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
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
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
However, major gaps remain:
- Variation by states
- Variation by populations

Source: CMS and Mathematica, December 2021
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)

<table>
<thead>
<tr>
<th>Percent of Unmet Needs</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Help with self-care/daily activities</td>
<td>21.1</td>
</tr>
<tr>
<td>Services that meet needs &amp; goals</td>
<td>30.0</td>
</tr>
<tr>
<td>Assistive technology</td>
<td>54.3</td>
</tr>
<tr>
<td>Home modifications</td>
<td>52.2</td>
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<tr>
<td>Transportation</td>
<td>26.7</td>
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</tbody>
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Unmet Needs Associated with Worse Community Living and Health Outcomes

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

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.

<table>
<thead>
<tr>
<th>Unaffordable Housing</th>
<th>Poor House Quality</th>
<th>Poor Neighborhood Quality</th>
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</thead>
<tbody>
<tr>
<td>Inability to pay rent or mortgage</td>
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<td>Higher relative housing costs</td>
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<td>Severe upkeep problems</td>
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<td>Structurally deficient housing</td>
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<tr>
<td>Low house rating</td>
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<tr>
<td>High incidence of serious crime in their neighborhood</td>
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<tr>
<td>Living in neighborhood with high natural disaster risk</td>
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<td></td>
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<tr>
<td>Low neighborhood ratings</td>
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</table>
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 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

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

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

3. 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.

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

5. 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

Society
- Systemic racism, ableism, other bias in policies & practices

HCBS Service & Delivery System
- Cultural & linguistic training & appropriateness,
  self-direction, peer support, leadership

Individuals needing LTSS
- Intersectional identities

Eliminate Disparities
- Access to HCBS
- Utilization
- Quality
- Inclusion
- Community Living & Health Outcomes
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
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/
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
Learn more/contact us

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Communitylivingpolicy.org

Communitylivingequity.org