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HCBS Equity

Understanding and Responding to Inequities in Access to, Utilization, and Quality of Medicaid Home and Community-Based Services

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August 31, 2023

Agenda

1. Introductions, Overview of Project Goals. Stakeholder Convening
2. Quantitative Study – Preliminary Findings
3. Qualitative Study – Identified Problems & Solutions

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Overview of Project

Project Objectives and Tasks

AIR's Equity Initiative

- Launched in 2021
- Five-year $100M+ investment in behavioral and social research and technical assistance to address the underlying causes of systemic inequities and to increase opportunities for people and communities
- Competitive internal funding was offered to Health staff in 2021 to support projects that aimed to address longstanding social and economic inequities that arise from systemic segregation by race and by place
- The Home and Community Based Services (HCBS) Equity project was awarded a two-year $500k grant to investigate inequities in HCBS in January 2022

Note. Placeholder for notes, sources, and permissions (if needed). "Note." (including a period) is italicized.

Objectives

Racial, ethnic, and geographical disparities in health care are pervasive, including in nursing homes, and we expect that similar disparities exist in Medicaid HCBS. Because Medicaid HCBS serve the most medically and economically vulnerable groups, disparities can lead to serious adverse health effects for HCBS populations of racial and ethnic minorities, and for geographically disadvantaged groups. Lack of knowledge about the extent of and reasons for disparities results in lack of actionable steps to improve HCBS equity.

OBJECTIVES

- MEASURE — systematically investigate if and to what extent there are racial and geographic inequalities and inequities in access to, utilization, and quality of Medicaid HCBS
- UNDERSTAND — account for the reasons for observed disparities
- RESPOND — engage diverse stakeholders, including policy makers, to collaboratively develop strategies that will address observed disparities

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Stakeholder Convening

Overview of Goals and TEP Brainstorm

Goals

Develop a roadmap for improving equity in HCBS

- **Inform**
  - Share and hear reactions to findings about disparities in Medicaid HCBS access, utilization and quality from the quantitative and qualitative studies
- **Identify issues**
  - Based on findings, work with stakeholders to identify specific issues and opportunity areas for improving equity in Medicaid HCBS across various domains
- **Develop solutions**
  - Identify key actions for improving equity in HCBS.

Format

- **Virtual meetings organized by The American Society on Aging (ASA)**
- **November 2023**
- **Two sessions**
  - Two hours each over two days
  - Session One: focused on sharing findings and working with stakeholder group to help identify top issues and opportunity areas
  - Session Two: focused on brainstorming solutions/roadmap for success with stakeholder group
- **Approximately 30 attendees**
  - Stakeholders and experts in the world of HCBS
  - Breakout discussion groups of 5-6 people

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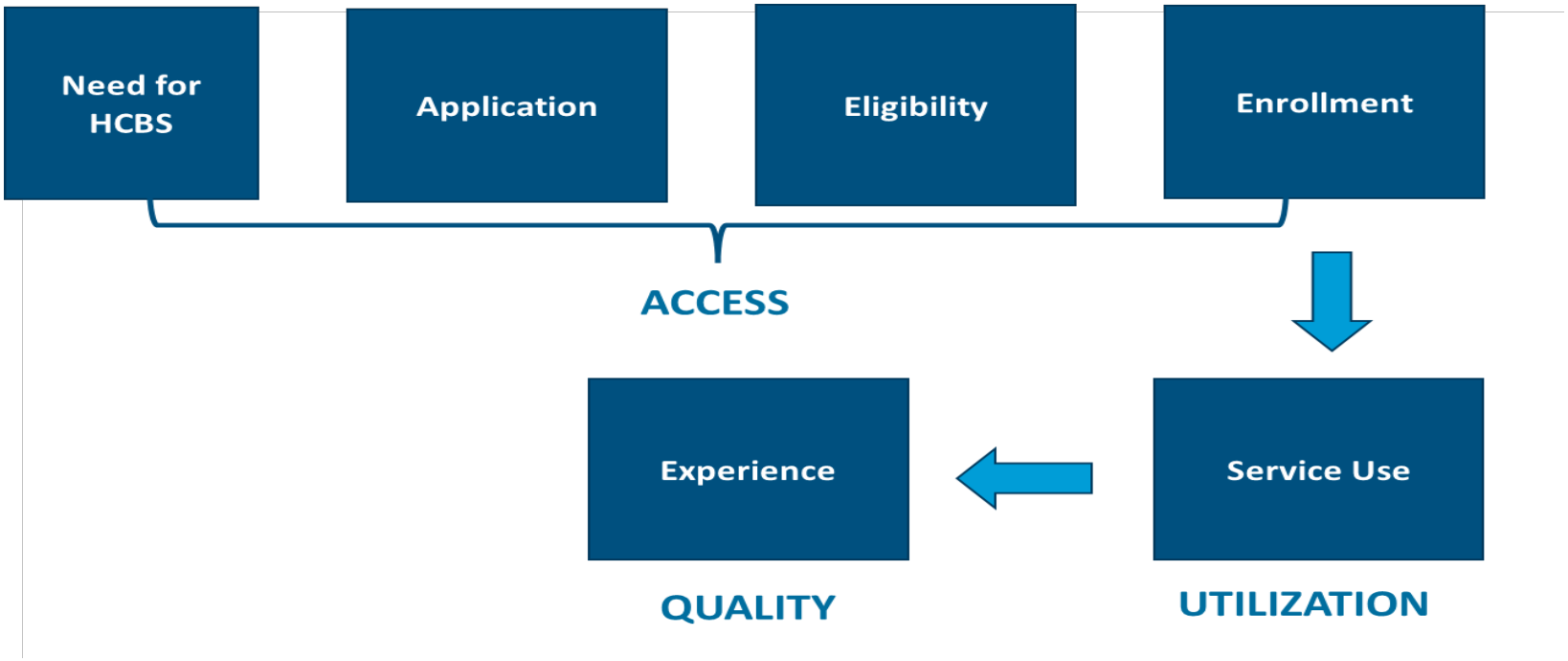
Quantitative Study

Preliminary Findings

Overview

Measuring disparities in access, utilization and quality



Disparities in Access to HCBS

Measuring Disparities in Access to HCBS is Challenging

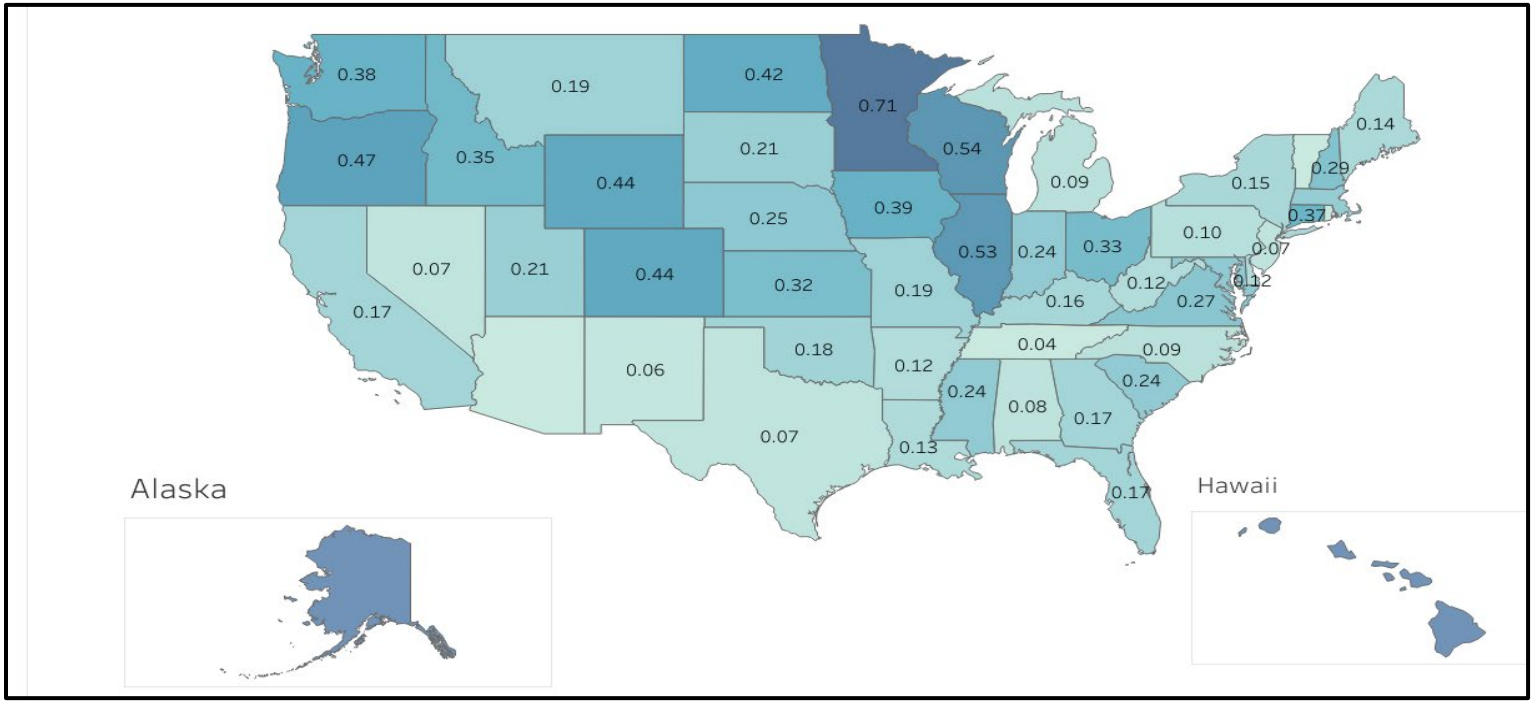
- **Key steps in measuring disparities in access to HCBS in Medicaid claims and survey data**
  - Identify appropriate dimensions of access applicable to HCBS
  - Identify appropriate data sources
  - Identify or construct quantitative measures of access

- **Challenges in measuring disparities in access to HCBS in Medicaid claims and survey data**
  - Lack of data and standardized measures
  - System-level factors common across racial, ethnic, and geographic groups

Proposed Measures of Access to HCBS

Outcomes	Data Sources	Type of Analysis	Racial/ Ethnic	Geographic
Availability Ratio: Ratio of maximum number of waiver slots to population potentially eligible for HCBS	MACPAC data table, ACS	Descriptive		X
Waitlist Ratio: Ratio of number of people on waiver waiting list to maximum number of waiver slots	MACPAC data table, ACS	Descriptive		X
Likelihood of Enrolment in HCBS:	T-MSIS	Regression	X	X

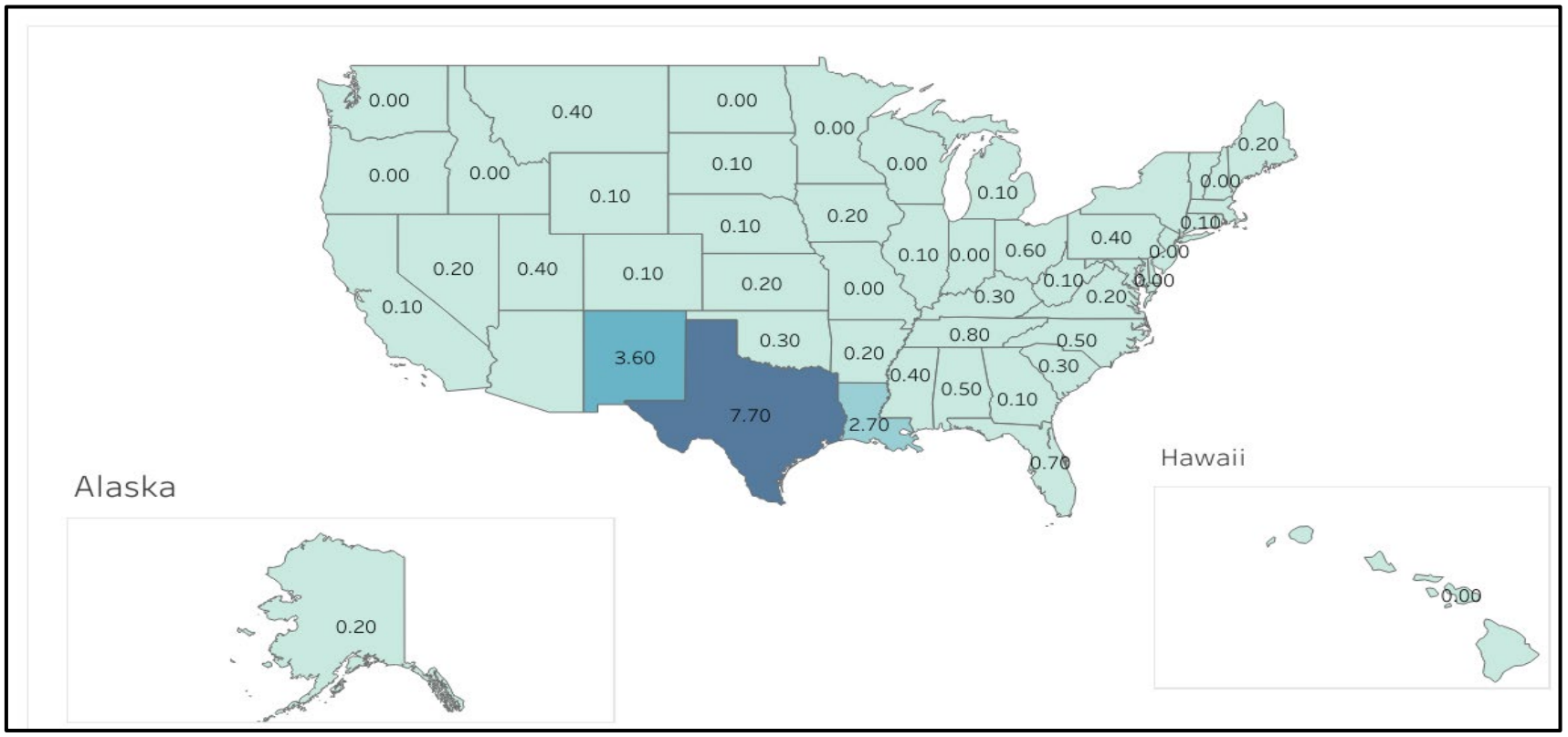
Availability Ratio Varies Widely across States



Availability Ratio: Ratio of number of waiver slots to potentially eligible population		
High	0.29 - 0.71	AK, CO, CT, DC, IA, ID, IL, KS, MN, ND, NH, OH, OR, WA, WI, WY

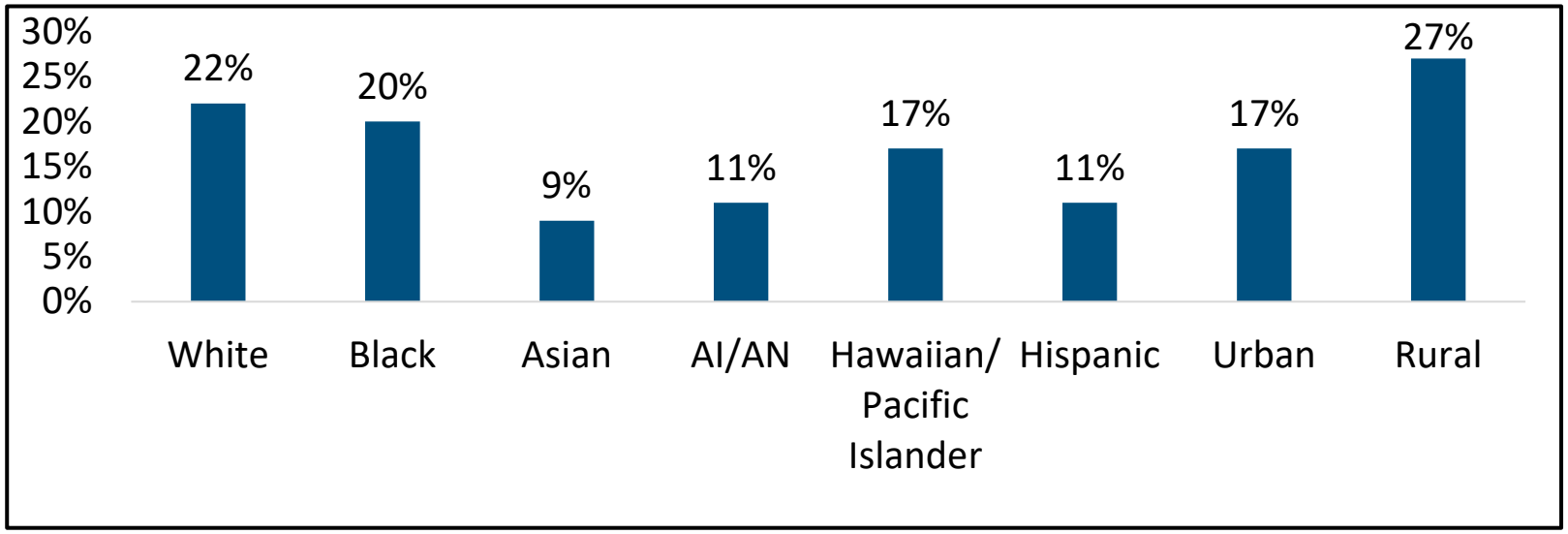
- **States with availability ratios >0.5: IL, WI, MN**

Few States have Large Waitlist Ratios



- **Several states with waitlist ratios<=0.05**
- **Three states with waitlist ratios > 1**

No Evidence of Disparities in HCBS Enrollment among Medicaid Beneficiaries



- Nationally, AI/AN and Blacks have higher disability rates but lower enrollment in HCBS compared with White Medicaid beneficiaries
- No differences in enrollment after controlling for demographics and health conditions
- Next steps:

  Enrolment Ratio: Ratio of number of Medicaid HCBS recipients to population potentially eligible for HCBS

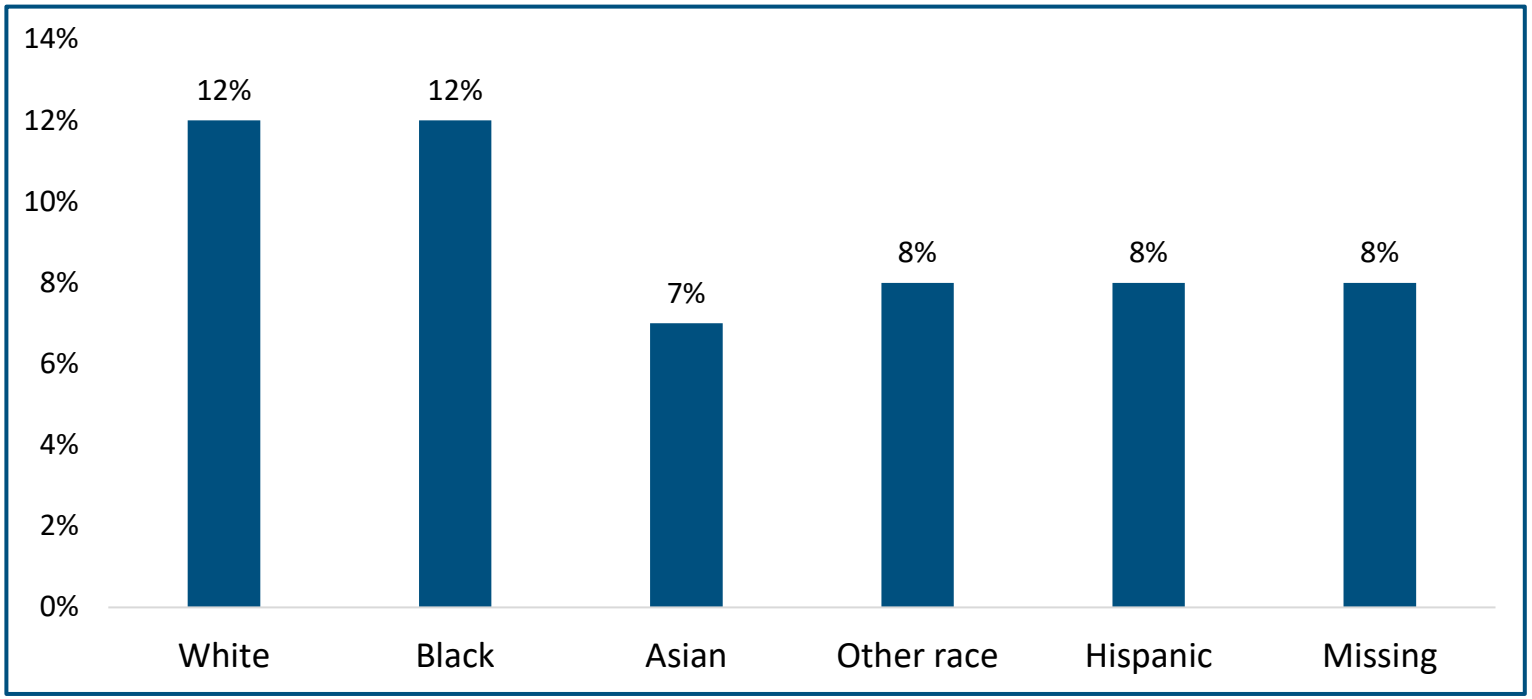
Disparities in Utilization of HCBS

Utilization of HCBS

- **Data Sources:** Transformed Medicaid Statistical Information System (**T-MSIS**)
- **Data Quality**
  - Missing data about race and ethnicity
  - HCBS taxonomy classification
- **Measures:**

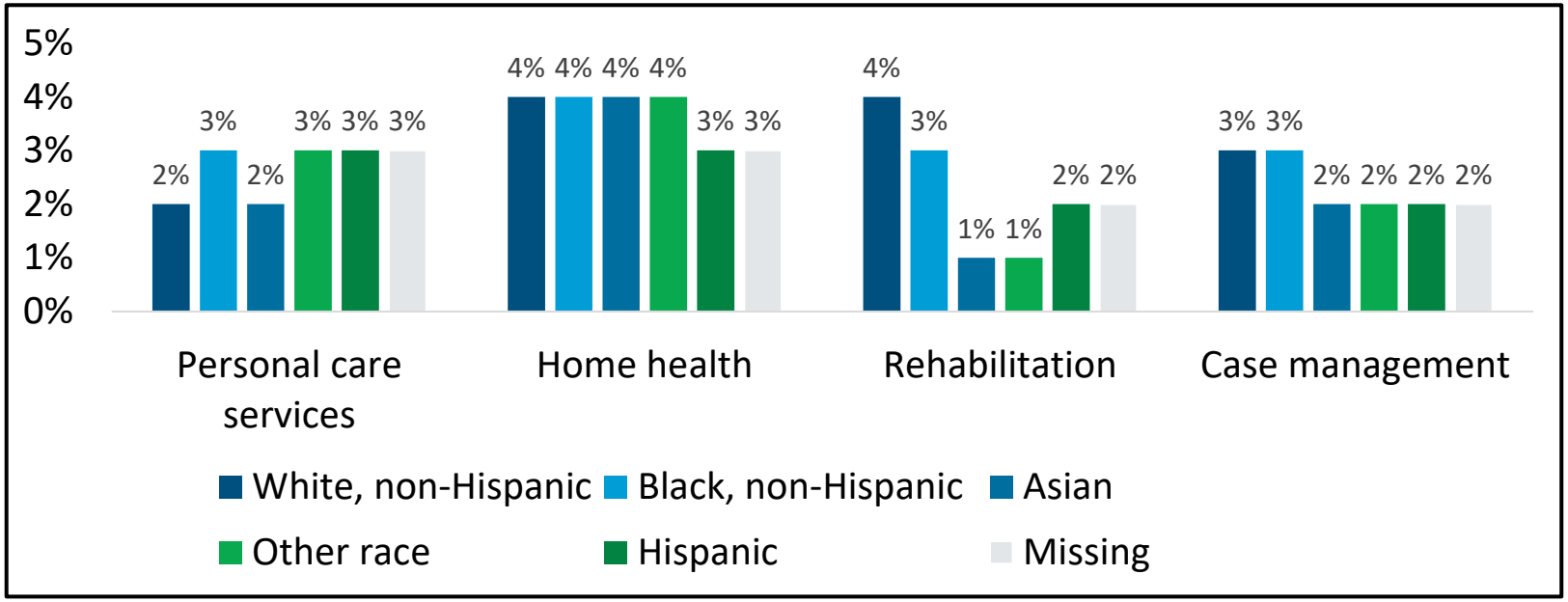
Outcomes	Data Sources	Type of Analyses
Any HCBS service (0/1)	T-MSIS	Descriptive, Regression
HCBS expenditure ($)	T-MSIS	Descriptive, Regression

Small and Insignificant Racial Differences in HCBS utilization among Medicaid Beneficiaries



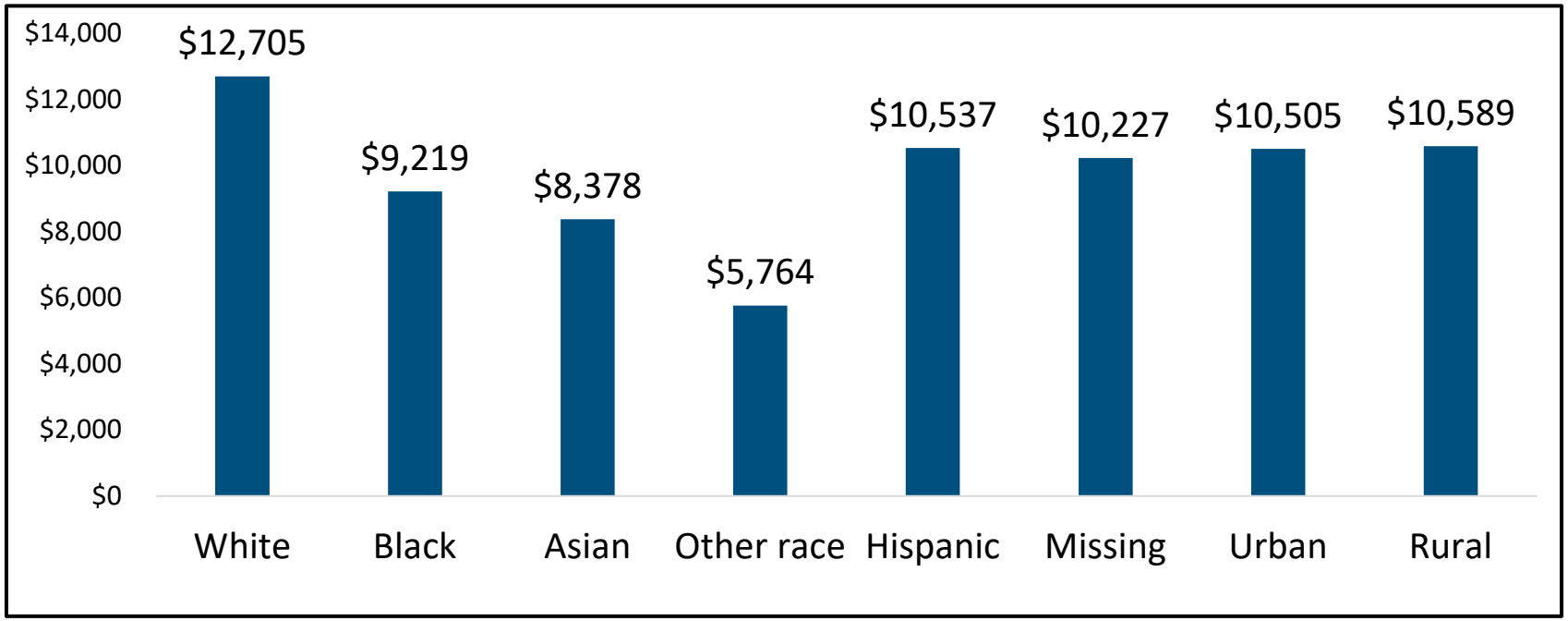
- Differences exist in unadjusted utilization rates by racial and ethnic groups
- No differences in utilization controlling for demographic characteristics, health conditions, dual status, and county-level differences

Types of Services Received Vary by Race/Ethnicity



- Regression adjusted estimates show that Black HCBS participants significantly more likely to receive personal care services
- Black and Asian HCBS participants less likely to receive home health and rehabilitation services, effects are larger for rural HCBS participants

HCBS Expenditures per Participant are Significantly Lower for All Racial and Ethnic Minorities



- Racial and geographic disparities in HCBS expenditures persist in regression estimates adjusted for demographic characteristics, health conditions, and county-level differences

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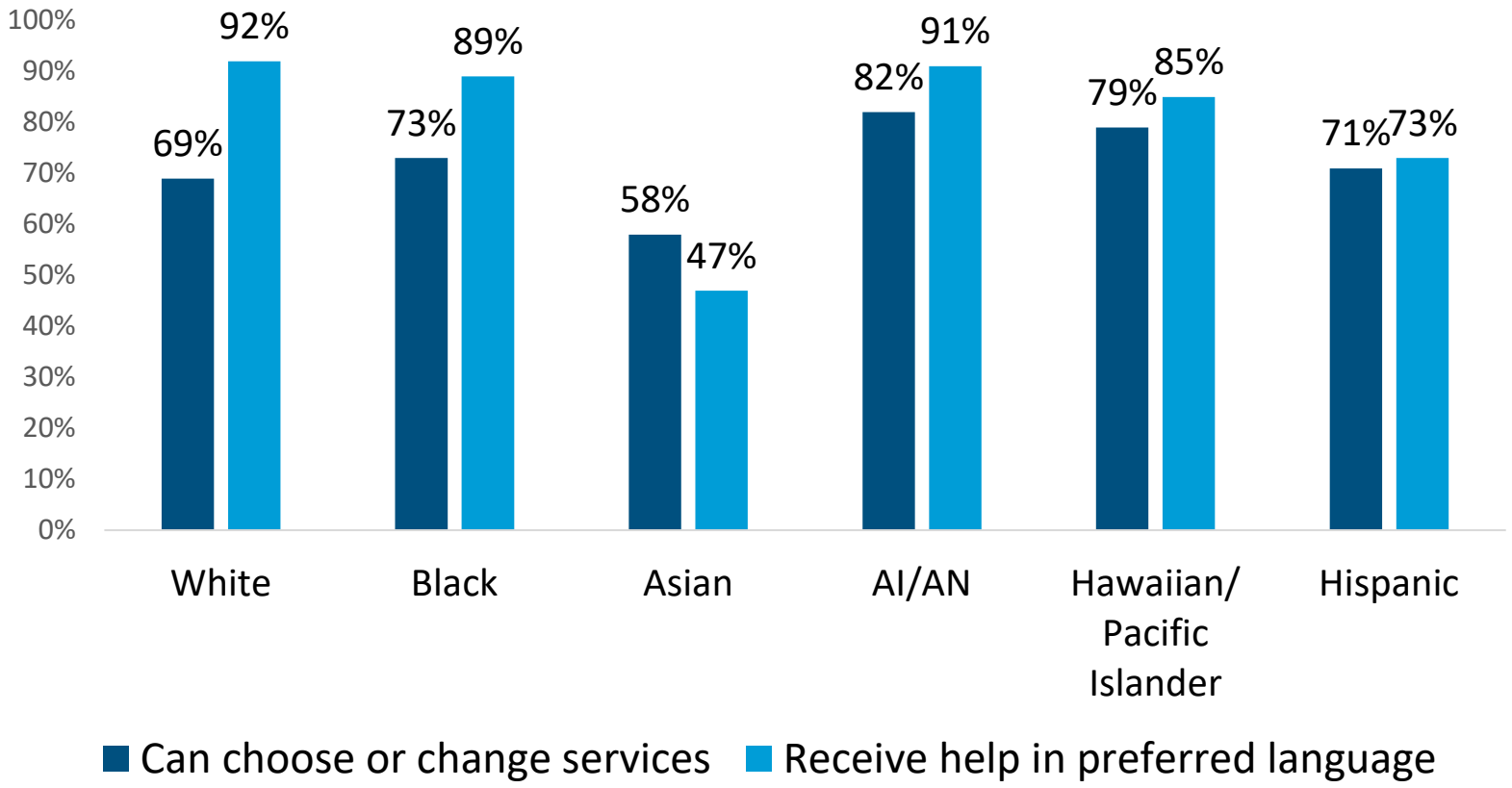
Disparities in Quality of HCBS

Quality of HCBS

- **Data Sources:** National Core Indicators-Aging and Disability (NCI-AD) and National Core Indicators-Intellectual and Developmental Disabilities
- **Measures:**

Outcomes	
• Able to choose or change services provided (0/1)	• Support staff do things the way they want them done (0/1)
• Able to choose or change staff if they want to (0/1)	• Have transportation when needed (0/1)
• Receive help in preferred language (0/1)	• Have enough assistance when needed (0/1)
• Staff show up and leave on time (0/1)	• Support staff change often (0/1)
• Respectful treatment by provider (0/1)	

Asian HCBS Participants Report Lower Satisfaction with Services



Magnitude of Racial and Ethnic Disparities in Quality of HCBS Vary Across Dimensions of Quality

Outcomes	Black	Asian	Other race	Hispanic
• Able to choose or change services provided (0/1)	↓		↓	
• Able to choose or change staff if they want to (0/1)			↓	
• Receive help in preferred language (0/1)		↓	↓	↓
• Staff show up and leave on time (0/1)	↑	↑		↑
• Respectful treatment by provider (0/1)				

Magnitude of Racial and Ethnic Disparities in Quality of HCBS Vary Across Dimensions of Quality

Outcomes	Black	Asian	Other race	Hispanic
• Support staff do things the way they want them done (0/1)	↓		↓	
• Have transportation when needed (0/1)			↓	
• Have enough assistance when needed (0/1)	↓	↓		↓
• Support staff change often (0/1)	↓	↓		↓

- Compared with urban HCBS respondents, no evidence of differences in quality of HCBS for rural respondents

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Qualitative Study

Review of Themes

Overview of Key Informant Interviews

30 KIIs with 3 stakeholder groups

- **11 HCBS Participants and Caregivers**
  - 6 HCBS participants
  - 5 Caregivers
- **10 State and Local Providers**
  - 6 State directors, key program staff, or LTSS-focused equity officers
  - 4 Local program or direct service provider directors or key program staff
- **10 Subject Matter Experts**
  - 10 Researchers, advocates, and policy experts in the field of HCBS
  - Working on issues related to equity based on race/ethnicity or rural HCBS service provision

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Inequities based on race and ethnicity

Systemic Inequities Exist in HCBS

Problem: Most state/local HCBS believed there were systemic inequities based on race/ethnicity, but some were not as clear on the issue

- Many participants noted examples of disparities in access and utilization of certain services.
- Many participants felt they did not have a full picture of what these inequities look like and/or what was driving the inequities.
- However, not all participants necessarily felt there was bias in HCBS programs and not all states were prioritizing equity issues.

Solution: Buy-in at the state/local levels is essential to address the issue

- Without buy-in at the leadership level, identification of inequities and plans to resolve them will not be feasible.

State and local services often struggle to adequately serve non-English language participants

Problem: State/Local HCBS struggle to serve groups that don't primarily speak English.

- Workforce may not match the language needs of service recipients.
- Language is a barrier to access, utilization, and quality of services.
- People with language barriers may be treated differently.

Solution: Provide language specific outreach and service options, where feasible.

- Two states gave examples of culturally/language specific day programs.
- Use community liaisons to communicate with ESL/non-English-speaking communities.
- Staff at all levels (state, local, and programmatic) should reflect the communities they serve.

People from certain ethnic groups may be less likely to seek services and instead rely on family

Problem: HCBS programs may not effectively reach certain ethnic communities, where family caregiving is often the norm

- People in some cultures may be less likely to seek out HCBS and instead rely on family caregivers.
- "There is a cultural thing in Asian and Latinx community where they do not reach out to services as much as they are family-orientated. We know those services are needed and could help. So, we definitely want them to know about it." (State Staff)

Solution: Target outreach to communities that have traditionally been overlooked or underrepresented in HCBS, including outreach to caregivers.

Data on race/ethnicity is inadequate or underutilized

Problem: There is a lack of reliable and publicly available data on race/ethnicity of HCBS participants.

- States are collecting some data, but it could be improved.
  - There is a lack of published data on race/ethnicity in HCBS.
  - Many states lack data on the race/ethnicity of people on their waitlists (if they are collecting waitlist data).
- Most states are not using this data to examine equity issues.

Solution: Data capture and standardized reporting on race/ethnicity is key to painting a clearer picture of inequities.

- It is also important for states to standardize the way they report on race/ethnicity across HCBS programs.

Housing Inequities Create HCBS Inequities

Problem: Lack of housing and home ownership is an issue of institutional racism that may serve as a barrier to access for HCBS.

- "In addition, housing. That is another equity issue. Redlining policies have affected homeowner rates for Black and Latino communities. Renters are getting hit. A lot of our homeless population is our aging populations. You can't receive home care if there is no home. You need a home." (State Staff)

- **Solution: Affordable housing must accompany HCBS offerings.**

Inequities based on place

Hard to find HCBS workers willing/able to travel to more rural locations

- **Problem: While in general it is hard to find paid HCBS caregivers, it is even harder to find paid caregivers in rural locations**
  - Pool of potential caregivers who can become certified caregivers is extremely small
  - Paid caregiving is a difficult job in itself, and adding the requirement to travel long distances to rural areas makes it more undesirable
  - Many individuals in workforce do not have cars and rely on public transportation, limiting their ability to travel to rural areas
  - Caregivers are not paid for travel expenses or are reimbursed at low rates
- **Solution: Federal and state governments need to provide:**
  - Free or low-cost certification programs to potential caregivers
  - Higher wages that take into account travel time and expense
  - Creative solutions that allow more caregivers to travel to rural areas, like carshare services

Innovative Approaches May Help Reduce Rural Workforce Burden

- **Solution: telehealth may help provide access to HCBS or other services**
  - Can be used to remotely monitor participant needs
- **Solution: Giving patients assistive technology can lower their reliance on direct service caregivers**
  - ""We have embraced assistive technology. We're using that whenever we can. We're showing older adults assistive technology and showing them that some of these devices can be used to continue to be independent. We provide assistive technology devices to individuals if it keeps them off of the waiting list. Because even if we have a spot open for internal services, it does not guarantee that there is a staff person that can help… It is so much less expensive to give someone a bath lift then paying someone $30/ hour to come into their home three times a week to give them a bath." (Local Leader 1)

Internet Access Remains a Concern in Rural Areas and Requires Public Investment

- **Problem: Remote participants are less likely to have internet access, restricting access to telehealth.**
- **Problem: Lack of internet access reduces workforce willing to come to rural areas, if system requires them to check into work on GPS enabled systems.**
  - "Looking at internet access is actually more important than telehealth. We need to figure out broadband and how people can access those services. That is tricky in every state you are in. There is an electronic verification change to the Medicaid statute that went into effective in 2021. That has certain requirements around direct care workers and the home-based service system basically registering that they're actually there. I surveyed my states a while ago, many of them said this does not work in rural areas because there is no coverage." (SME)
- **Solution: Expansion of internet access as part of infrastructure development policy.**

Lack of Access to Transportation Services for HCBS Participants

- **Problem: Respondents noted a distinct lack of access to affordable transportation in rural areas, driven by:**
  - Lack of access to public transit systems
  - Lack of staff who have the means to transport participants
  - Lack of transit reimbursement for staff who have the means to transport participants
- **Solution: States should conduct needs assessments to understand the differing costs of providing transit in rural areas**
  - Use this information to inform reimbursement rates that incentivize transit providers to service rural areas
  - "Transportation is a much harder issue. We have to understand the access barriers are and that requires in a change in statute so states can contract and secure the different contracts." (State Leader)

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Inequities based on race and place

Lack of programs available in certain areas

- **Problem: Respondents noted that rural areas lacked programs**
- **Problem: However, other respondents noted a lack of programs in densely-populated urban areas where people of color live**
  - "There's a lot of inequity in where programs are located. There are dense urban areas where often people of color are living and needing services and there are none available. Or, they are approved for services but there isn't enough availability. Thus, people in dense urban areas end up in nursing homes." (State/Local)
- **Solution: Using data to understand service gaps**
  - Some states have been working to understand where service gaps are based on population size and respondent background

There is a shortage of HCBS workforce

- **Problem: With lack of shortage of HCBS caregivers, it is more difficult for the workforce to reflect or understand the culture of participants**
  - This also affects certain minority groups that are also rural, such as Native American and Alaska Native Populations
- **Solution: States can invest in training caregivers in culturally competent care**
  - "Definitely cultural competency training. They are dealing with so many different types of people. It is person-centered-ness. It is being able to meet that person where they are. Each family is different. It is about being able to walk in a home, how are we going to deal with this family. I think of the person-centered training is the upmost important." (State Leader)
- **Solution: Removing barriers to allow family to be paid caregivers also ameliorate shortage**
  - "If I could give my husband all my hours I wouldn't be in this situation. I wouldn't be scrambling for care. Right now I have no care. I can't use the restroom or escape in the case of emergency… this would cut back the risk of injury and things like that because my husband knows my care and it significantly less dangerous to have him doing my care." (Rural respondent)

Poor community (rural and certain ethnicities) outreach may contribute to access issues

- **Problem: Lack of effective communication modalities in rural areas**
  - Communication efforts are increasingly over the internet, which is not as available in rural communities
- **Problem: States have said they have not been making inroads in terms of outreach to groups that have cultural beliefs around caregiving**
- **Solution: States need to use multi-modality strategies that include "online" and "offline" modalities**
- **Solution: States also need to better understand cultural roles of caregiving to better craft messaging to let communities know that help is available if wanted**

There is a need for more community engagement when designing programs and policies for HCBS

Problem: States don't always include stakeholders when designing programs and developing policies.

- If HCBS participants/caregivers are left out of discussions to design programs/policy that aims to serve them it increases the likelihood that inequities will be designed into those programs/policy.

Solution: State must thoughtfully engage participants and caregivers in policy and program design.

- "Caregivers of different ethnicities and different subgroups like income levels should be engaged in the development and design of services. Getting away from this idea of we will just adapt it. And sometimes adapt means we're just going to translate something into another language, whether that's a caregiving intervention, or a community service." (SME)

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