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ISSUE BRIEF

An Equity Framework for Evaluating and Improving Medicaid Home and Community-Based Services

INTRODUCTION

Most older adults and people with disabilities will require assistance to remain living in their homes and communities at some point over their lifetime. Medicaid is the largest payer of the wide range of services and supports—known as home- and community-based services (HCBS) —that enable many people with disabilities of all ages to live independently and fully participate in their communities as they choose.

Like in health care broadly, the systemic drivers of health inequities—racism, ageism, ableism, classism, sexism, xenophobia, and homophobia—are embedded in laws, policy, governance, and culture that shape HCBS programs. HCBS programs are particularly prone to inequities. From the outset, HCBS availability, or rather lack thereof, has been shaped by discriminatory views about people with disabilities of all ages as less valuable to society, borne out by segregating and isolating them into confined settings.[1] Policymakers enshrined these discriminatory views into federal Medicaid law, which requires states to pay for care provided in institutional settings while making it optional for states to offer HCBS.

Disabled advocates have led the effort to address this institutional bias. In 1999, the U.S. Supreme Court in *Olmstead v. L.C.* held that the unnecessary institutionalization of individuals living with disabilities violates their rights under the Americans With Disabilities Act to receive services in the least restrictive setting.[2] Since the *Olmstead* decision, federal and state policies, guidance, and resources have significantly shifted to better rebalance the provision of long-term care away from institutional settings toward home and community-integrated settings.

Yet, because states are not required to cover HCBS, the "system" is a patchwork of HCBS programs with wide variation among and within states, leading to inequities in who has access to the supports and services needed to

live in the community and who has no option but to receive care in an institutional setting.[3] Racial discrimination and segregation in housing further compound these inequities, because without accessible and affordable housing, people cannot receive HCBS.[4] To achieve health equity, it is therefore necessary to evaluate seemingly neutral HCBS program policies and rules to ensure they are not preserving existing inequities or causing unintended inequities.

Justice in Aging developed an HCBS Equity Framework to support policy makers, payers, providers, advocates and consumers in making equity a primary focus at every stage of HCBS program design and implementation. The Framework describes five domains in which inequities can arise in HCBS: 1) Program Design; 2) Provider Availability; 3) Program Awareness and Enrollment; 4) Assessments and Authorization of Services; and 5) Provision of HCBS.

For each domain, the Framework provides examples of policies, program rules, and decision points in which an equity evaluation should be considered. This Framework is not meant to be exhaustive, but instead provide a starting point for thinking about and evaluating the ways in which equity can be embedded in HCBS to ensure all eligible individuals have access to adequate and quality services.[5] Across all domains, data collection and publication are key to transparency and oversight, and are needed to evaluate whether policy initiatives and interventions are accomplishing their intended purpose.

Justice in Aging originally developed the [Equity Framework](#) for the California Long-Term Care Equity Series supported by the California Health Care Foundation.

HCBS EQUITY FRAMEWORK

PROGRAM DESIGN. In the initial design of HCBS programs, inequities can arise from policies that establish who is eligible for HCBS programs, where programs are available regionally, and what services are offered by an HCBS program.
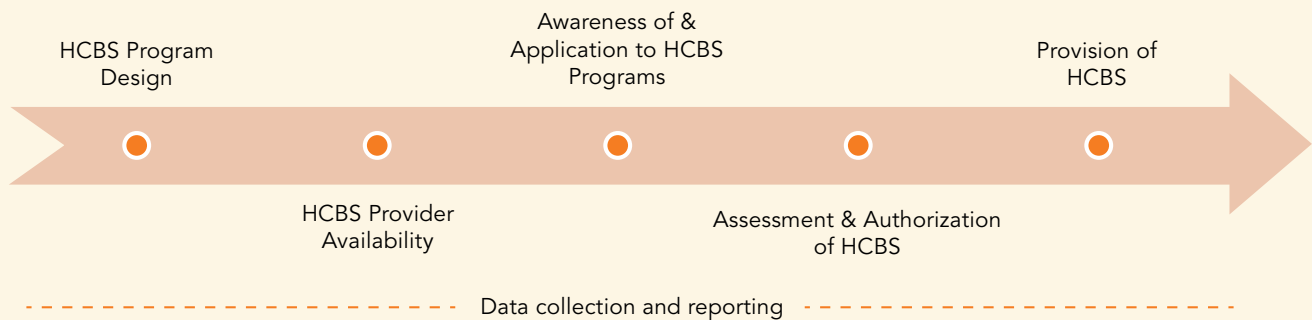
PROVIDER AVAILABILITY. Inequities in provider availability can arise from policies that dictate network adequacy, reimbursement rates, and provider investments, trainings, and supports.

AWARENESS AND ENROLLMENT IN HCBS. Inequities arise when information on program availability and eligibility requirements is not easily available and application processes are overly burdensome.

ASSESSMENT FOR/ AUTHORIZATION OF SERVICES. Implicit bias can be built into service assessment and authorization processes that can lead to inequities in who is deemed eligible.

PROVISION OF HCBS. Inequities can arise in the provision of HCBS when the unique needs and lived experience of service recipients are not built into the accessibility of services and means of measuring quality of services rendered.

HCBS Program Design

Awareness of & Application to HCBS Programs

Provision of HCBS

HCBS Provider Availability

Assessment & Authorization of HCBS

Data collection and reporting

To ensure equity is a focus across all stages of HCBS program design and delivery, policymakers, providers, advocates, and other interested parties should evaluate the impact a policy or program rule has or would have on specific and co-existing marginalized communities and identities including older adults, people with disabilities, people of color, women, LGBTQ individuals, immigrants, individuals with limited English proficiency, and individuals living in rural, urban, suburban, and tribal regions.

DOMAIN #1: HCBS PROGRAM DESIGN

States provide HCBS through a variety of Medicaid authorities, and the majority of states have multiple programs serving different populations.[6] Hundreds of decisions go into each program—from what authority to use to who to serve. Each decision point in program design is an opportunity for federal, state, and local policymakers to make equity a primary focus.

Policy elements that should undergo an equity evaluation to increase equitable access through HCBS program design include:

- **HCBS Medicaid Authority**: States choose which Medicaid authorities to utilize, which can result in inequities in who has access. Some authorities require access statewide while other authorities allow states to limit regionally where services are available. The most common authority, the 1915(c) waiver, allows states to limit program eligibility to certain populations (e.g., older adults or people with intellectual and developmental disabilities) and cap enrollment. Most HCBS waiver authorities also have a cost neutrality requirement that can limit HCBS access to those with the highest needs. (For more on Medicaid authorities see our HCBS Primer).

- **Community Engagement**: Community voice and lived experience are critical to equitable HCBS program design. Inequities can arise if states do not seek input from a diverse cross-section of HCBS users and providers when designing HCBS programs and policies.

- **HCBS Program Benefits**: Each HCBS program, regardless of Medicaid authority, has a defined set of benefits or services. Inequities can emerge in which services are included or omitted to meet the particular needs of HCBS users.

- **HCBS Regional Access**: Under certain HCBS Medicaid waiver authorities, states can elect to only provide HCBS in certain regions or counties in the state. Inequities can arise based on which counties the state selects for the waiver due to multiple factors such as differences in county demographics, population density, and economic differences. Inequities can also arise based on how many waiver slots are allocated to a particular county or region in relation to its demographics.

- **HCBS Waiver Waitlist Administration**: Some HCBS waivers that cap the number of participants who can receive services maintain a waitlist when the cap is reached. Inequities can arise in policies that guide whether waitlists are used and how individuals get on and advance in waitlists.

MICHIGAN'S MI CHOICE WAIVER: HOW INEQUITIES CAN ARISE IN HCBS PROGRAM DESIGN

Half of Michigan's population lives in 10 counties in the southeast part of Michigan. In one of those counties, Wayne County, 40% of older adults are people of color. However, when researchers evaluated the state's HCBS waiver program, MI Choice, they found there is only one waiver slot for every 58 eligible people in the most populous counties compared to one slot for every 20 eligible people in the rest of the state. Such inequities may also be present in HCBS waivers across the country that cap enrollment.

AARP Michigan, "Disrupting Disparities: A Continuum of Care for Michiganders 50 and Older", at 17 (Apr. 2019).

DOMAIN #2: PROVIDER AVAILABILITY

The availability of service providers to render services – particularly service providers who can meet the complex and unique needs of HCBS users—often impacts equitable access.

HCBS policy elements that should undergo an equity evaluation to improve provider availability include:

- **Network Adequacy Standards**: Network adequacy standards for HCBS and other long-term care services are minimal. Inequities can arise when network adequacy standards are absent; maintain the status quo; perpetuate residential racial segregation (e.g. location of residential care facilities); or when they do not adequately account for HCBS users' needs and preferences.

- **HCBS Provider Reimbursement Rates**: Adequate reimbursement rates are necessary to ensure an adequate HCBS workforce. Inequities can arise when states' reimbursements are too low. Low reimbursement rates discourage opening new operations in underserved areas, can lead providers that primarily serve Medicaid enrollees to close, and can result in fewer choices of HCBS programs or providers. Low reimbursement rates also lead to workforce shortages, particularly in areas with a high cost of living and in rural regions.

- **Caregiver Supports**: Unpaid caregivers play an essential role in supporting older adults and people with disabilities to live in the community. HCBS programs often include caregiver supports. Inequities can arise in which caregivers learn of these supports, the type of supports available, and whether the supports are culturally appropriate and meet the diverse needs of caregivers.

NEW JERSEY'S ASSISTED LIVING FACILITIES: HOW INEQUITIES ARISE IN PROVIDER AVAILABILITY

New Jersey offers an assisted living benefit to older adults through a number of programs including the assisted living residence benefit (ALR).

Under the ALR benefit, individuals receive services in a purpose-built facility with apartment-style units with a kitchenette, private bathroom, and at least one unfurnished room. When examining where in the state ALR facilities are located, more facilities are in located in less racially diverse counties.

The six counties with the most older residents in New Jersey are Bergen, Ocean, Middlesex, Essex, Monmouth, and Morris (in that order). Ocean, Monmouth, and Morris counties are less racially diverse with fewer older adults compared to Bergen, Middlesex, and Essex counties. Yet, of the 75 total facilities accepting Medicaid in these six counties, 68% (or 51 facilities) are available in Ocean, Monmouth, and Morris counties.

NJ Health, Health Facilities, accessed June 1, 2023.

As a result, 32% of Medicaid enrollees receiving the ALR benefit statewide reside in Ocean, Monmouth, and Morris counties while just 19% of Medicaid enrollees receiving the ALR benefit reside in Bergen, Middlesex, and Essex counties.

NJ FamilyCare, Long-Term Care: Month at a Glance, accessed May 31, 2023 (select MLTSS AL hyperlinks).

These data demonstrate that provider availability is inadequate in the state's most populous and racially diverse counties. The data is consistent with research finding that assisted living facilities are located disproportionately in higher income and less racially diverse communities.

Morales, M. & Robert, S., Black White Disparities in Moves to Assisted Living and Nursing Homes Among Older Medicare Beneficiaries, Journal Gerontology (Nov. 2020); see also, Stevenson, D.G. & Grawbowski, D.C., Sizing up the market for assisted living," Health Affairs, 29 (Jan-Feb. 2010).

DOMAIN #3: AWARENESS OF AND ENROLLMENT IN HCBS PROGRAMS

Information about a state's HCBS programs is often decentralized, with each program having its own name, application process, and forms administered by different organizations or government agencies. Because eligibility criteria often differ between the different programs, states typically do not have a universal HCBS application. People who need HCBS have to know that these programs exist and how to apply, and then navigate and complete the application process.

HCBS policy elements that should undergo an equity evaluation to increase awareness and enrollment in HCBS include:

- **HCBS Program Information**: Most HCBS programs, which often have their own names that say nothing about HCBS or Medicaid, may be hard to find and even harder to navigate. Program information is often not centralized or searchable (i.e., there is no equivalent of Healthcare.gov for HCBS). Inequities arise in who is able to learn about and enroll in these programs, favoring people with more resources.

- **Education of Enrollment Entities**: Inequities can arise when the agencies or organizations that are responsible for processing enrollment do not consistently describe or promote HCBS programs, eligibility pathways, or application processes, possibly due to implicit biases or a lack of understanding of the programs.

- **HCBS Application Forms**: HCBS application forms are often not easily found or available online. They can also be complex and long. Inequities can arise when people who need services cannot locate the application or when the applications are inaccessible (e.g., not in language, large print, braille) or are overly burdensome.

CALIFORNIA'S ASSISTED LIVING WAIVER: HOW INEQUITIES CAN ARISE IN AWARENESS AND ENROLLMENT IN HCBS PROGRAMS

The assisted living waiver (ALW) is an HCBS program in California that provides support to individuals in residential care facilities for the elderly (RCFEs) or in subsidized housing. The ALW operates in 15 counties and currently has a waitlist of over 4,700 individuals, with some individuals waiting up to two years for services. Yet, the waitlist is not reflective of actual eligibility and need. This is because the ALW is not widely known.

Furthermore, navigating the ALW application and waitlist process is exceedingly complex. Individuals must be referred to the program or apply. **"Many people don't know that this benefit is available because there is generally not a lot of public outreach about the program. But if there was, the waitlists wouldn't be two years long, they'd be five years long,"** Maura Gibney, Cal Matters, Sept. 7, 2022.

Once they apply, individuals are assessed for services and placed on a waitlist. Applicants are not able to track where they are on the list. **"I have to imagine that if two highly educated, white women are struggling to get answers and find placement for their low-income loved ones then there is a lot more going on here. Especially for immigrants or non-native English speakers, and those who do not have connections."** Kelsey McQuaid-Craig, Cal Matters, Sept. 7, 2022

Cal Matters, Operating Under Water: Families Trying to Place Loved Ones in Medi-Cal Assisted Living Program Wait Years, (Sep. 7, 2022).

DOMAIN #4: ASSESSMENTS AND AUTHORIZATION OF SERVICES

In HCBS, the assessment tools used to allocate HCBS services or to monitor quality of services can be biased, including assessment tools that rely on algorithms or other automated decision-making systems. Further, the individuals tasked with using these tools to conduct assessments may also have biased subjective perceptions.[7] [8]

HCBS policy elements that should undergo an equity evaluation to improve HCBS assessments and authorization of services include:

- **HCBS "level of care" Evaluations**: Eligibility for HCBS is based on care needs that meet a certain "level of care"—nursing facility level of care for most HCBS programs. Inequities can arise in determining whether applicants meet level of care requirements, particularly for people with mental health disabilities, developmental disabilities, and aging-related cognitive disabilities, such as dementia or Alzheimer's, which disproportionately impacts Black and Latino older adults.[9]

- **HCBS Evaluation and Needs Assessments**: After being found eligible for an HCBS program, individuals are assessed for the types and level of services they will receive. Inequities can arise in the tool assessing an individual's needs or ability to participate in a program or when an assessor's subjective assessment is biased (see textbox: Money Follows the Person).

MONEY FOLLOWS THE PERSON: HOW INEQUITIES CAN ARISE IN ASSESSMENT AND AUTHORIZATION OF SERVICES

Money Follows the Person is an HCBS program that helps adults with disabilities of all ages move out of institutions and into the community. However, data demonstrates that individuals over age 65 are transitioned out of facilities at lower rates than individuals under age 65.

Since the program's inception through 2020, Money Follows the Person has transitioned a total of 107,128 people out of nursing facilities, including 38,775 older adults, 41,098 people with physical disabilities, 16,738 people with intellectual and developmental disabilities, 7,924 people with a mental health impairment, and 2,593 people that do not fall in these categories. Older adults constitute 64% of people receiving Medicaid in institutions but only 36% of Money Follows the Person program participants.

Mathematica, Money Follows the Person: State Transitions as of December 31, 2020, (Jul. 20, 2022).

Mathematica, Medicaid Beneficiaries Who Use Long-Term Services and Supports: 2019, (Jul. 22, 2022).

This disparity could be in part a result of an age-based bias intersecting with disability bias in assessing who is identified and deemed appropriate to participate in the program. Unfortunately, race, ethnicity and other demographic data is not available to assess whether there are other compounding disparities in access to Money Follows the Person for older adults of color or people whose primary language is not English, for example.

DOMAIN #5: PROVISION OF HCBS

Inequities can arise during provision of HCBS, including the quality of services rendered and the adequacy of the services in addressing a recipients' unique needs.

HCBS policy elements that should undergo an equity evaluation to improve the provision of HCBS include:

- **HCBS Quality Measures**: Equitable access to high-quality services requires on-going monitoring. Inequities can arise or be perpetuated if quality measures are not developed in a way that adequately measure disparities in the quality of services rendered to marginalized communities or if they do not include the collection and reporting of demographic data.

- **Language Access**: The quality of HCBS is contingent upon whether recipients trust and can adequately communicate with their providers. Inequities can arise when HCBS programs and providers do not provide information in the recipient's primary language.

- **Cultural Competence & Humility**: Inequities can arise in the provision of services if they are not rendered with cultural humility or competence. For example, HCBS providers are not currently required to receive cultural competency training, giving rise to inequities in both access to and quality of HCBS for LGBTQ+ older adults and other marginalized communities. Similarly, there are no current requirements for HCBS providers to deliver services in a culturally appropriate manner including, for example, culturally relevant activities in adult day settings and serving and delivery of culturally appropriate meals.

LGBTQ+ EXPERIENCE: HOW INEQUITIES ARISE IN PROVISION OF HCBS

LGBTQ+ older adults face discrimination in all aspects of health care, including long-term care. For example, in a recent survey, half of LGBTQ+ older adults reported mistreatment of themselves or a loved one in a long-term care facility. Another survey found that 78% of older adults in long-term care facilities were not comfortable sharing their sexual orientation or gender identity with their caregivers.

HCBS providers are typically not required to receive LGBTQ+ training. This can limit the number of HCBS providers LGBTQ+ people feel they can safely use, impact the quality of care they receive, and put them at risk for neglect, abuse, and exploitation. Requiring all HCBS providers to receive LGBTQ+ training and accreditation by organizations such as SAGECare, would help to improve the provision of services for LGBTQ+ HCBS users.

CONCLUSION

Nationally, there has been significant progress in expanding access to HCBS. However, little has been done to ensure that HCBS is equitably available to the many diverse communities throughout the country. Much like the drivers of health inequities broadly, systemic inequities in HCBS programs are driven by racism, sexism, ageism, ableism, classism, xenophobia, and homophobia. Addressing inequities in HCBS requires intentional and affirmative steps to make equity a primary focus in policies and guidance at every stage of design and implementation of HCBS programs and services. This Framework provides a starting point in this work, which, combined with robust data collection and reporting, can better ensure equitable access to HCBS that meets the needs of the nation's most marginalized communities.

ADDITIONAL JUSTICE IN AGING RESOURCES

- California's Assisted Living Waiver: An Equity Analysis (March 2023)

- An Equity Framework for Evaluating California's Medi-Cal Home and Community-Based Services for Older Adults & People with Disabilities (December 2022)

- Beyond Spending: Measuring California's Progress Towards Equitable Home and Community Based Services (August 2022)

- Building an Equitable Medicaid HCBS Infrastructure in New Jersey for Older Adults (June 2022)

- Using Data for Good: Toward More Equitable Home and Community-Based Services in Medi-Cal (December 2021)

- Medicaid Home and Community-Based Services for Older Adults with Disabilities: A Primer (April 2021)

ENDNOTES

1   Tanis, E. S., The Cost of Doing Business: Institutional Bias and Community-Based Services and Supports, 27 Georgetown Journal on Poverty Law and Policy 291–304 (2020); see also, Watson, S.D, From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History, 26 Georgia State Univ. Law Review 937–69 (2012).

2   Olmstead v. L.C., 527 U.S. 581, 583 (1999).

3   Community Living Policy Center, Care Can't Wait: How Do Inadequate Home- and Community-Based Services Affect Community Living and Health Outcomes?, (2021).

4   National Center on Law and Elder Rights, Housing and Home-and-Community-Based Services: What It Takes to Age in Place, (June 2021).

5   For an alternative HCBS framework, see, Bercaw, L. et. al., Assessing Disparities in Medicaid Home and Community-Based Services: A Systemic Review, Journal of Aging & Social Policy, (Jun. 2022).

6   See, Justice in Aging, Medicaid Home- and Community-Based Services for Older Adults with Disabilities: A Primer (Apr. 2021).

7   Tong, M. & Artiga, S., Use of Race in Clinical Diagnosis and Decision Making: Overview and Implications, (Dec. 9, 2021); Santaguida, L. et. al, Assessing Risk of Bias as a Domain of Medical Test Studies, Chapter 5 of Methods Guide for Medical Test Reviews, (Jun. 2012).

8   Greenlining Institute, Algorithm Bias Explained: How Automated Decision-Making Becomes Automated Discrimination, (Feb. 18, 2021).

9   Studies show that Black Americans are 1.5 to 2 times more likely than whites to develop Alzheimer's and related dementia, but had 35% lower odds than whites of having the diagnosis at the initial visit. National Institute on Aging, "Data Shows Racial Disparities in Alzheimer's Disease Diagnosis between Black and White Research Study Participants," (Dec. 16, 2021).