

Stakeholder Feedback on Addressing Racial and Ethnic Differences in Home and Community-Based Services

A report to the Minnesota Department of Human Services

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Executive Summary

Home and community-based services (HCBS) are services people receive in a community setting and are an alternative to those provided in an institutional setting, such as a hospital, nursing facility or intermediate care facility for people with developmental disabilities (ICF-DD). HCBS include various personal care, mobility supports, and social services to assist individuals with functional limitations due to a disability or other physical or cognitive conditions. Services are wide-ranging including – but not exclusively – customized living, transportation services, meal delivery, caregiver services, foster care, adult day services, and homemaker services. People may receive HCBS in their homes or through their choice of residence, including community-based residential facilities, such as customized living and adult foster care settings. HCBS are most commonly paid for via Medicaid waivers, but private pay and Medicare are also payment options. Existing research shows that nationally, Black, Indigenous, and people of color (BIPOC)^a have uneven access to HCBS due to a number of individual, structural, and systemic factors. Yet, this work is not specific to Minnesota context. We need Minnesota-specific data on HCBS use by BIPOC communities and understanding of mechanisms that create barriers.

In 2019, the Minnesota Department of Human Services (MN DHS) started a mixed methods project with the goal to analyze access to and use of HCBS by race/ethnicity in Minnesota to identify mechanisms for change. The project included quantitative analyses and qualitative work via feedback from a Community Advisory Board (CAB). This executive summary provides highlights on the qualitative work for this project: national literature review and the summary of the Community Advisory Board’s feedback and recommendations regarding the findings from the quantitative analyses.

The Community Advisory Board (CAB) consisted of 22 members representing various racial/ethnic groups from across metro and rural areas in Minnesota. The CAB members met four times in the period between August 2020 and December 2020 for two and a half hours each. CAB members also provided feedback via e-mail or other forms of communication in-between meetings.

During the four meetings, CAB members discussed a wide range of issues related to racial/ethnic disparities in HCBS access and service utilization. We identified the following five common themes on CAB member feedback across all meetings:

1. Lack of access to HCBS information, services, and funding for BIPOC and rural communities
2. Need for more nuance on race/ethnicity coding in data

^a In this paper, BIPOC- Black, Indigenous, and people of color is used to describe historically minoritized and marginalized people who experience negative impacts of systemic racism in the United States. We acknowledge that this term is not perfect and recognize that marginalized groups are not homogeneous.

3. Long-term services and supports (LTSS) and medical services are not culturally inclusive-service navigators (such as case managers and care coordinators) perpetuate bias and stereotypes and lack awareness on cultural humility
4. Stigma in BIPOC communities associated with LTSS and HCBS utilization, especially for mental health and intellectual and developmental disabilities (IDD)
5. Historical mistrust of government related to historical trauma, limited capacity, and competency in addressing the health needs of BIPOC and marginalized communities

Our findings can inform MN DHS of opportunities to better shape its HCBS waiver programs and decrease existing racial/ethnic disparities. This report can also be useful as a guidepost for future direction for research on racial/ethnic disparities in HCBS at DHS and engagement with BIPOC communities.

Introduction: Racial/Ethnic disparities in home and community-based services access

Definition and background

Home and community-based services (HCBS) are forms of long-term care provided in a non-institutional setting¹. Services are wide-ranging including – but not exclusively – nurse home-visits, transportation services, meal delivery, in-home physical therapy, in-home occupational therapy, in-home speech therapy, and homemaker services¹. HCBS are most commonly paid for via Medicaid waivers, but private pay and Medicare are also payment options². Medicare only covers eligible services under Part A and Part B³, and Medicare Advantage programs usually cover similar services⁴. Medicare typically only pays for certain health services such as rehabilitation services and does not cover commonly used HCBS programs including adult day services and personal care assistance. The expense of home and community-based services is often out of reach for individuals with lower incomes, making Medicaid coverage essential for many to access in-home care. Services are most often paid for via Medicaid waivers, most commonly Section 1915 (c) and Section 1115 waivers, but there are other state options including Community First Choice. Following the Olmstead Decision of 1999, there has been a federal push to keep those in need of long-term care services in the community as long as possible. Olmstead shifted long-term care funding to place more emphasis on financing HCBS. An increasingly higher percentage of Medicaid funding has gone towards HCBS since Olmstead with the goal of increasing community integration for those needing services⁵.

Racial/ethnic groups: Our report uses racial/ethnic categories based on the 2000 Census groupings - this is the way that race/ethnicity was also analyzed for quantitative analyses on which the CAB was asked to comment. These include: white, Black or African American, American Indian or Alaska Native, Asian American, Hispanic and Latino and people of two or more races.

Racial categories, which have been included on the US census since the first one in 1970, have continued to change over time, reflecting that race/ethnicity is a social construct without an inherent biological meaning. In fact, an article published in the journal *Science*⁶ based on sequencing of the human genome, reaffirmed that racial categories are weak proxies for genetic diversity but rather represent social and cultural differences between different populations of people. As is reflected in the feedback from the CAB, we need more nuance in the existing racial/ethnic groupings to allow for heterogeneity or diversity within each category and for more information about one's origins and cultural experience (e.g., African American vs. Somali).

Concerns about racial disparities in HCBS access

Although some articles reported a decrease in racial/ethnic disparities in use of long-term care services (LTSS in general) over time, most data were related to nursing homes and may not reflect HCBS⁷, and the increase in non-institutional care options may not be showing similar results for HCBS⁸. The national literature review found that Black, Indigenous^b, and people of color (BIPOC) have uneven access to care opportunities due to lack of insurance and ability to pay for many HCBS programs which may currently be exacerbating racial/ethnic disparities in access instead of decreasing them⁸.

One definition of racial and ethnic disparities is differences in outcomes for different racial/ethnic groups that occur because of factors outside of a person's control⁹. There is much debate on the definition of this, though, with the crux being how great a difference must exist or how much lack of personal control is needed to distinguish a difference from a disparity⁹. The Centers for Disease Control and Prevention defines health disparities as "preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups, and communities. Health disparities exist in all age groups, including older adults"¹⁰. The Institute of Medicine more narrowly defines racial/ethnic health disparities as "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention"¹¹.

Conclusions from a review of the literature

The major conclusions from a review of the literature on HCBS suggest that there are racial/ethnic disparities in access to HCBS^c. There were many commonalities in barriers to

^b Please note that the terms "Native American" and "Indigenous" are used in this report interchangeably, consistent with how they were used during CAB meeting discussions by meeting facilitators and board members.

^c A robust literature review on racial/ethnic disparities in HCBS access was completed in early 2021. We have included excerpts of the literature to provide some background information, however the purpose of this report is not a literature review, but a summary of stakeholder feedback.

access throughout the literature. Across Black^d and African American, Korean American, and Hispanic groups, these barriers include lack of knowledge of services available, eligibility to receive services, and how to access services were areas of concern^{12 13 14}. Other barriers discussed were organizational (such as waiting lists, lack of referrals for services, and communication difficulties), geographic (e.g., rural), and cultural^{15 16}. For individuals who were Korean American, reasons related to unmet service needs included chronic conditions, caregiver educational attainment, and level of informal care available¹². Also, for individuals who were Korean American, greater physical and mental limitations, more years spent in the U.S., and previous use of HCBS increased a person's chance of using HCBS or nursing home care¹⁶. Certain types of HCBS use was more likely to be accessed for individuals who were Black and African American and of older age, had Medicaid coverage, lived in a poorer neighborhood, did not drive, lived alone, lacked informal care support, and had access to affordable services¹⁷. None of the articles found that individuals who were BIPOC were disinterested as a whole in receiving services. Therefore, cultural opposition may not be a major reason for not receiving services, although it is important to note that this inference may exclude groups such as recent US immigrants and those who have lower English proficiency^{18 16 12}.

In terms of quality of care once home and community based services are accessed, individuals who were Black or Hispanic tended to receive lower-intensity care following joint replacement than individuals who were white¹⁹. In contrast, individuals receiving HCBS who were Black were more likely to be hospitalized while receiving services than individuals who were white²⁰, suggesting that HCBS recipients who were Black either tended to be in a more fragile state when receiving services than recipients who were white, and/or that they were receiving poorer quality of care than recipients who were white. One study noted that despite similar service utilization across racial/ethnic groups, individuals who were Hispanic and individuals who were Asian had less gains in physical functioning while receiving services than did individuals who were Black and individuals who were white²¹. Another study found that although fewer individuals who were Hispanic received home health care than individuals who were Black or individuals who were white, after adjusting for income and other individual and geographic variables, the differences became non-significant, pointing to access barriers such as ability to pay²². One study found that, once health and demographic characteristics were accounted for, those in the lowest tertile of non-housing assets were much more likely to receive services than those in the highest tertile²³. This may be accounted for by individuals with higher incomes receiving services in assisted living communities, though. As for the quality of HCBS care received, in one study, agencies serving a higher percentage of Native American/Alaska Native population tended to have lower quality outcomes²⁴. Other studies found similar results when comparing individuals who were Asian/Pacific Islander, Black, or Hispanic to individuals who were white; individuals who were African American, Asian, or

^d Conclusions from the literature review use racial/ethnic group exactly as they are reported in the articles, which most often referred to the exact groups included in the article, as opposed to the census groupings described earlier in the report.

Hispanic receiving home health care were more likely to go to the ER or to be re-hospitalized during a period of time when they were receiving services than recipients who were white^{25 20}. This implies that quality of care provided in areas with high proportion Black, Indigenous and people of color is lower than in comparable primarily white areas, an issue that needs to be addressed further in research.

While important, this is a relatively small body of literature with some limitations. None of the studies focused on accessibility for those individuals who qualified for Medicaid but could not receive waivers to pay for needed services. Many states use waiver eligibility requirements to control the number of individuals receiving HCBS coverage beyond the required home health state plan services, resulting in most states having waiver waitlists for services since 2017²⁶. This information points to significant need for greater funding to address community need for HCBS.

Community input to inform Minnesota Department of Human Services project

The purpose of this Minnesota Department of Human Services (DHS) project is to evaluate disparities among Black, Indigenous and people of color who are enrolled in HCBS programs and their patterns of enrollment, service use, and self-reported satisfaction by race/ethnicity. This multi-stage project used a combination of quantitative and qualitative methods to examine the assessment process and understand disparities. All qualitative methods were led by the University of Minnesota (U of MN) whose main objective, in addition to the literature review, was to assemble a Community Advisory Board (CAB). The purpose of CAB members was to act as a partner in the project and a representative for their respective communities and experiences in reviewing findings from quantitative analysis and to provide recommendations to guide the project's next phases.

Community Advisory Board selection process

A recruitment survey was distributed to 40 organizations across the state the week of June 15th, 2020 and remained open through July 3, 2020. In addition, DHS posted this community engagement opportunity on their website, through e-announcement or e-newsletter update. In total, 146 respondents completed a survey and 2 were removed (one was a repeat entry and the other was from out-of-state) leaving 144 valid respondents. The goal of CAB member selection was to have a sufficient representation of people who are BIPOC recipients (Older Adults/ People with Disabilities), and from rural areas. We excluded people who indicated they worked as a care coordinator and/or worked at a lead agency because they are already/will be engaged as part of DHS work.

The following framework guided the selection of CAB members:

- Strive to have an equal mix of:

1. aging only;
 2. disability only; and
 3. experiences with both aging and disability
- Strive to include rural members, at least 20% from outside the Twin Cities metro area
 - Strive to have an equal mix of providers, consumers, family members and caregivers

See Appendix A for the list of organizations that were sent recruitment surveys.

See Appendix B for more information about the CAB selection process.

Results

Community advisory board members

The Community Advisory Board was comprised of twenty-two members: 17 (77%) women and 5 men. All men identified as African American or of African Heritage and the majority of women were from a variety of diverse racial/ethnic backgrounds (See Table 1 for details). Most CAB members were less than 65 years of age (82%) with 4 members or 18% reporting they were over the age of 65. We included all 4 respondents (18%) from rural Minnesota in order to include rural perspectives with the remaining 18 CAB members coming from urban areas. There was an overlap of role identification, where some members identified as having multiple roles; 64% of CAB members were providers, 59% were family members and/or caregivers and 45% identified as HCBS recipients.

See Appendix C for CAB member names.

Community Advisory Board meetings

We conducted a total of four CAB meetings in 2020. Due to the COVID-19 pandemic, these meetings were held virtually via Zoom on September 1st, October 20th, November 17th, and December 8th. The main findings are described below. We present detailed descriptions of the CAB meetings below with summary of themes and subthemes of findings separately in Appendix C.

All meetings were recorded, and the recordings were reviewed, and comments were coded based on themes that emerged from each meeting.

Key themes and details across all CAB meetings:

- I. Lack of access to HCBS information, services, and funding for BIPOC and rural communities.

CAB members noted **language barriers and communication barriers to service access** are experienced by communities of color throughout Minnesota. Members of African immigrant, Hispanic immigrant, and Native American communities all expressed

difficulties in communication and language barriers. Many members followed up on **barriers to service utilization** noting difficulties due to written language barriers such as important documents that need to be filled out to receive services not being available in many of the languages, other than English, that is spoken in their communities, nor are interpreters readily available.

“So whether people know about the services or not, they're not built for them; it doesn't make any difference. There's also the lack of having things in other languages so that people can gain the knowledge that they need in other areas.”

“We're not getting a lot of help or explanation at the county level. A lot of Native and Indigenous people don't understand how to navigate new and changing systems. I think they've [service navigators] made things very difficult to understand, even if they were explained at the county level.”

CAB members noted that **the HCBS service system is complicated**; it has too much paperwork which makes it hard to manage and navigate efficiently. Numerous CAB members also pointed out that many people in their communities are unaware what services exist and those that do, struggle to navigate them. CAB members were not aware of any efforts to educate BIPOC communities on these services.

“There is no awareness of available services. I did not know what services my daughter qualified for because we assume her dad made too much money. Until she was 11 no one told me, then I learned from another parent.”

“How much research can you do when you're taking care of someone 24/7?”

Some CAB members mentioned that the fear of deportation in their communities prevented numerous migrants from seeking services.

“For Hispanic people, we run into the issue of whether or not they are considered a US citizen as well. I am getting this from previous experience that we have had with trying to help with the Hispanic Community and the push back we actually received from some families because they were worried about that.”

Community members continued to express worry about their communities' lack of knowledge of available services which creates a **service access barrier**. In addition, they highlighted state and county level gaps in working to educate BIPOC and rural communities on available services and how to use them. Additionally, the people

seeking service information may have limited access to technological devices and limited knowledge of these devices and the internet to access information they need.

“There is a need for simplification of HCBS access systems and translation of information to the various languages people speak.”

“There are plenty of accessibility issues regarding having to drive to and from services or appointments, living in rural areas, and having a low internet IQ and/or poor access to technology.”

“If they're in the state of Minnesota, most of the (East Indian) families' (adult) kids live in different states. So, parents do not have the right help or technology, which they need to get services.”

“But who will do the work for you, when you have visibility or disability issues? Because they are dealing with transportation barriers and moving and doing things on their own.”

“In the Native American community, I see a lot of people who are suffering. They maybe don't have a vehicle, way to access services, or telephones to even call a social worker.”

CAB members agreed that addressing these issues would help increase services access for BIPOC and immigrant communities.

In thinking through the data presented on barriers that contribute to racial disparities in HCBS, some CAB members found the presented data to be insufficient for analyzing service breakdown and utilizations in rural communities. Rurality and data by geography needed further analyses. This is an issue, as some pointed out, as *“some services are not available in rural areas”*. The data does not sufficiently highlight barriers to service access in rural areas. One example is a lack of funding resources in rural areas. A CAB member shared that in the rural county they lived in, his son could not get on a developmental disability (DD) waiver. They also shared that their case worker said this was because *“the county ran out of funding”*. The county also refused to open a new waiver case for the family after their son was rejected the first time. They decided to move to a new, more populous county, so their son would receive a waiver - which he did in a few months following the relocation. This highlights another point, shared by several CAB members: while there is not a formal *“waiting list”*, county level funding disparities are making it more difficult for some families to receive waivers compared to others.

Culturally competent providers, who have similar cultural backgrounds to those they serve, often face challenges to providing HCBS. One CAB member shared that these cultural concordant providers are often smaller operations. CAB members noted a few times that small HCBS service providers who predominantly serve recipients of color face barriers to funding access to improve service and support they provide. They highlighted how larger providers have access to resources that make them more likely to receive contracts and funding compared to smaller organizations that, for example, predominantly serve Somali recipients. Members discussed the cons of an approach to HCBS service regulation which can result in disruption of service provision vs. strategies that center partnership, collaboration, and co-creation. This concern of focus on regulation and licensing instead of working to foster the success of small HCBS providers was brought up in more than one CAB meeting.

“As a community provider, sometimes I feel policed by DHS when it comes to license and reporting requirements rather than engaged as a genuine community partner in meeting the shared needs of the community (along with DHS, together they are both there to serve those in need whether directly or indirectly).”

II. Disagreements with generic racial/ethnic categories used in data and the need for more nuanced groupings.

BIPOC CAB members brought up a **critique of the racial/ethnic categories used in the data** at each of the four meetings. They commented that the current racial breakdowns ignore significant cultural differences, do not provide an accurate depiction of what’s really happening in various communities of color, and so shouldn’t lump people of color together in overly broad racial/ethnic groups.

“I would like to support members' suggestions not to lump many communities under one banner. There are very vast differences in those communities, their culture is different, their needs are different and what kind of help they need is different too.”

CAB members noted the need to be aware of the **differences in lived experiences based on one’s cultural background**. They highlighted the need to differentiate African American from foreign-born Black persons and talked about how “Asian American” is a very broad category and needs to be more nuanced.

“In case of the data, there needs to be more information and deeper understanding can come if there is clarity about the groups, like for example, we have Punjabi Asian and Pacific Islanders. That is a very big group, maybe in the beginning it was a very small number of people, but now it's increasing and

clumping them in one lump is not the right justice done to that group, because 'Asian' could be Southeast Asian, it could be Chinese, it could be anything."

"People of color cannot be lumped together in research. You can't understand all communities' unique qualities this way."

In reference to racial breakdowns in data: *"The benign neglect policies ignores the issues of American Descendants of Slavery (ADOS)... it's a lineage that does not have access to a lot of the services."*

Furthermore, there were discussions in the first CAB meeting about **differences between different "Black" sub-groups**, which could include African immigrants who have different cultural experiences, African Americans, and American Descendants of Slavery (ADOS) people. Similar comments were made about various experiences for Asian groups and the differences between HCBS and cultural needs of those who are refugees (e.g., Hmong) vs. other Asian groups.

III. Long-term services and supports (LTSS) and medical services are not culturally inclusive; service navigators perpetuate bias and stereotypes and lack awareness of cultural humility.

Some CAB members shared **personal experiences of potential treatment bias** by case managers when seeking long-term services and supports. Feelings of being "talked down to" by some workers, and "us vs. them" sentiments also came up.

"There is a need for cultural competency/training/humility at all levels, including DHS. This needs to connect to case managers and programming, including race/ethnicity and other areas of inclusion (socio-economic)."

There were also comments from several CAB members around **bias in service need assessment encounters** involving Black young men, especially for DD services, who are often criminalized for their behavior.

"From an ethnic/racial disparity perspective, I posit that it can possibly lead into a broader psycho/socio/economic construct that breaks down 'behaviors' that are 'clinicalized' and those that are 'criminalized' according to race/ethnicity (e.g. expulsions and suspensions in school, drug abuse etc.). Waiver/Help vs. Jail Incarceration."

Lack of cultural humility among service navigators and providers was also discussed by CAB members. In addition, several CAB members pointed to insufficient education and cultural awareness among state and county workers who provide services for BIPOC

users that lead to the potential for differential assessment of service eligibility for these populations.

“Cultural (race/ethnic, class/socioeconomic) training at the county level for case managers on how to appropriately interact with their clients. Also, county and state workers are not always well-versed in what clients are eligible for, not knowing their own programs and eligibility criteria.”

“DHS needs some cultural competency around class/socioeconomic and racial/ethnic differences. DHS makes it hard for the counties which in turn makes it hard for the end user. DHS is an Ivory Tower of best practices and research heavy, which makes their systems and programs hard for the end users in the community to access.”

CAB members raised the need for **cultural sensitivity and awareness training to mitigate bias** when providing HCBS and support for recipients from communities of color and Indigenous populations. They emphasized the importance of partnering with community members and utilizing their expertise in developing and executing these cultural training programs.

“Using a culturally competent lens, I think some short-term action steps DHS can take include building culturally sensitive relationships with multicultural communities and organizations that work in these communities, to create additional education, awareness, and training on the available HCBS that are available to different demographic groups in these communities. People cannot access what they do not know about. Building these relationships will help promote trust and community collaboration between DHS staff and stakeholders, mobilizers, and key actors within the community.”

IV. Stigma in BIPOC communities associated with using long-term services and supports, especially for mental health needs and stigma for being not cared by a family member

There was a lot of discussion around the existing stigma and taboo within BIPOC and immigrant communities associated with seeking services such as mental health support, which prevented people from seeking out such services. A CAB member shared experiences in the taboo against asking for help or being dependent on services that exist in BIPOC communities. They said, *“There is often shame or judgement for not being able to take care of one’s self or not having children that can take care of a person.”*

Mental health was a key concern of CAB members who expressed the **need for MN DHS and counties to invest in resources** towards the following for communities of color: a)

Help destigmatizing mental health and disability; b) Waivers for services that considers their needs; and c) The separation of mental health issues and drug abuse.

“People in many African immigrant communities do not want to openly accept or talk about disability. There is some level of stigma within many African immigrant communities. We just submitted an application to the DHS innovations grant to work with cultural brokers and actors in the Somali community in the Twin Cities to help fight some of that stigma through community education, outreach and awareness.”

“From an Asian perspective - Cultural views on mental health services, might impact the probability of people of color seeking care, especially if it is stigmatized, they don’t believe in mental health.”

CAB members shared **experiences specific to stigma associated with living with developmental disabilities** that potentially result in lower DD waiver related service utilization within the Latino and Asian communities. They highlighted the cultural expectation of self-reliance, and views of deficit associated with seeking help. It may be that BIPOC communities are not likely to use residential care due to cultural norms.

“Taboo/Stigma is so true in [East] Indian communities. Also, they do not want to be categorized as going on public support/ help outside home. Younger people think it's not good in the social setting if their parents are cared for by outsiders or if they go to assisted living or get care from outside.”

“In the Latino community specifically, it is hard to speak about disability too, and [start the] journey to help. Then there is the fact that some of the people will be undocumented and it will be hard for them to [seeking help].”

In addition to the stigma surrounding mental health needs within historically marginalized communities, **rural communities, also struggle with low levels of available mental health providers**. This complicates matters and can be frustrating especially for Indigenous people in rural areas, who are trying to overcome this stigma and seek out mental health services.

“For Native Americans in rural areas, there is a lack of providers, lack of mental health services, lack of specialists, no mental health specialists, no beds available right now, huge lack of resources. People in need of service sometimes have to drive 2 hours away at the minimum to see a heart specialist and access other

services-- people give up. If you look at Native American lifespan, it's longer than it used to be but still lower than the national average."

Finally, multigenerational housing and stigma attached to being cared for by non-family members was mentioned by several CAB members and was also shared as the reason for why BIPOC communities are not as likely to use residential care such as assisted living or nursing homes.

"In the Native American Community, we have multigenerational homes, where we have each age group taking care of one another.

V. Historical mistrust of government related to limited capacity and competency in addressing the health needs of BIPOC and marginalized communities.

There were various comments related to the **history of racism** in the U.S. (e.g., how services were set up to break up Black families) impacting how and if services are used by people of color. Specifically mentioned by Black and Native members of the CAB was that historical trauma from governmental abuse still deters people from utilizing and trusting services. However, this "lack of faith in the system" was also addressed by various other members as well, which pivoted to members noting that HCBS service user and provider racial concordance matters, and may have consequences for experiences and health outcomes of people who are BIPOC over their life course. Some CAB members also brought up that Native Americans have a **limited trust** in the Indian Health Service (IHS) to provide sufficient quality health care services related to historical disenfranchisement of Indigenous populations in the U.S.

"Back in the day, people that look like me (Black Americans) didn't have access to good quality healthcare, there was mistrust too, given experiments of Black people back in the day, this could lead to unchecked/unaddressed health issues that manifest as people in these groups age."

"There is a big mistrust due to historical mistreatment and disenfranchisement of Native American people. There are issues with IHS (Indian Health Service), they provide substandard care and there is typically discontinuity of care over the life course. In rural areas, there is a lack of providers, lack of mental health services, lack of specialists, no mental health specialists, no beds available right now, huge lack of resources."

“For Native Americans, diet has changed over time which has impacted their health- increase in diabetes, food choices tied to the American diet. Also, there is a big mistrust due to historical mistreatment and disenfranchisement of Native American people. There are issues with IHS (Indian Health Service), they provide substandard care and there is typically discontinuity of care over the life course.”

“There is some distrust amongst Native American/Indigenous people and the government/government agencies/medical agencies...because of historical issues that have taken place amongst the Native Americans and reservations. Some of these things directly have to do with sustenance, medic[in]e, and the lack thereof.”

Similar to service access barriers and stigma around service use, some CAB members reiterated how the **fear of deportation** for some members within Hispanic communities impacts the level of HCBS service use.

During a CAB discussion on the differences in **emergency department (ED) use** across various racial/ethnic groups, members noted that in general, **lack of insurance and access to preventive care services** lead to increased and potentially excessive ED use for BIPOC groups. Some shared there are those who fall through the cracks - such as people who don't qualify for Medicaid/Medicare and cannot afford insurance. Several members shared from personal experience that it can be difficult to find a doctor who takes Medicaid/Medicare. Participants discussed how within Native American populations, many people have complex health diagnoses that may result in higher health care use. This multimorbidity, coupled with not having a primary doctor, can lead to care discontinuity, which in turn leads to increased ED use as a way to try and manage the illnesses and chronic conditions. One member highlighted the additional point that “access to healthcare does not necessarily mean access to quality care”.

“Let’s talk about high Native American numbers for ED use and the reasons: transportation issues; logistics for rural areas in access to care; time of regular doctor appointments.”

“Indian use of ED and hospital use: could be tied to certain types of insurance. Many Asians (specifically East Indians) have good insurance, so they don’t need emergency visits as much.”

“Chronic diseases don’t get diagnosed as fast because symptoms may not be severe or that obvious, so people avoid going to the doctor. Some of these chronic diseases have onset later in life. Like I expressed before, many people end

up in ER because they have no other option, but some people make conscious decisions not to get insurance and just use ER as a regular doctor.”

Lastly, participants shared that **BIPOC communities are not likely to use residential care due to lack of culturally sensitive food options**. Majority of CAB members noted that many BIPOC service recipients do not utilize food services because of cultural values placed on food (which make having your food prepared outside of the home uncomfortable), and that often food is not made for BIPOC palettes. Some mentioned that the food is very bland and may not adhere to cultural food norms or even dietary restrictions. Some participants also shared criticism about nursing facilities primarily focusing on white culture, and how they are not conducive for various cultures and ethnicities that are not white.

“Most of these cultural ethnic groups have a certain way of cooking [with elderly people practicing these traditions for 40/50+ years] so they will not use [these services]. They want their own, ready-made meals, right at that moment. For example, [East] Indian communities will not eat bread that has been out of the oven for longer than 10 minutes. So, they will not use these delivery services”.

“Based on our respective cultures some of us don’t like...people handling and bringing food into our homes. We all want to secure our own food. I honestly do not want people preparing food somewhere else and bringing it to me. I want to prepare my own food and cook it from scratch.”

“The home delivery food doesn’t come with any of our traditional spices...”

Discussion

The goal of this project was to review and summarize national literature on the role of race/ethnicity for HCBS use and solicit feedback from community members via a Community Advisory Board on the use and quality of HCBS for Black, Indigenous and HCBS users of color as well as those in rural areas.

- 1) We identified the following five common themes shared by CAB members across all meetings: Lack of access to HCBS information, services, and funding for BIPOC and rural communities,
- 2) Disagreements with generic racial/ethnic categories used in data and the need for more nuanced groupings;
- 3) LTSS and medical services are not culturally inclusive, service gatekeepers perpetuate bias and stereotypes and lack awareness on cultural humility (“self-reflection to learn about other’s culture and examine one’s own beliefs and cultural identify);
- 4) Stigma in BIPOC communities associated with LTSS and HCBS utilization, especially for mental health and long-term residential care needs; and

- 5) Historical mistrust of government related to limited capacity and competency in addressing the health needs of BIPOC and marginalized communities.

While these themes are unique to the focus on HCBS access and use, they also reflect previously documented findings on overall distrust of many in the BIPOC community of the healthcare system that also affects HCBS. Our findings also reinforce existing disparities identified by the national studies and call for action. Across all meetings, CAB members discussed the importance of access to HCBS, which varies greatly by rural/urban areas and also based on other factors, including available information for non-native English speakers. CAB members also emphasized the cultural importance of food, which is often white-centric in residential care settings and is one of the barriers to care use for cultural communities.

Besides the identified themes, participants raised several other important issues throughout the CAB meetings, as summarized below:

- 1) CAB members felt that further discussion is warranted concerning the process of assessment for waiver process eligibility as the issue was not sufficiently covered by the quantitative analysis that was presented.
- 2) CAB members called attention to differential needs of multigenerational households, which are more common in BIPOC communities and how the needs of HCBS users in such households may be different from those who live alone or with a partner only.
- 3) Across most meetings, CAB members talked about the importance of attention to rural areas across the state, which have differential access to HCBS compared to metro areas. Hence, in future work, more information is needed on rurality and access to HCBS.
- 4) Overall sentiment across meetings was the need for DHS to reduce the complexity of HCBS and not to place further burden on BIPOC users to identify services for which they are eligible. Most BIPOC users are already at capacity due to various structural and system inequities (in addition to often serving as primary caregivers) and cannot research and/or spend time looking into complexities of getting services through waivers. This issue is also reflected in recommendations for action steps below.

Conclusions/Recommendations to DHS

Based on our literature review and CAB meetings, it is evident that racial/ethnic disparities in HCBS in MN are prevalent and need to be addressed. Our recommendations for action are grouped into four categories: 1) making services more person-centered; 2) the role of HCBS providers; and 3) the role of lead agencies; and 4) system-wide changes.

I. Making services more person-centered.

Many of the CAB members' recommendations focused on making HCBS services more person-centered. To do so, they suggested five key steps DHS can take, listed below. These include: a) need to increase awareness of existing HCBS services; b) reduce state bureaucracy and paperwork required; c) combat stigma for receipt of services, especially those for mental health and long-term residential care needs; d) identify barriers for HCBS to specific cultural communities; and e) build meaningful partnership with BIPOC community.

First, DHS needs to **increase awareness of existing HCBS**. Many respondents talked about the need to better promote available HCBS for BIPOC communities, including in schools and hospitals. Others also suggested community radio and TV as useful outlets for certain cultural communities.

Second, DHS needs to **reduce bureaucracy** to make the system more person centered. Most CAB members shared concerns around the paperwork and bureaucratic challenges needed for HCBS access, including for those on waivers. This is an especially big barrier for non-native English speakers and immigrants. CAB members also talked about the need to reduce bureaucracy when it comes to being able to hire for one's own services.

Third, DHS needs to **combat stigma for receipt of services, especially for mental health and long-term residential care needs**. CAB members talked about cultural considerations for many BIPOC communities on the stigma and shame in accessing publicly funded HCBS. This was especially true for mental health and long-term residential care services. To address this issue, DHS can offer targeted training to culturally specific service providers to inform them on mental health and long-term residential care services and supports available from MN DHS, so they can educate and advocate on behalf of those services and programs within their communities.

Fourth, **DHS needs to identify barriers specific to different cultural groups and those in rural communities and work with them on how to address those**. As reflected in findings, greater nuance is needed in understanding racial/ethnic differences in HCBS and not grouping everyone into generic categories (e.g., Asian). CAB members suggested DHS should re-engage community stakeholders and hold listening sessions with different demographic groups to understand factors responsible for current racial/ethnic differences in service utilization and access. As a CAB member said: *"I think access is a bigger piece of the pie. These services are more accessible to some communities than others. Besides, they may not be equitable."*

Finally, CAB members called for DHS to **build partnerships with BIPOC communities**. Building culturally sensitive relationships with multicultural communities and organizations that work in these communities is essential to address existing HCBS disparities. Such relationships can create additional education, awareness, and training on the available HCBS to different demographic groups in these communities. CAB members said: *"People cannot access what*

they do not know about.” Building these relationships will help promote trust and community collaboration between DHS staff and stakeholders, mobilizers, and key actors within the community. As part of greater partnership with BIPOC communities, some CAB members discussed the importance of having more BIPOC volunteers within HCBS delivery. DHS would need to create incentives for volunteering that can also provide other benefits (e.g., via Social Security).

II. **The role of HCBS service providers.**

Specific recommendations include: a) having more diverse HCBS providers; b) training of existing providers on culturally sensitive care and cultural humility; c) need to better support community providers who serve BIPOC communities; and d) need to address high rates of staff turnover. In discussions about residential care, most CAB members talked about the role and meaning of food and culturally sensitive programming for BIPOC communities.

First, DHS needs to **increase the diversity of service providers**. To do so, DHS needs to review their current HCBS providers and how the contracts are determined. CAB members asked for health equity and cultural sensitivity to be considered as they are often missing factors in who is contracted for HCBS services. They also noted that culturally sensitive providers can lead to higher use of HCBS by BIPOC communities; if providers represent their communities, more community members may participate.

Second, CAB member suggested **training of existing providers on culturally sensitive care**. This is especially relevant for providers who serve BIPOC communities; ensuring they have an adequate understanding of the community needs is critical.

Third, CAB members called for **greater support of community providers who serve racially/ethnically diverse users**. Some of the community providers shared that when it comes to licensing and reporting requirements, they felt over-scrutinized by DHS rather than engaged as a genuine community partner in meeting the needs of the community. The recommendation is for DHS to undertake a dialogue with the existing community providers that serve diverse communities on how DHS may support them better.

Finally, there was a shared sentiment for the need to **address high rates of staff turnover in HCBS and overall lack of staff, especially in rural areas**. CAB members discussed higher pay for aids as essential and also strategies to combine state and federal policies in how to reduce staff turnover. Many called for increases to reimbursement for services, demonstrating the value of HCBS work.

III. **The role of lead agencies.**

These recommendations echo many of the recommendations listed above for providers, including the need for cultural sensitivity training, preventing case manager burnout, and providing more support to lead agencies and county support.

First, many CAB members discussed the **need for cultural (racial/ethnic, class/socioeconomic) training for case managers** on how to appropriately interact with their clients. CAB members related personal experiences and experiences of those in their respective cultural communities about county and state workers who needed training on programs and eligibility criteria, as they were not always well versed in what clients were eligible for CAB members also identified the need for that information to be shared in a culturally sensitive way.

Second, many CAB members talked about the need for DHS to **address case manager and care coordinator burn out** because of large caseloads. The recommendation was to review case manager caseloads and develop strategies on how to prevent burnout with existing cases.

Third, many felt that **lead agencies need more independence to meet HCBS users' needs**. Some CAB members shared that DHS makes it hard for the lead agency to exercise independence which in turn makes it hard for the end user. Some talked about DHS as an Ivory Tower that supposedly focuses on best practices and research but makes their systems and programs hard for the end users in the community to access. The recommendation is for more meaningful engagement of counties, lead agencies, case managers, and other engaged parties as partners with DHS in serving the community.

IV. **System change.**

Specific recommendations include: a) greater integration of efforts related to equity across DHS; b) make the HCBS system more age-integrated; c) carry out a system-wide cultural competency training; d) undertake future initiatives to understand experiences of different racial/ethnic and cultural group; e) adapt greater use and coverage of technology services; and f) have people from specific racial/ethnic groups at the helm of change.

First, CAB members asked for **greater integration of efforts related to equity across DHS**. They commented that they felt like the state has competing agendas related to health equity taking place and solutions are being developed in silos. An example is to hold other project meetings, such as the CAB meetings for this project to generate ideas on equity action. Yet, they noted that potentially overlapping efforts are happening as well, with examples listed such as the “waiver reimaged” group. Hence, the recommendation is the need for consolidation of ideas, greater integration, and collaboration across agencies on health equity related issues, and ways to bring similar groups on related issues to work together.

Second, there was an overarching sentiment about ageism in the HCBS system and the need to **make the system more age-integrated**. As one participant said: *“We need to change the whole*

system and not make it so age segregated. Older people want to stay productive and it is not all just about “bingo and eating ice-cream.” Hence, the suggestion is to work on intergenerational collaboration across aging and disability services and ways to create meaningful contributions and meaningful engagement for all HCBS users.

Third, as reflected in previous recommendations, DHS needs to carry out a **system-wide cultural competency training** around class/socioeconomic and racial/ethnic differences as well as rural/urban differences for providers of services, case managers, and other decision-makers.

Fourth, CAB members asked **that DHS continue to undertake initiatives to better understand experiences of different racial/ethnic and cultural groups**. Some CAB members suggested future surveys and data collection that would allow DHS to look beyond the major demographic groups. As CAB members said: *“For example, more nuance is needed for experiences of Black vs. African American HCBS users.”* Another member said: *“We need to differentiate the perspective of those who are Black vs, African American. We should ask: What do we know about differences within these different demographic groupings? What do we know about how people from different age groups are utilizing services or what's preventing them?”* CAB members emphasized that when such initiatives are undertaken, the results should be made available to different communities in an accessible format.

Fifth, many talked about how **DHS needs to adapt its approaches for greater use of and reimbursement for remote delivery of services**. This was also particularly relevant for rural users. Some felt that technology can help address the HCBS worker shortage that was a concern for many. As one CAB member said: *“There are many things where [technology] eliminates the need for so many PCAs which are in shortage. But the state does not cover these technologically superior things which could help people live a much better life. It is an investment of the future. Our life has changed so much. Now because of COVID my daughter is home and one person can come here and there. We both have our own health issues but because of the ceiling lift we can take care of her at home. So state should stop thinking in short term saving money and think about saving money in the long run and people will be served much more efficiently.”*

Finally, all CAB members emphasized the need to **have people from under-represented racial/ethnic groups at the helm of change**. They highlighted the need to have individuals in leadership and decision-making with pertinent understanding of culturally appropriate needs. This sentiment is reflected by a CAB member quote below: *“The [under-represented] communities that these HCBS (services) are targeting should be highly involved in policy decisions and planning. They need to be consulted regularly, and their views sought. They should become active players and not be sitting on the sidelines, as the so-called “policymakers” make decisions that are not in their best interest or are not culturally relevant.”* Many said that

such engagement should form part of DHS's long-term strategic plan. Authentic engagement could address many of the existing myths about some public services and programs in various communities and help dispel these myths. Overall, there was strong endorsement and call for community members to be involved in decisions at the state level, as well as at the national level.

Recommendations for future DHS work/research in this area.

CAB member recommendations also provide a guidepost for future directions for research on racial/ethnic disparities in HCBS to inform DHS strategy. We list three specific areas below.

First, future analyses should examine in greater detail the role of rurality and geography in accessing HCBS and the quality of HCBS received. Such analyses should sufficiently capture the complexity of factors for receiving HCBS in rural areas, including resources, availability of services, transportation, etc., which are important to understand to remove existing barriers.

Second, all CAB members recommended that future HCBS work needs to provide a more nuanced analysis of racial/ethnic differences in HCBS. Specifically, analyses should go beyond the standard Census categories and capture the role of nativity, refugee status and other key aspects of heterogeneity within particular racial/ethnic groups to identify actionable and culturally sensitive steps to remove barriers to HCBS care. In order to do so, and since quantitative data are limited in their collection of different racial/ethnic categories, CAB members suggested DHS engage community stakeholders and hold listening sessions with different demographic groups to understand factors responsible for current racial/ethnic differences in service utilization and access, and to identify action steps. This should not be treated as an afterthought but should involve extensive data collection and systematic analysis.

Third, DHS needs to identify key areas of engagement with counties and lead agencies as listed in recommended action steps above. Some of such engagement may pertain to gaps in BIPOC DD enrollment that may be related to systemic issues across sectors, case manager training and developing strategies for engagement of non-English speaking users, among others. This work could happen in partnership with BIPOC communities to help identify priorities for action.

Limitations

This work is not without limitations, which we list below. First, the timeframe for this project was relatively short, in part due to COVID. The project started in 2020 but we could not engage CAB members until late summer due to COVID restrictions on outreach to communities. Second, we had a total of four meetings in a span of four months and could have used more time to break down quantitative presentations in more detail and have more time for input. Third, CAB dynamics could have been altered due to virtual format instead of in person meetings. Yet, one positive was that by using zoom we were able to engage stakeholders across

the whole state without having to travel to one central location. Finally, our CAB participants reflected diverse racial/ethnic groups, but certain groups were not represented, such as various groups in the Asian American community, and queer identities were underrepresented.

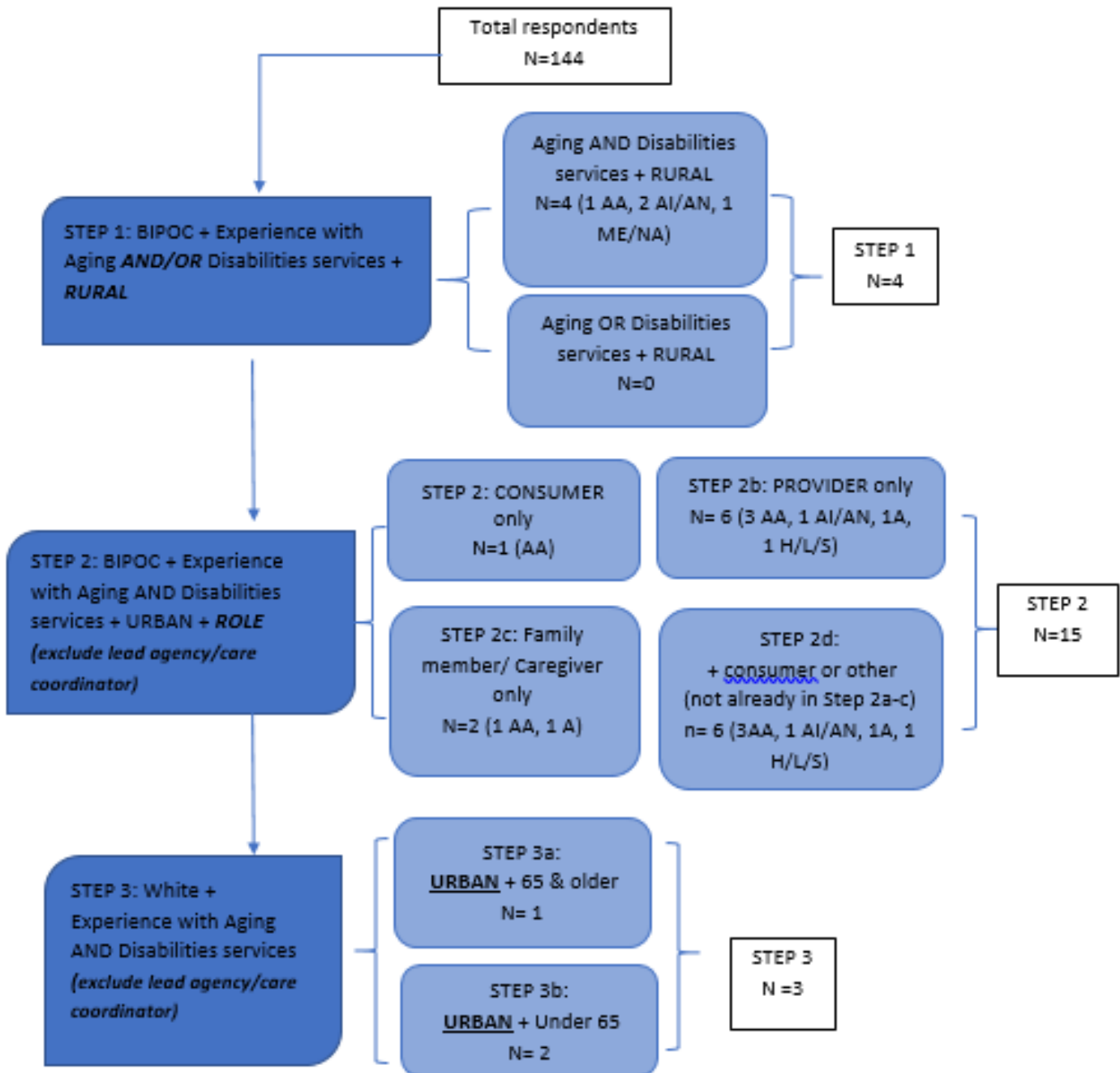
To conclude, as illustrated by findings from our literature review and CAB member feedback, BIPOC individuals share disparities in waiver program utilization compared to their white counterparts. Our findings are specific to Minnesota, but similar patterns are reflected across the country. Providers, policy makers and other stakeholders have a responsibility to ensure equity in access to and quality of HCBS for all. This can only happen through meaningful engagement with BIPOC communities, with authentic opportunities for leadership and decision making for those from BIPOC communities. More attention also needs to be given to address access barriers in rural areas. DHS needs to develop a clear strategy on meaningful engagement, but also action steps on how information gathered from CAB stakeholders is used for program improvement. As stated by a CAB member, words without action do not result in change and leave us with a question often asked at CAB: *“How will DHS actually take all this information into consideration to redesign waiver programs to resolve disparities over the next few years?”*

Appendices

Appendix A: Organizations sent recruitment survey

- Abubakar As-Sadique Islamic Center
- Alzheimer’s Association MN/ND
- American Indian Family Center
- Bhutanese Community Organization of Minnesota
- CAPI USA
- Care Providers of Minnesota
- Centro Tyrone Guzman
- Council of Somali Imams
- Dar Al-Hijrah Mosque
- DHS-Aging List serve
- DHS-DSD List serve
- East Africa Health Project
- East Side Neighborhood Services
- Ethiopian Faith Community Health Program
- Governor's Council on Developmental Disabilities-Partners in Policymaking
- Hallie Q. Brown
- Hmong American Partnership
- Hmong Cultural Center
- Hmong Health Care Professionals Coalition
- Hue-MAN Partnership
- Islamic Dawah Center (Minnesota Dawah Institute)
- JS Impact
- JustUs Health
- Ka Joog
- Karen Organization of Minnesota
- Korean Service Center
- Little Brothers-Friends of the Elderly
- Metropolitan Area Agency on Aging
- Minneapolis American Indian Center
- Minnesota Department of Health- Center for Health Equity e-newsletter
- NorthPoint Health & Wellness Center, Inc.
- Ramsey County Public Health
- Somali Action Alliance
- Somali American Parent Association
- Stairstep Foundation
- Stratis Health
- University of Minnesota-School of Public Health (past focus group participants)
- Vietnamese Social Services of Minnesota

Appendix B: Community Advisory Board selection processes



° AA: African American or African Heritage, AI/AN: American Indian or Alaskan Native, A: Asian, ME/AN: Middle Eastern or North African, H/L/S: Hispanic/Latino or Spanish origin.

Table 1: Descriptive Characteristics of Selected CAB members

Category	Total count	% of total count (n=22)
Total selected CAB members	22	100%
Gender		
Male	5	23%
Female	17	77%
Race/Ethnicity**		
African American or African Heritage	8	36%
American Indian or Alaskan Native	3	14%
Asian	3	14%
Hispanic, Latino, or Spanish Origin	2	9%
Middle Eastern or North African	0	0%
White	3	14%
One or more race/ethnic groups, options selected	3	14%
Age group		
Under 65 years old	18	82%
65 years and older	4	18%
Location		
Rural	4	18%
Urban	18	82%
Role Category (Aging and/or Disabilities services) ***		
Consumer (Older Adult/ People with disabilities)	10	45%
Provider	14	64%
Family member / Caregiver	13	59%
Other	2	9%

** Middle Eastern/North African (n=1) is in the one or more subcategory

***Due to combination, sum of counts does not add up to 22.

Appendix C: Community Advisory Board members and roles

- Deq Ahmed, Provider
- Christy Caez Claudio, Family Member/Caregiver
- Wilmar Delgado, Provider
- Andei Douglas, Provider
- Casey Erickson, Provider
- Debbi Harris, Family Member/Caregiver
- Abdiwadi Husen, Provider
- Pat Jones, Provider
- Tru' Love, Recipient
- Macdonald Metzger, Community Member
- Molly Montana, Provider & Family Member/Caregiver
- Awana Moye, Community Member
- Carolyn Ouradnik, Provider
- Rijuta Pathre, Family Member/Caregiver
- Mary Pendergast, Provider & Family Member/Caregiver
- Roxanee Pierre, Provider
- Sneha Singh, Community Member
- Grace Song, Family Member/Caregiver
- April Sutor, Provider
- Beth Timmins, Provider

Note: 2 members selected for the CAB were unable to participate

Appendix D: Summary of key themes and subthemes

Key themes and subthemes across all meetings:

1. Lack of access to HCBS information, services and funding for BIPOC and rural communities
 - a. Language barriers, challenges for immigrant communities
 - b. The HCBS service system is complicated, hard to manage and navigate the system efficiently
 - c. Culturally competent providers, who have similar cultural backgrounds, as those they serve often face challenges related to resource shortage and barriers to funding
 - i. There is too much focus on regulation/licensing instead of trying to foster success
 - ii. Punitive approach vs. partnership/collaboration/co-creation between the community providers and DHS
 - d. Barriers on where to find information
 - e. Particular challenges for rural and for Indigenous communities
2. Disagreements with broad racial/ethnic categories used in data and the need for more nuanced groupings
 - a. Critique of the racial/ethnic categories used in the data
 - b. Differences in lived experiences based on one's cultural background- People of color are not a monolithic group, need to be aware of the heterogeneity.
 - i. "Asian American" and "Black" are very broad categories and need to be more nuanced (e.g. East Indian)
3. Long-term services and supports (LTSS) and medical services are not culturally inclusive; service gatekeepers perpetuate bias and stereotypes and need to practice cultural humility
 - a. Potential for case manager bias
 - i. Bias in service need assessment encounters
 - b. Lack of cultural humility
 - c. Need for cultural sensitivity and awareness training to mitigate bias and differential assessment of eligibility

- i. Bias in assessment for Black young men, especially for DD services, who are often criminalized for their behavior
- 4. Stigma in BIPOC communities associated with LTSS and HCBS utilization, especially for mental health and needs.
 - a. Asking for help or being dependent on services (especially mental health and long-term residential care) is a taboo in some BIPOC communities
 - b. DHS and counties need to invest in resources towards the following for communities of color:
 - i. Help destigmatizing mental health and long-term residential care
 - ii. Waivers for mental health and long-term residential care services that considers their needs and,
 - iii. The separation of mental health issues and drug abuse.
 - c. Stigma associated with living with developmental disabilities
 - d. Lack of mental health services in rural areas disproportionately impacting Indigenous communities
- 5. Historical distrust of government related to limited capacity and competency in addressing the health needs of BIPOC and marginalized communities.
 - a. Historical trauma due to racism and disenfranchisement leading to distrust of governmental agencies
 - b. Fear of deportation within BIPOC communities
 - c. Increased ED use due to lack of insurance and limited use of preventive care services (tied to historical trauma and distrust).
 - d. Importance of person/provider concordance for receiving services, which also impacts experiences over the life course
 - e. BIPOC communities are not likely to use residential care due to lack of culturally sensitive care options (e.g. food options)

Appendix E: References

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