Using an Equity Framework to Evaluate & Improve Medicaid Home and Community-Based Services

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Housekeeping

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Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we’ve focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ individuals, and people with limited English proficiency.
To achieve Justice in Aging, we must:

- **Advance equity** for low-income older adults in economic security, health care, housing, and elder justice initiatives.

- Address the enduring harms and inequities caused by systemic racism and other forms of discrimination that uniquely impact low-income older adults in marginalized communities.

- Recruit, support, and retain a diverse staff and board, including race, ethnicity, gender, gender identity and presentation, sexual orientation, disability, age, and economic class.
Today’s Webinar

- Medicaid Home and Community-Based Services (HCBS) Overview
- Inequities in HCBS Access
- Justice in Aging’s HCBS Equity Framework & Examples
- Questions
What Are Home And Community-Based Services (HCBS)?

Long-term health care, services, and supports provided to an individual in their own home or in an integrated community-based setting.

Source: Justice in Aging, Medicaid Home-and-Community Based Services for Older Adults with Disabilities: A Primer, 2021
Examples of HCBS

- Home Health
- Personal care to assist with activities of daily living (ADLs)
- Transportation
- Homemaker & Chore Services
- Case management
- Financial and legal services
- Home repairs & modifications
- Adult day care, group, or center-based day supports, etc.
HCBS Authorities – State Plan

• HCBS through State Medicaid Plan
  • Medicaid Home Health (the only required benefit)
  • Optional services: Personal care, case management, etc.
  • Optional authorities: 1915(i), 1915(j), and 1915(k) Community First Choice

• All must be offered statewide

Source: Justice in Aging, Medicaid Home-and-Community Based Services for Older Adults with Disabilities: A Primer, 2021
HCBS Authorities - Waivers

• Always optional
• Typically under Sections 1915(c); 1115, etc.
• Can include caps on enrollment and be limited to certain geographic areas or certain populations
• More generous financial eligibility
Medicaid Home and Community-Based Services Users, FY 2020

- Home Health Services (Mandatory, 51 states): 734,500
- Personal Care Services (Optional, 37 states): 1,200,000
- Community First Choice (Optional, 9 states): 458,700
- 1915 (i) (Optional, 13 states): 165,800
- 1915 (c) waivers (Optional, 47 states): 1,900,000
- 1115 waivers (Optional, 12 states): 1,100,000

Source: KFF, 10 Things About Long-Term Services and Supports (LTSS), 2022
Inequities in HCBS Access
Gaps in Accessing HCBS

• Because states are not required to offer HCBS there are significant gaps in access
  • 656,000 people on waiting lists
  • Many more with unmet need
• Wide variation from state to state
• Delays in services due to limitations around prompt and retroactive coverage
  • See Medicaid’s Unfair Choice: Wait Months for In-Home Assistance – or Get Nursing Facility Coverage Today
Gaps Cause Inequities (1/2)

• HCBS inequities occur by age, type of disability, geography, race, and other demographic factors
  • Example: 2 in 5 older Californians who report needing help at home are either receiving no help or not enough
    • Black older adults report highest levels of unmet need

• Most people who need HCBS rely on unpaid caregivers
  • Only 13% of people with LTSS needs in the community receive paid support
  • 92% receive unpaid support
Gaps Cause Inequities (2/2)

- Black and Hispanic/Latinx families report greater financial strain from caregiving
  - Annual out-of-pocket expenses are 34% (Black) and 47% (Latino) of their income compared to 26% for all families
- LGBTQ+ older adults and Black women more likely to live alone
  - May not have any family caregivers available to fill the gaps while waiting for HCBS
State and Population Based Inequities in Access to HCBS

• Population-based inequities:
  • Half of states spend 2x as much on institutional care for older adults as they do on HCBS
  • States spend an average of 35% of all LTSS dollars for older adults on HCBS, compared to an average of 56% on HCBS across all populations

• State-based inequities:
  • Only 8 states spend more that 50% of LTSS dollars on HCBS for older adults
  • The lowest spending on HCBS for older adults is 10% (IA) and the highest is above 70% (WA, MN, OR)

Source: Justice in Aging, Medicaid Home-and-Community Based Services for Older Adults with Disabilities: A Primer, 2021
Race-Based Inequities in Access to HCBS

• Race-based inequities:
  • Growth in nursing homes declining among white older adults, but growing among communities of color
    • 75% adults with dementia-related conditions live in a facility by age 80 compared to 4% of the general population; Alzheimer’s and dementia significantly higher among Black and Hispanic older adults
  • Access to HCBS more limited

Source: Justice in Aging, Medicaid Home-and-Community Based Services for Older Adults with Disabilities: A Primer, 2021
Centering Equity in HCBS Design

Drivers of inequity:
• Racism
• Ageism
• Ableism
• Classism
• Sexism
• Xenophobia
• Homophobia

Embedded in law, program policy, design and implementation:
• Structural and historical barriers
• Disparate Impact
• Implicit Bias
HCBS Equity Framework

• A tool to center equity by examining how a program’s design or policy impacts specific people and populations
  • E.g., Older adults, people of color, native populations, women, LGBTQ+ individuals, people with limited English proficiency, people in urban or rural settings
• A starting point for advocates & policy makers
Five Domains Where Inequities Arise in HCBS

1. Program Design
   • Who is eligible, where programs are available, what services are offered

2. Provider Availability
   • Network adequacy, reimbursement rates, investments training & support

3. Program Awareness and Enrollment
   • Communication, information and application processes

4. Assessments and Authorization of Services
   • How bias in the process impacts who gets approved

5. Provision of HCBS
   • Person-centered service accessibility and quality measures

Note: Data collection and reporting are key to transparency and oversight across all domains

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
1. Program Design

- Medicaid Authority
  - Is the program available statewide or only in certain regions?
  - Do all populations have access or is a program limited to older adults or people with intellectual/development disabilities?
  - Is there a cap on enrollment?

- Community Engagement
  - Were people with lived experiences consulted and engaged?

- Program Benefits
  - Which services are included or excluded?

- Waiver Waitlist Administration
  - Is there a waitlist?
  - What are the processes/barriers to getting on the waitlist and advancing?

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
Equity Evaluation of Program Design Example

- Michigan’s MI Choice Waiver
  - 50% of Michigan’s population lives in 10 counties.
    - In one of those counties, Wayne County, 40% of older adults are people of color.
  - Only 1 waiver slot per 58 eligible people in the most populous counties compared to 1 slot per 20 eligible people in the rest of the state
2. Provider Availability

• Network Adequacy Standards
  • Does the state have network adequacy standards for HCBS?
  • Do standards maintain the status quo or perpetuate racial segregation? Are individuals’ actual needs incorporated?

• HCBS Provider Reimbursement Rates
  • Are state reimbursement rates high enough to maintain an adequate workforce, especially in areas with high cost of living or rural locations?
  • Are underserved areas growing?

• Caregiver Supports
  • Which caregivers know about these supports? Do they meet the diverse needs of unpaid caregivers?

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
Equity Evaluation of Provider Availability Example

• New Jersey’s Assisted Living Residence (ALR) program
  • The 3 counties with the highest older adult populations are also the most racially diverse
    • Bergen, Middlesex, and Essex counties
  • Only 24 ALR facilities are located in these 3 counties
    • compared to 51 facilities in Ocean, Monmouth, and Morris counties
  • Only 19% of ALR enrollees live in Bergen, Middlesex, and Essex counties
    • compared to 32% in Ocean, Monmouth, and Morris counties

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
3. Program Awareness and Enrollment

• HCBS Program Information
  • Is information centralized and searchable?
  • Can people who don’t know the HCBS system find this information?

• Education by Enrollment Entities
  • Are states and programs doing outreach? To whom?
  • Is the information entities provide consistent and accurate about who is eligible?

• HCBS Application Forms
  • Are the application forms easy to find and accessible to people with disabilities or limited English proficiency?
  • Can someone fill out the form and navigate the application process by themselves?
  • Is help with application forms readily available?
Equity Evaluation of Program Awareness and Enrollment Example

• California’s Assisted Living Wavier (ALW)
  • ALW operates in 15 counties and 4,700+ people are on the waitlist, but the need for ALW services is much greater
  • Many people do not know the ALW program exists, especially in underserved communities
    • State provides very little consumer-facing information about the ALW
    • Info about the ALW is only in English
    • Most people find out by word of mouth
  • The application and waitlist processes are barriers
    • No public application form, an agency must submit and can decide who should be screened
    • People who do apply have to wait 2 years for services

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
4. Assessments and Authorization of Services

• Assessment tools & assessors
  • Are implicit and explicit biases impacting eligibility determinations and assessments?

• HCBS “Level of Care” Evaluations
  • Are people with certain types of disabilities less likely to be determined eligible?

• HCBS Needs Assessments
  • Are there differences by population, disability, race, etc. in the types and level of services a person is assessed as needing?
  • Does the assessment appropriately account for the individual’s situation and preferences?

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
Equity Evaluation of Assessments and Authorization of Services

Example

• Money Follows the Person Program (MFP)
  • Helps adults with disabilities of all ages move out of institutions and into the community
  • 45+ states & territories have had MFP programs
  • People age 65+ receive MFP at disproportionately lower rates than younger people
    • 64% of people in institutions are age 65+ but only 36% of MFP participants are 65+

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
5. Provision of HCBS

• Adequacy and quality of services provided
  • Are the adequacy and quality of services being monitored and measured?
  • Are their grievance processes and other enforcement mechanisms?

• HCBS Quality Measures
  • Do quality measures include demographic data to measure disparities for marginalized communities?

• Language Access
  • Can HCBS participants communicate with their providers?
  • Are language resources, including translated information about the program and services provided?

• Cultural Competence & Humility
  • Are providers ensuring direct care workers receive cultural competency training to serve LGBTQ+ individuals and other marginalized communities?
  • Do states require providers to deliver services in a culturally appropriate manner?

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
Equity Evaluation of HCBS Provision Example

• Serving LGBTQ+ Older Adults
  • LGBTQ+ individuals often face discrimination in long-term care settings and many report not being comfortable sharing their LGBTQ+ identity with their caregivers
  • HCBS providers typically are not required to complete LGBTQ+ training
    • Limits provider choice
    • Impacts service quality
    • Risks discrimination and harm

Source: Justice in Aging, An Equity Framework for Evaluating and Improving Home and Community-Based Services, 2023
Resources

• An Equity Framework for Evaluating and Improving Home and Community-Based Services
  • Issue Brief
  • Fact Sheet
• HCBS Primer
• HCBS 101 Webinar
Questions?

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