure digital literacy to ensure that people can efficiently navigate web-based information.

B. Quality

Improve quality measures for HCBS. In order to better understand quality and focus on what matters most to utilizers of HCBS, providers, researchers and policymakers should deploy and improve upon the [Home and Community-Based Services Quality Measure Set](). To assess the quality of HCBS programs effectively, it is essential to utilize a comprehensive set of quality measures that align with the priorities and outcomes most relevant to beneficiaries. By incorporating dimensions such as safety, effectiveness, person-centeredness, equity, and efficiency, a holistic assessment of HCBS program quality can be achieved. One critical aspect of quality measurement is addressing inequities and social determinants of health. By monitoring and addressing disparities in access, outcomes, and patient experiences, healthcare systems can work towards eliminating unjust differences in care and outcomes for patients from underserved communities. This focus on equity can ensure that HCBS programs are designed to meet the specific needs of underserved populations and promote fair and inclusive access to high-quality services. Furthermore, it is crucial to engage underserved communities in the prioritization and validation of quality measures. By involving community representatives, particularly those from underserved communities, researchers and policymakers can ensure that the selected quality measures accurately capture the experiences and outcomes that matter most to

individuals in these communities. This validation process enhances the relevance and applicability of the quality measures, ultimately improving their usefulness for assessing and improving the quality of HCBS programs. By actively involving underserved communities, researchers and policymakers can foster a sense of ownership and empowerment, ensuring that the measures truly reflect the needs and perspectives of the populations they aim to serve.

C. Building Cultural Responsiveness

Develop trauma-informed culturally-appropriate HCBS practices. Focus group participants and key informants put forward the view that experiences with structural and interpersonal racism have contributed to a lack of trust in the HCBS service system. Further, participants and informants emphasized the lack of culturally appropriate care – e.g., treatment environments that do not reflect the traditions in music, food, and art of the people they serve, or care planning that does not incorporate cultural norms around family or aging. One path forward is to ensure meaningful community engagement is embedded in the design, implementation, and ongoing maintenance of HCBS systems of care in order to ensure community needs and preferences are at the center of service delivery. Examples include cultural translation, co-design, and community advisory boards. Another idea is to ensure that the engagement touch points are trauma-informed – recognizing that collective and individual trauma has a profound impact on people's needs and relational style. For example, trauma-informed outreach, enrollment, and services could all contribute to building trust among beneficiary populations.

While there are many examples of how to design trauma informed programs and engage in trauma informed care, there are fewer concrete examples of how to ensure policy making and state or federal level system design is trauma-informed.

Engaging with and encouraging use of the resources, toolkits and trainings of the [Trauma-Informed Care Implementation Resource Center](#) is one concrete way to move forward on this objective. However, it is an important concept that requires further investigation.

> **66** ...my research primarily focuses on Black African American and Hispanic Latino persons with dementia and their care providers. When I talked with these communities oftentimes in engaging with caregivers for example, they often say they struggle with finding culturally relevant resources that they can use to assist their person that they're caring for. An adult day program for example might not have the right appropriate fix in terms of culture that they might prefer in terms of amenities, different services that are provided.
>
> **Academic Researcher from Key Informant Interviews**

D. Workforce Quality

> " I get a lot of feedback from direct care workers that communicate they just feel undervalued with lack of wages and benefits. And more importantly, they don't feel adequately trained to provide services.
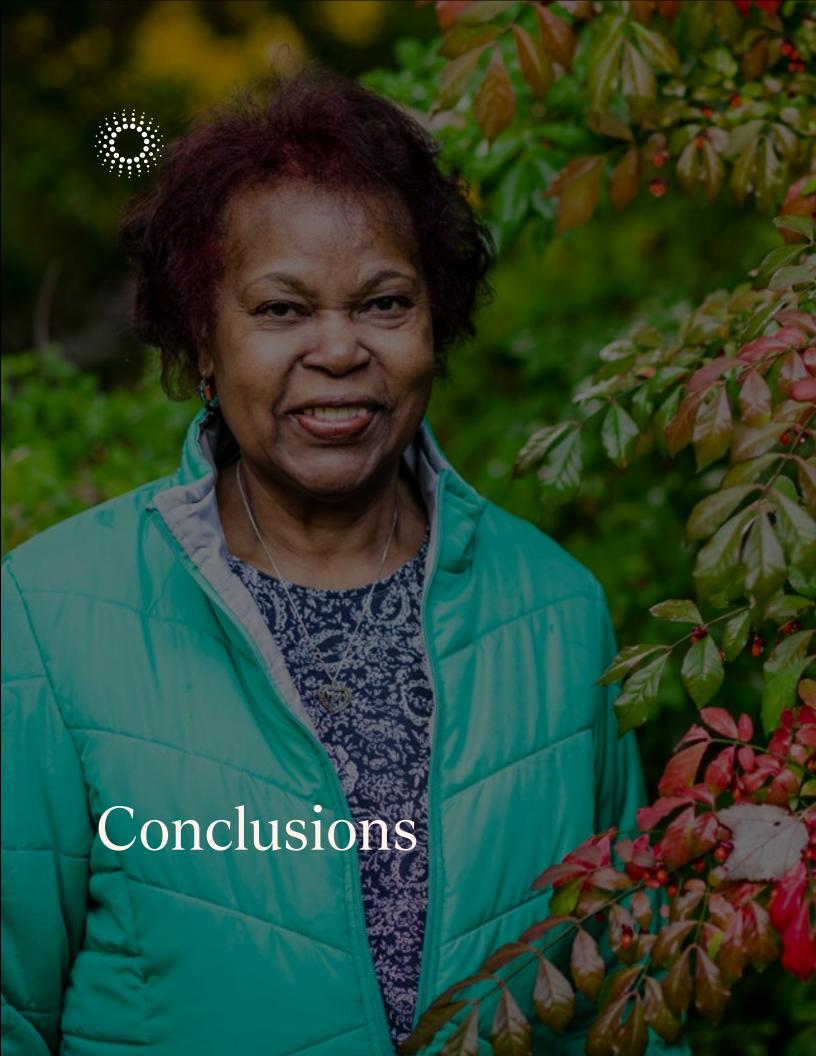>
> **State Official from Key Informant Interviews**

Federally-mandated minimum standards for staff training. Should the federal government enact a policy making the HCBS benefit mandatory, establishing federal minimum standards for HCBS workforce training (e.g., using trauma-informed, and culturally-competent approaches) would be warranted. This is important since training requirements for the direct care provider workforce are highly variable across states. There is also little guidance and few consistent requirements on when training needs to be repeated or refreshed, which can make "portability" of direct care workers across states very challenging and encumber the ability to address geography-specific shortages. However, increased credentialing would need to be done in a way which does not unintentionally create further barriers for people to enter the workforce. For example, funding and incentives would be needed for trainings and states would need to ensure trainings prioritize meaningful skill building by engaging beneficiaries and low-wage direct care workers in training design and implementation.

E. Improved Data Practices

Expand and Improve Data. The limited information available to researchers and policymakers makes it difficult to understand outcomes for HCBS users. As a starting point, policymakers should require the collection and reporting on HCBS utilization and patient experience data by race, ethnicity, and language. This data will be crucial to understanding racial and ethnic disparities at a sufficient level of depth. Included in such efforts should be a focus on specific health equity measures related to both access and outcomes.

HCBS Data Clearinghouse. Given the wide range of services provided under the rubric of HCBS, and their highly localized nature, it is challenging to obtain an overall picture of system performance. This encumbers policymakers, practitioners, and researchers from learning about best-practices in service delivery around the country, cataloguing the user experience and factors related to successful outcomes, and understanding the relationship between specific policy actions and outcomes. For these reasons, investing in developing a data and research clearinghouse for community-based HCBS research could help to diffuse local successes more quickly across the country. As part of this effort, it is important to directly engage HCBS recipients in data development efforts and research project development.

Conclusions

Our efforts to identify issues involved in accessing HCBS among older adults of color who are enrolled in both Medicare and Medicaid have uncovered a variety of challenges to obtaining high quality care. These range from supply–side constraints like shortages of workers, cultural competency and training issues among HCBS workers, to the effects of historical and ongoing structurally racist policies which have led to segregated neighborhoods that are underserved by providers, and more. The relative diversity of challenges presents opportunities for making improvements in both policy and practice – improvements that run the gamut from additional training of the workforce, to encouraging enrollments in managed care in order to obtain a usual source of care, toward policy responses such as increasing federal and state investments in the program to attract labor through higher wages, targeting dollars to underserved areas and populations, and requiring that HCBS be made a mandatory benefit under the Medicaid program.

These actions would affect all HCBS users. However, given their unique experiences and challenges with the system, older adults of color would potentially benefit the most. While the larger policy changes may take more time and effort to implement, nothing prevents putting in place many of the practice recommendations derived from the insights gleaned from the qualitative and quantitative work completed and reported herein. The nature of the growing challenge and options for system improvement suggest that there are real opportunities to move the needle on reducing disparities in access and outcomes and create a more equitable HCBS system. To do so would help ensure that **everyone** who requires HCBS is able to benefit fully from the system.

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