



State of the Science: Community Living Policy

Virtual discussions hosted by the Community Living Policy Center



Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute
for Disability Policy

State of Science Overview



Reflection on Community Living Policy and Equity

Monday, June 12, 1 pm – 2:15 pm ET

Joe Caldwell and Teresa Nguyen



Community Living Research: What Do We Know and What Do We Need to Learn?

Friday, June 23, 11 am – 12:15 pm ET

John Tschida, Silvia Yee, Amy Hewitt, Ari Ne'eman, and Natalie Kean



Community Living Priorities and Issues: Feedback from Stakeholders

Tuesday, June 27, 2 pm – 3:15 pm ET

Henry Claypool and Kim The

Future Webinars

Register for webinars on Community Living Policy website:
www.communitylivingpolicy.org

Will be recorded and available on the CLPC website

Community Living Policy Center

The CLPC receives support from the National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR) within the Administration for Community Living, U.S. Department of Health and Human Services (#90RTCP0004). The contents of this webinar do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Community Living Policy Research

Provide background on community living and current state of research

Highlight recent work and research in some key areas

Reflect on gaps, needs and opportunities for future research

- **Access to HCBS and Unmet Needs**
- **Person-Centered Planning**
- **Impacts of COVID-19**
- **Housing**
- **Equity**

Background

Over 14 million individuals in the US need Long-Term Services and Supports (LTSS)

- Vast majority rely on unpaid support from family and friends
- 1.5 million reside in nursing homes and institutions
- Approximately 7.5 million receive Medicaid Home and Community-Based Services (HCBS)



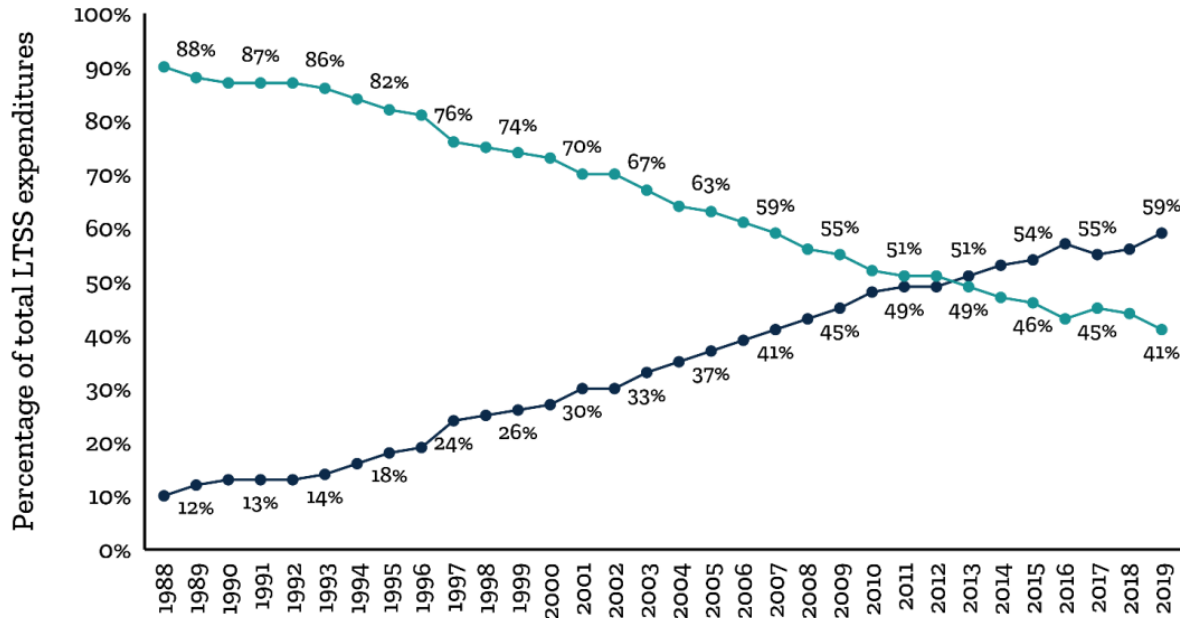
Institutional Bias within Medicaid

Nursing Homes are **mandatory** within Medicaid, while HCBS are **optional**

- States can limit availability of HCBS
- Eligibility and services vary considerably from state to state
- In many states, long waiting lists for HCBS
- Forces people into more costly, undesirable nursing homes and other institutions

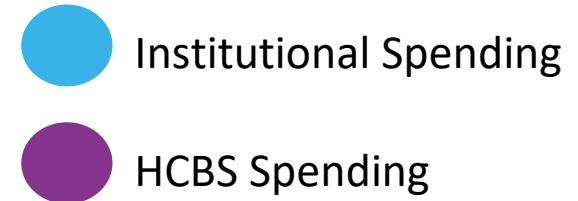


Progress Increasing Access to HCBS



However, major gaps remain:

- Variation by states
- Variation by populations



Source: CMS and Mathematica, December 2021

CLPC Policy Research

Money Follows the Person

- States with robust MFP programs rebalanced their systems
- Short-term Congressional extensions contributed to states dropping the program and 50% reduction in transitions
 - **Congress extended MFP through 2027**

HCBS Infrastructure

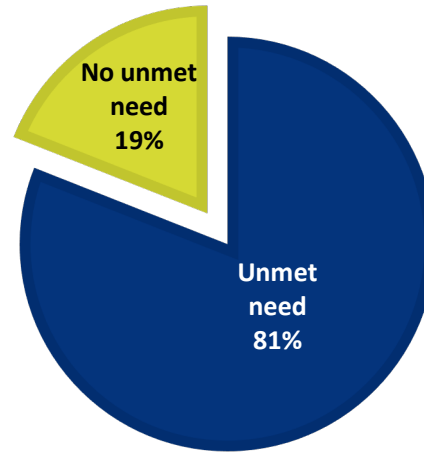
- Workgroup developed a framework to inform new federal legislation
 - **Bipartisan HCBS Infrastructure Improvements Act introduced in Congress**



Unmet Needs Among HCBS Recipients

Examined Data from National Core Indicators–Aging and Disability Survey (NCI-AD)

Percent of Unmet Needs	
Help with self-care/daily activities	21.1
Services that meet needs & goals	30.0
Assistive technology	54.3
Home modifications	52.2
Transportation	26.7



Unmet Needs
Associated with
Worse Community
Living and Health
Outcomes

Source: Chong, Akobirshoev, Caldwell, Kaye, & Mitra (2022)

Needs and Unmet Needs for LTSS

Limited population data on needs and unmet needs for LTSS, particularly among younger adults with disabilities (under 65)

- Two states (Washington and Texas) added LTSS questions to the Behavioral Risk Factor Surveillance Surveys (BRFSS)
- California Health Interview Survey supplement on LTSS
 - **Allow states to better understand LTSS needs, disparities, and plan**



Person-Centered Planning

While person-centered planning is required in HCBS programs, we know little about implementation and outcomes

- Examined facilitators and barriers in three states through interviews with HCBS recipients and care managers
 - **Importance of facilitator competencies, relational communication, administrative barriers**
- Examined self-reported data from NCI-AD survey
 - **Person-centered planning strongly associated with better community living outcomes (community participation, control, and how days are spent)**



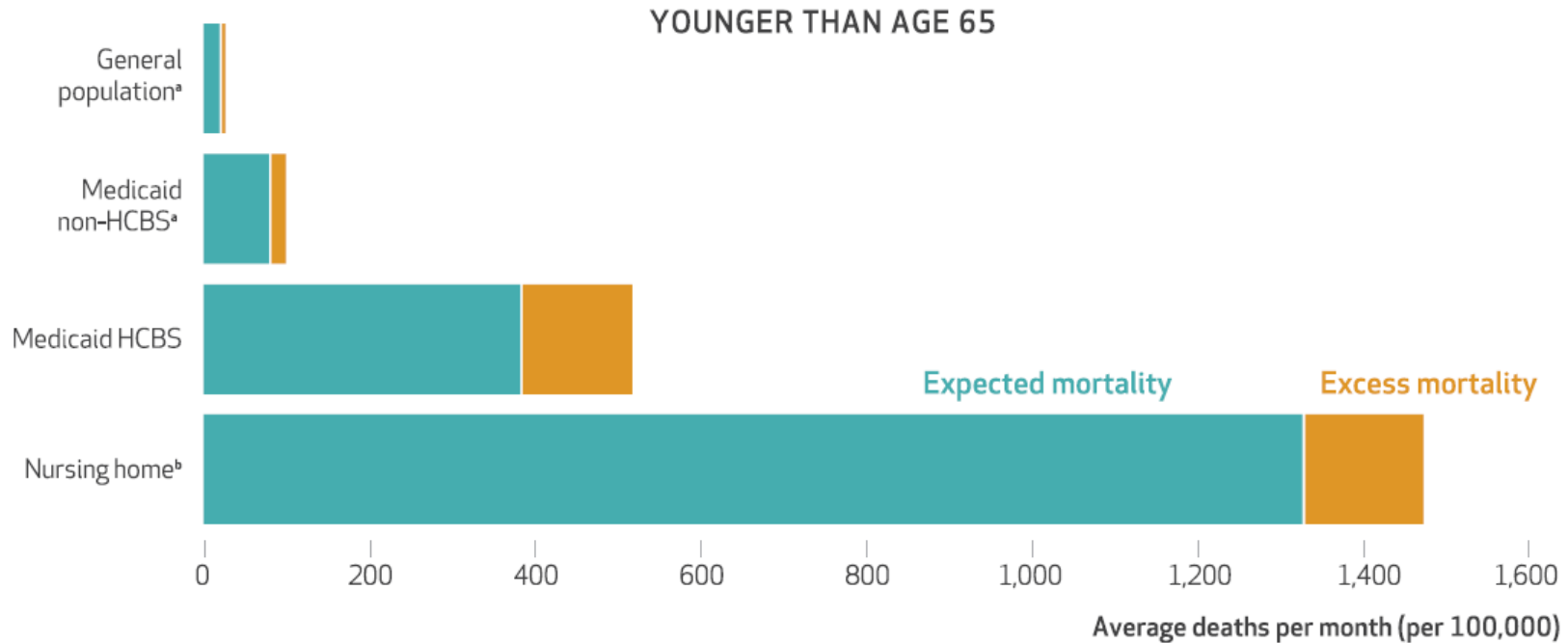
Source: Caldwell, Heyman, Katz, & Ho (2023)

Impacts of COVID-19 on HCBS Recipients

More than 23% of all COVID-19 deaths linked to nursing homes. However, lack of data on HCBS recipients.

- Partnered National MLTSS Association and health plans
- Analyzed monthly mortality data from 14 health plans in 12 states from 2018-2020.
- **Provided first multistate data on excess mortality among Medicaid HCBS recipients**
 - **Excess mortality rates were high across age groups**
 - **For younger HCBS recipients (under 65), excess mortality was:**
 - **7.4 times that of other community-dwelling Medicaid beneficiaries**
 - **26.6 times that of the general population**

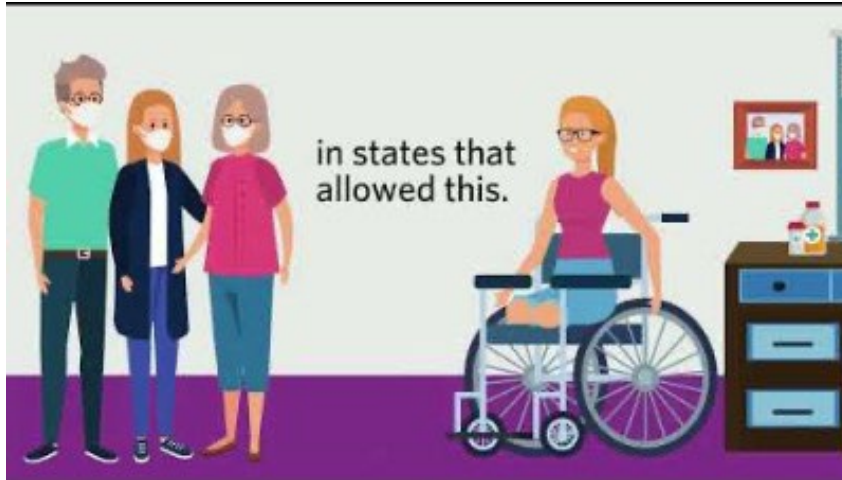
Excess Mortality of Medicaid HCBS Recipients



Source: Kaye and Caldwell (2023)

Impacts of COVID-19 on Medicaid HCBS Recipients

Conducted qualitative study on individuals self-directing their HCBS during COVID-19



Still much more to learn:

- **Obtaining Medicaid claims data (T-MSIS) to explore impacts on mortality and broader healthcare utilization and outcomes for HCBS recipients.**

<https://www.youtube.com/watch?v=OOlBY9Q-Zn8&t=5s>

Housing and Neighborhood Inequities

Analyzed Data from the American Housing Survey

- **Households with disabled members and those with LTSS needs have significantly higher odds of living in poor quality housing and neighborhoods and were less likely to live in affordable housing.**

Unaffordable Housing

Inability to pay rent or mortgage

Higher relative housing costs

Poor House Quality

Severe upkeep problems

Structurally deficient housing

Low house rating

Poor Neighborhood Quality

High incidence of serious crime in their neighborhood

Living in neighborhood with high natural disaster risk

Low neighborhood ratings

Housing Case Studies

OakDays Pilot:

Permanent Supportive
Housing + Services During
Covid-19 and Beyond



- Housing + healthcare + HCBS
- Person-centered preferences for unhoused people with multiple disabilities
- Medical care on site (voluntary!)
- Personal care services for help with bathing, toileting, dressing, etc.
- Meals
- Transportation
- Hospice available
- Case/care management
- Program will help person move to apt. w/ supports, if desired



Community Living Equity Center

Centro para la Equidad en Vida Comunitaria

Goal of the Community Living Equity Center

Address gaps in
our knowledge
about inequities in
community living
and participation

Address gaps in our knowledge about inequities in community living and participation experiences and outcomes faced by disabled people of color and develop interventions to address equity, by leveraging existing and new data sources, developing new policy and systems change initiatives, and provide active dissemination of findings and trainings for stakeholders

Community Living Equity Center Principles



Disabled people of color with LTSS needs face significant barriers in access to HCBS and culturally and linguistically appropriate services



Disabled people of color with LTSS needs are the experts in what they need



Disabled people of color with LTSS needs have intersecting identities that comprise their lived experiences, and particularly their experiences with the HCBS service and delivery system

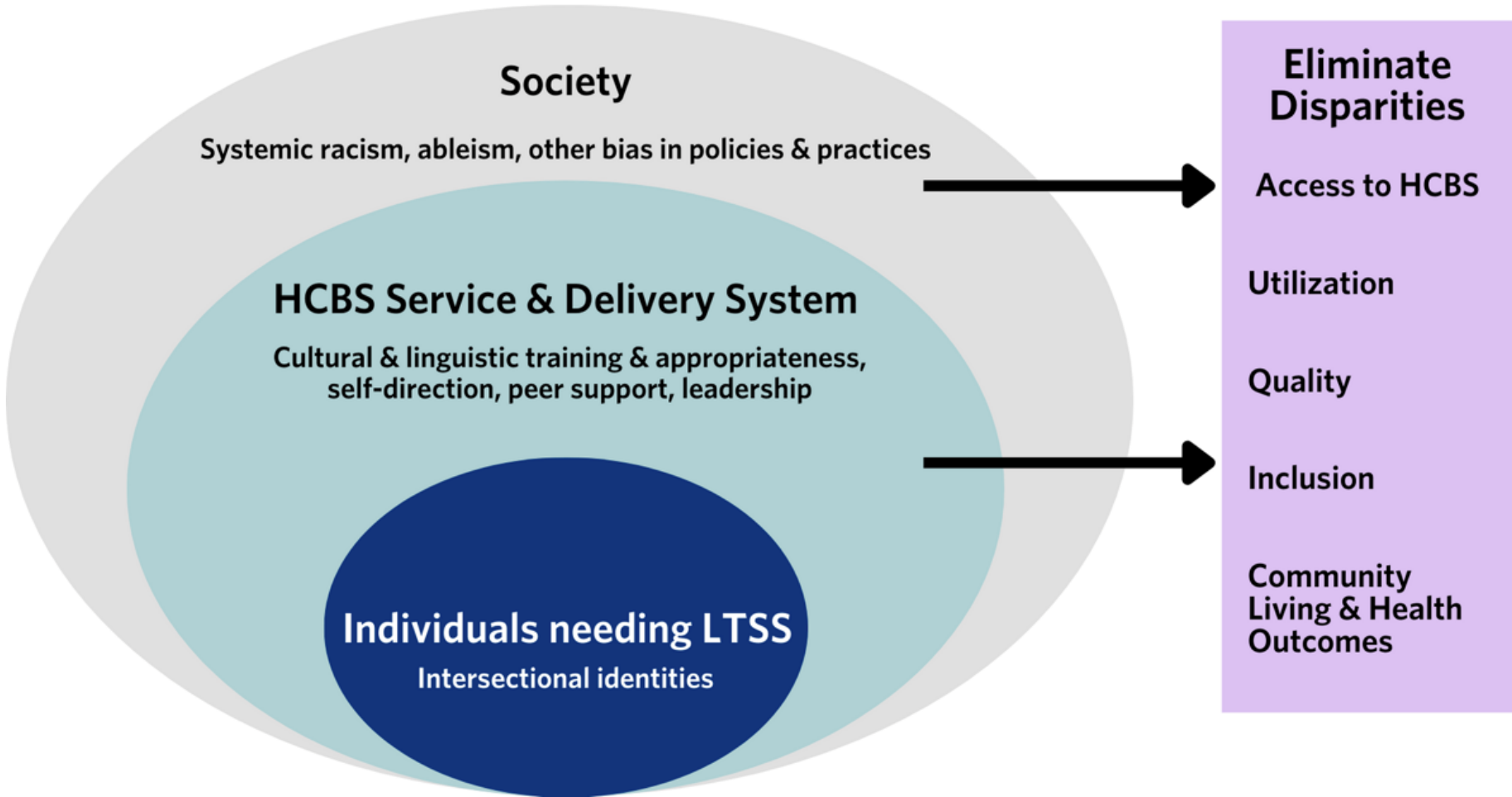


Disabled people of color with LTSS needs must be meaningfully involved in all aspects research and knowledge translation activities

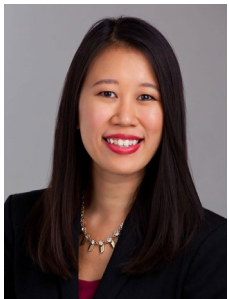


Disabled people of color with LTSS needs must be in leadership positions and receive capacity-building and mentoring opportunities related to community living research, advocacy, and service delivery

Conceptual Framework for Community Living Equity



Community Advisory Committee



Christine Liao,
American Association of
People with Disabilities



Dr. Janie Mejias,
Women Enabled
International



Dr. LaWanda Cook,
Cornell University



Andy Arias,
Self-advocate and
Policy SME



Bernard Baker,
Self Advocates
Becoming
Empowered



Melody Cooper,
Self Advocates
Becoming
Empowered



Conchita Hernandez
Legorreta,
Mentoring Engaging and
Teaching All Students



Tyree Brown,
Self-advocate and
visual artist



Jean-Luc Pierite,
Indigenous activist
and designer



Elaina Seep,
Aniwahya
Consulting Services



Germán Parodi,
The Partnership for
Inclusive Disaster
Strategies

Disparities in Access to HCBS and Utilization



Examine racial and ethnic disparities in access to HCBS

- Medicaid claims data (T-MSIS)
- American Community Survey

➤ **Data dashboard for advocates and policymakers**

Barriers and Facilitators in Access to HCBS for People of Color

Qualitative interviews with disabled people of color living who have experienced placements in nursing homes and other institutions and have transitioned to the community

- Participatory Action Research project
- Hired Lived Experience experts

Barriers and Facilitators in Access to HCBS for People of Color

Looking for Disabled People of Color Who Have Lived in Nursing Homes or Other Institutions to Share Their Experiences



<https://www.youtube.com/watch?v=DqAu2LosuFs>

Self-Direction and Community Living Outcomes for People of Color

Analyses of NCI-IDD and NCI-AD data to examine racial/ethnic differences in the use of self-direction

Qualitative interviews with people of color self-directing their HCBS to explore equity in access, systemic barriers and facilitators to self-direction.



Photo Source: <https://affecttheverb.com/disabledandhere/>

Future Community Living Policy Research

- Join us for future discussions
 - Panel discussion among advocates and researchers
 - Highlights from roundtables with stakeholders
- Share your recommendations for future research via CLPC survey
- CLPC will release a report later this Summer with findings

Disability and Health Journal

Supplemental Issue on Community Living Policy

- Co-Editors: Joe Caldwell and Ari Ne'eman
- Submissions Due: September 1, 2023



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