Key Informant Interviews Initial Analysis
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The qualitative analysis component of the project seeks to provide greater context to our quantitative results while improving our understanding of barriers and challenges to reducing disparities in access to home and community-based services (HCBS). We seek to develop the evidence base needed to push for urgent policy change that will impact dually eligible individuals of color. This set of stakeholder interviews includes executives and leaders in HCBS, provider organizations, researchers, federal officials and advocates. The key informant interviewees were predominately people of color and are racially and ethnically diverse. We interviewed 7 key informants from June to September 2022.

To analyze the key informant interviews, we developed a qualitative coding guide based on our primary research questions and key informant interview protocol[1]. Our key research questions were:

1) What disparities in access to home and community-based services (HCBS) exist for dually eligible beneficiaries of color?
2) How can we mitigate the disparities through policy change?

Each interview was coded for challenges, disparities, promising practices, and policy recommendations, then sub-coded depending if the informant spoke about quality, access, outcomes, or other HCBS issues. In addition to this main coding structure, we coded for any systemic or socioeconomic factors that key informants identified as contributing to HCBS access or quality issues and any information about how the Latinx population uses HCBS services.

Each interview was independently coded by two members of the research team. After this independent coding, the research team met to discuss any discrepancies in coding or additional codes that should be added to the coding structure.

Key informants identified several barriers to HCBS which are particularly impactful for older adults of color. These themes identified within interviews can broadly be categorized as issues related to access and/or quality of HCBS services.

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[1] Our key informant interview protocol can be found in the Appendix A.

Access: Challenges, Barriers & Disparities

Issues related to access to HCBS mainly fell into two themes:
1. challenges due to knowledge and navigation of the system, and
2. challenges due to HCBS care and service infrastructure.

Access: Knowledge and Navigation Challenges

"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

In order to utilize HCBS, individuals and families have to know that services exist. Key informants discussed disparate experiences in the availability of information. For example, informational materials are often not translated in a way which accounts for health literacy or cultural needs. Additionally, large swaths of rural areas lack access to broadband services, effectively eliminating an important way of accessing care and information sharing. This makes it incredibly difficult for individuals whose first language is not English and rural communities to find basic information on HCBS eligibility and services. As a result, many individuals and families lack information, awareness of resources and have a limited understanding about the differences between Medicaid and Medicare coverage.

Fears that participation in HCBS may threaten a person's immigration status or jeopardize a family member also pose a barrier to care. Many providers ask for a beneficiary's social security number at intake which can be a loaded question. Additionally, experiences of interpersonal discrimination and the lack of language accessibility are commonplace among racial and ethnic minorities. Key informants discussed that these experiences may deter people from services.

Access: Care and Service Infrastructure

When individuals and families determine they are eligible and try to receive services, limitations in existing HCBS infrastructure present an additional barrier. Long waitlists, underfunded programming, and fragmented service areas all mean that eligible individuals may not be connected to care right away. Some agencies may choose not to serve a particular area or neighborhood, and others may not have the capacity to offer services in languages other than English. Individuals in rural communities may be unable to participate in services due to limited transportation options and long travel distances.

Access: Disparities

The access challenges and barriers discussed above have disparate impacts on racial and ethnic minority groups, especially when combined with the compounding effect of other social and

systemic forces. An example was given of one state which had a seven-year waitlist for their HCBS waiver. While all people on the waitlist continued to grow sicker and more impoverished, Black older adults and other racial/ethnic groups navigated the waitlist with greater levels of impairment and fewer resources. One key informant discussed a study which found that a whole region of a state where 40% of the population identified as Black, Indigenous, and/or people of color completely lacked HCBS waiver services. The Indian Health System was given as another example. Due to chronic underfunding, IHS is struggling to meet the demands of COVID-19, let alone provide access and supports to elders to help them age in place.

Quality: Challenges, Barriers & Disparities

Quality barriers and challenges to HCBS also fell into two themes:
    (1) challenges due to a lack of equity focused data, and person-centered data in general; and
    (2) a lack of culturally appropriate and linguistically accessible care.

Quality: A Lack of Data, Measures and Nuance

A prominent theme across key informants is the dearth of meaningful data and measures that capture equity and quality within HCBS services. Interviewees highlighted the significant gaps in knowledge created by the lack of widespread, stratified, and consistent data. Concerns were also raised that even when data is gathered that it is of low quality.

"...we found that HCBS beneficiaries often have chronic conditions and their functional ability declines over time and if we're thinking about quality metrics focusing on improvements related to health status and function is not adequate enough given that they will decline over time. Rather thinking about improvement in quality of life and community integration is extremely important and this applies to all HCBS beneficiaries and not necessarily just for people of color." ~ Federal Official

Key informants also highlighted that variations between states, rural and urban areas, agencies and communities create a complex and nuanced situation with many within group differences. These differences need to be parsed out and considered carefully. For example, while the majority of information about indigenous communities focuses on tribal settings, 70% of indigenous people now live in urban areas. People's needs, barriers, challenges and experience of disparities may vary greatly depending on context. Another example discussed in interviews was the digital divide related to technology. While affordability may be an issue across the board, certain areas lack technology access, which translates to both decreased access to care and decreased data collection. This issue impacts subgroups of people living in rural areas more than their urban counterparts.

Quality: Culturally Appropriate Care

Key informants also discussed that when services are available, they are often not culturally or linguistically appropriate – culturally adapted nutrition, music, decorations, along with recruitment and attainment of staff who speak the same language as beneficiaries are frequently overlooked. However, many people prioritize providers who can meet their cultural and linguistic needs. These providers are typically smaller community organizations who are underfunded and consequently able to offer a narrower array of clinical services. In turn, people may forgo services or broader service options in order to obtain culturally appropriate services.

"But those access points work hand in hand with the preferences. So if you don't make the food, for example, that people want to eat, they're not going to prefer it. If you don't have language-specific adult day centers, where folks can spend their days or a couple of days a week or a couple of hours a day, they're not going to prefer it." ~ Academic Researcher

Quality: Disparities

"…there's really no quality measures for HCBS." ~Academic Researcher

As discussed above, similar to waitlists, the lack of nuanced and high-quality data likely has disparate and magnified impacts on the quality of HCBS services received by Black, Indigenous, and people of color (BIPOC) communities. From a data perspective, the narrative of how HCBS services are experienced by BIPOC populations is thin and in desperate need of broadening. However, key informants made clear their impression that disparities exist among BIPOC HCBS service beneficiaries and often mirror larger societal trends and forces.

"So where people live, determine sort of the services that are available to them. And what has been found in the literature, or at least reported in the literature, regarding something like Medicare home health, for example, is that living in a more disadvantaged neighborhood, lower-income, more poverty, with high concentrations of racial and ethnic minority groups is associated with receiving lower quality or low star home health care from home health agencies. And so I could imagine, even though we don't have those measures for HCBS, that it looks pretty similar in terms of the timing of care delivery, starts of care, the turnover challenges, whether there are preferences of the agency to even serve a particular area or neighborhood." ~ Academic Researcher

Lower-income areas are likely to have fewer services available yet higher needs, resulting in poorer quality. Further, while the quality issue of culturally appropriate care impacts the HCBS system as whole, it disproportionally impacts racial and ethnic minority groups. While the data is lacking, key informants painted a picture of how these issues compound and intersect, ultimately impacting low-income and BIPOC communities in magnified way.

"…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

In addition to access and quality issues, key informants also identified other important challenges, barriers, and disparities in HCBS. Ongoing challenges building and maintaining a quality HCBS workforce, and systemic and socioeconomic factors impact access to and the quality of HCBS.

Building & Maintaining a HCBS Workforce

The shortage of HCBS providers has been a building crisis for many years. Low wages, limited training and educational opportunities, inadequate benefits and low reimbursement rates all contribute to the difficulty attracting and retaining direct-care workers. These same factors may also contribute to poor quality care. Several key informants mentioned workers feeling inadequately equipped to provide dementia care and other specialized services. This shortage means that there aren't enough workers to provide in-home care to everyone who wants those services. Similarly, when a direct-care worker decides to leave for another job it can mean certain neighborhoods or zip codes lose access to services entirely.

"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

Key informants identified the importance of having providers who have the same ethnic, cultural, and linguistic background as the people they care for. Individuals seeking services look for workers who share their background and speak their language. Two key informants raised an important point about who often makes up the direct-care workforce. BIPOC women, particularly immigrant women, are heavily relied on to provide care.

Systemic and Socioeconomic Factors

Key informants identified several societal factors that impact HCBS, including: an underfunded and overstretched health system, prejudice and racism, cultural norms, and the ongoing COVID-19 pandemic. Across the country, health systems (particularly federal systems like the Indian Health Service) struggle with underfunding. This impacts care delivery, service availability, and the ability to attract and retain care professionals. Without adequate funding, health systems cannot provide all of the services the community needs. Rural areas face additional challenges due to poor broadband access, which not only makes it more difficult for families and individuals to find information on HCBS, but also limits the possibility of telehealth services filling in service gaps. The COVID-19 pandemic has only pushed an already stretched health system to the brink, causing some providers to scale back what kinds of services they can offer.

Systemic racism, ableism, and ageism also impact HCBS. Racist policies that have economically depressed neighborhoods, such as segregation and redlining, mean that fewer resources are available in communities with larger BIPOC populations. Some providers may choose not to serve certain neighborhoods or communities, further limiting care options. Other racist policies, like public charge, mean that immigrants avoid seeking out health services due to fear that participation in these services will negatively impact their own, or a family member's, immigration status. Negative perception of older adults and disabled people can also impact

whether or not a person receives services and the perceived importance of improving these care systems.

> *"I mean, you could start with segregation, you could start with things that are sort of beyond the reach of HCBS. So where people live, determine sort of the services that are available to them...living in a more disadvantaged neighborhood, lower-income, more poverty, with high concentrations of racial and ethnic minority groups is associated with receiving lower quality or low star home health care from home health agencies." ~ Academic Researcher*

Specific Learnings: Hispanic & Latinx Community

Within the key informants interviewed, those that had expertise specific to Hispanic and Latino communities were few. However, specific learnings from those interviews warrant further inquiry and reflection given the findings in the quantitative portion of the project. A prominent point specific to Hispanic and Latinx communities that came up is the harm caused by assuming decreased utilization, at its root, is due to a cultural preference for family support.

Instead, questions about decreased utilization of HCBS services among Hispanic and Latino communities should be framed in terms of what about current HCBS services cause a generally less-resourced group at high risk for health issues to at times go without them. Cultural emphasis on family should not be fully discounted, but investigated further, particularly in terms of how HCBS services are currently inclusive, or exclusive, of family and meet related cultural needs. Key informants highlighted that many of the issues discussed above such as language accessibility, immigration status and related stereotypes, culturally adapted care, and a lack of trauma-informed approach to treatment impact Hispanic and Latino communities in a compounding way.

As discussed by one key informant, navigating cultural expectations and attempting to get needs met can be a stressful experience, especially for younger generations who may not fully agree with the expectations of their family's culture. Some Hispanic and Latinx family caregivers may find themselves expected to provide care with limited resources, at times to people they don't wish to provide care to. Navigating this double bind can be challenging and isolating, especially when culturally appropriate, integrated, and high-quality HCBS services are lacking.

Promising Practices for HCBS Providers

Access

Key informants mentioned improving access to information about HCBS in order to reach more eligible care recipients. One key informant suggested increasing the availability of HCBS information in inpatient settings, such as at hospital discharge. Another suggested improving overall Wi-Fi access through community hotspots, which is particularly important in rural areas.

"I think that that is the first start because some of the larger policy issues that we often think are the solution—which they are part of the solution—they don't touch on those sort of day-to-day experiences that people have, and actually interacting and interfacing with the system. If people can't find the resources or know where to look for information, it's difficult for them to even begin to navigate the system. So I think that talking to folks." ~ Academic Researcher

Caregiver registries were offered as one option for increasing access to information about HCBS, and is being piloted in some states. Another option is respite care maps that show respite availability by county.

Quality

In order to better understand quality at a larger scale, HCBS providers should co-develop a core set of quality measures with HCBS users, including quality measures that address the needs of specific subpopulations (for example, young adults with developmental disabilities). The current lack of standardized quality measures limits capacity to understand where unmet needs are in terms of quality.

Building community-based models of care can also improve overall quality. As one key informant suggested, many families want to be involved in their family member's care, and would be better served by HCBS that involve families of care recipients.

Building Cultural Responsiveness

Key informants identified best daily operational practices that HCBS providers can employ to promote culturally appropriate and responsive services to care recipients of all backgrounds. At a foundational level, it's important for HCBS providers to have a staff that looks like the communities they serve. Key informants reported that service providers are often not of the same cultural backgrounds, which is especially challenging when care recipients speak different languages than service providers. HCBS providers should prioritize hiring bilingual staff to ensure that a care recipient always has access to staff that can communicate with them in their primary language.

One key informant mentioned the practice of having language-specific opportunities for connection at adult day centers – for example, an adult day care center could have a Haitian Creole-speaking room. Culturally-specific foods and music also help make an environment welcoming, and can make a significant difference in making services feel useful, meaningful, and safe for care recipients and caregivers.

In order to build culturally appropriate home and community-based services, providers need to directly engage care recipients for feedback. What is needed for cultural appropriateness and responsiveness is different depending on the community the services are occurring in. HCBS providers that engage their care recipients and their families can understand how to design their service delivery to be reflective of those needs.

Workforce

Key informants also identified the HCBS workforce as an important pillar to improving overall HCBS quality and access. One of the most important ways to ensure access is to build pathways to direct health care worker careers. One key informant mentioned a program in their community that recruits high school students for certified nursing assistant training, preparing them to work for HCBS providers by the time they graduate.

Key informants also pointed to the importance of continuing education, especially specialized, disease-specific trainings such as for Alzheimer's diseases and other related dementias. Often, HCBS workers have general training but not specified knowledge on certain types of disability. Continuing education should also employ the knowledge of seasoned direct care workers, who offer strong insights on best practices. There should also be continued efforts to train, credential, and certify direct care workers in order to build the capacity of the workforce.

Other Promising Practices

In addition to improvements in quality and access, key informants emphasized the need for greater public awareness and outreach. They suggested a variety of ways to increase awareness of HCBS services, including public awareness campaigns and community health workers doing outreach to under-engaged populations. One key informant suggested a school-based campaign, because families are more likely to trust and respond to information they receive at schools than in other contexts. Another key informant reported success with doing outreach to Area Agencies on Aging.

"We really need to seriously explore value versus focusing on volume. I think we should be revisiting community-based models that will encourage more of a systems change. We have to consider that aging across ethnicities, cultures, communities of colors, it's not just a privilege to age, but it's a right. And if we don't understand diverse cultures and build on trust and awareness, just actively engaging with solutions, equity will always remain just a goal and will never be achieved." ~ State Official

There was a strongly expressed need for better research and data infrastructure. This included recommendations to build a research clearinghouse for community-based HCBS research, as well as overall more streamlined data collection and infrastructure. Multiple key informants mentioned the importance of community-based research that directly engages HCBS recipients, and the need to make a strong value proposition to HCBS users on the importance of participation in research.

Recommendations for State and Federal Policymakers

Access

One of the most frequently repeated policy recommendations was eliminating waitlists for services. Due to the continuing Medicaid institutional bias, community care remains in short supply. Knowing that evidence suggests Black individuals on waitlists have greater care needs than their White peers on average, one key informant suggested using algorithms that prioritize those who have been on waitlists the longest or who have the greatest need. Another common recommendation was to make HCBS a mandatory Medicaid benefit. One key informant also suggested using presumptive eligibility to better streamline Medicaid enrollment.

"It's really time for policymakers and politicians to take an active role in looking at where the HCBS industry is headed. The demand for the home and community-based services far exceeds the supply of available providers. To further support these communities of color, it's important for legislation, I think, to focus on changing practices. It's certainly a more, as I keep saying, comprehensive issue than just even increasing wages, but it certainly provides a starting point." ~ State Official

Quality

One of the most frequently cited policy recommendations was increasing the wages of direct care workers and other HCBS providers. In addition to worker pay, key informants recommended increases in funding for HCBS programming.

"I think if we had…I mean, what we need is much more financial support for all of these programs, organizations, you know, all these services. And that would take a lot of pressure away that sucks the energy away from, you know, service and interfacing with clients, to the anxiety of how to actually run it and get the numbers that ends up, paradoxically, making the clients feel… it makes the client feel like a number, and then they don't show up again." ~ Academic Researcher

In order to address caregiver shortages that limit quality, one key informant suggested permitting beneficiaries to hire a spouse to provide their care or provide support for their care, which is currently not allowed in some states. Multiple key informants emphasized the recruitment and retention of HCBS providers, especially for rural and tribal areas.

Outcomes

Key informants emphasized 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 data by race, ethnicity, and language. This data will be crucial to understanding racial and ethnic disparities at a sufficient level of depth.

Based on the interviews with key informants, we were able to identify some initial practice and policy suggestions. However, these recommendations are preliminary as they are limited to contents of the interviews and do not capture the full breadth of the project learnings (focus groups, literature review and quantitative analysis).

Appendix A: Key Informant Interview Protocol

General Questions:

- Can you please state your name for the record? What is your role within the organization? How long have you been working in this field?

- From your perspective, do you see disparities in access to home and community based services among individuals of color who are dually eligible for Medicare and Medicaid?

    - Can you briefly describe the disparities you have observed?
    - What do you think accounts for these disparities in access?

- Do you see disparities in the quality of home and community-based services provided to individuals of color who are dually eligible for Medicare and Medicaid?

    - If yes, what do you think accounts for these disparities in the quality of care?

- What about disparities in outcomes? What have you observed and what factors are driving this?

- Do you observe different issues affecting the access to or quality of HCBS services among older Hispanic adults compared to other racial and ethnic groups?

    - If yes, what are some of these issues?

- What policy solutions would you recommend to address these issues **for all groups?**

- Are there certain practice issues (education, training, scheduling, interpreter assignment, etc.) that should be changed to address these issues?

- What underlying systemic/socio-economic or other issues do you feel are contributing that need to be changed but may be more difficult to address?

- What additional information, research or evidence needs to be developed in order to improve the situation and reduce disparities in access, quality and outcomes of HCBS for individuals of color who are dually eligible for Medicare and Medicaid?

- Are there issues affecting the access to HCBS among people of color who are dually eligible for both Medicare and Medicaid that are not well known or understood? If so, do you have ideas about what might be done to improve both the knowledge of these issues and opportunities for addressing them?

Questions for Academic Key Informants

- Can you share with us your research experience in the HCBS space, that is, how many years have you been researching these issues and is there a particular focus of your work?

- What are some of the key learnings from your research and knowledge in this area, as it relates to both the presence of disparities and ways to address the issue?

- Are there significant gaps in the knowledge base or pieces of information/data collection or evidence that would be critical to know in order to more effectively address the disparities issue at both the practice and policy level?

Questions for Policy Experts & National Organizations

- What would be the top three regulatory or policy changes that you think would go the furthest toward addressing issues related to disparities in access to and quality of HCBS provision?

- Are there unique barriers faced by people of color who are dually eligible for both Medicare and Medicaid in accessing care and if so, what are they?

- Are there policy and/or regulatory levers that could be used to address the disparities issue that have not been used and if so, what are they and what would it take to implement them?

- What key metrics would you be looking for to know that this issue has been addressed?

  - Are these currently collected?

- What do you think providers should be doing to better address this issue and are there specific changes at the regulatory or policy level that could support their efforts?

- Are there "best practice" models within an organization or state that you would suggest as a useful standard for examination?

Questions for HCBS Providers

- What are the key challenges or barriers that you face organizing and providing HCBS services to people of color who are dually eligible for both Medicare and Medicaid?

- What would be the top three regulatory or policy changes that you think would go the furthest toward addressing issues related to disparities in access to and quality of HCBS provision?

- Can you share your perspectives on HCBS reimbursement rates? What role do rates play in HCBS and disparities?

- Are there specific initiatives that you have undertaken that have worked well?

- Are there specific initiatives that you have undertaken that have not worked at all, and if so, what were the reasons?

- Do you think if individuals had a "usual source of care" this would make a difference and if so, are there initiative that you have put forward to get people a "usual source of care"? What are the barriers to this?

- Are there unique barriers faced by people of color who are dually eligible for both Medicare and Medicaid in accessing care and if so, what are they?

Questions for Federal Officials

- Is the issue of access and quality disparities among people of color who are dually eligible for both Medicare and Medicaid a focus of your office? If not, where does responsibility for this issue reside? Or where should it reside?

- Have there been specific strategies or changes in policy put in place to address this issue?

  - If yes, have they succeeded in meeting their objectives?

- Are there policy and/or regulatory levers that could be used to address the disparities issue that have not been used and if so, what are they and what would it take to implement them? [*probe here on reimbursement rates/payment policies*]

- What key metrics would you be looking for to know that this issue has been addressed?

  - Are these currently collected?

- What do you think providers should be doing to better address this issue and are there specific changes at the regulatory or policy level that could support their efforts?