



Needs and Priorities for Community Living Policy Research:

Summary of Stakeholder Roundtables and Community Living Policy Survey

Final Report

September 2023

Background

In the Fall of 2022, the Community Living Policy Center (CLPC) convened a series of roundtables with key stakeholders to gain their insights about needs, opportunities, and priorities for future Community Living Policy Research. Stakeholders included disability and aging advocates, state officials and associations representing states, providers and health plans, and individuals with disabilities, including individuals from diverse racial, ethnic, and other backgrounds. In June of 2023, in conjunction with the CLPC's State of the Science convening, we also distributed a Community Living Policy survey to further enhance community input.

Community Living Policy Stakeholder Roundtables

We partnered with the following entities to invite participants:

- The Disability and Aging Collaborative - a coalition of more than 40 national disability and aging organizations that work together to advance community living policy.
- Long-Term Quality Alliance - an association of organizations that aim to improve outcomes and quality in long-term services and supports. Membership includes over 30 organizations that represent the full range of health and social services and supports, including providers, health plans, and associations representing states, unions, and disability and aging organizations.
- Community Living Equity Center Advisory Committee - advisory committee consisting of 15 members who are disabled people of color and other intersectional identities that advise and guide research on disparities and equity research in community living.

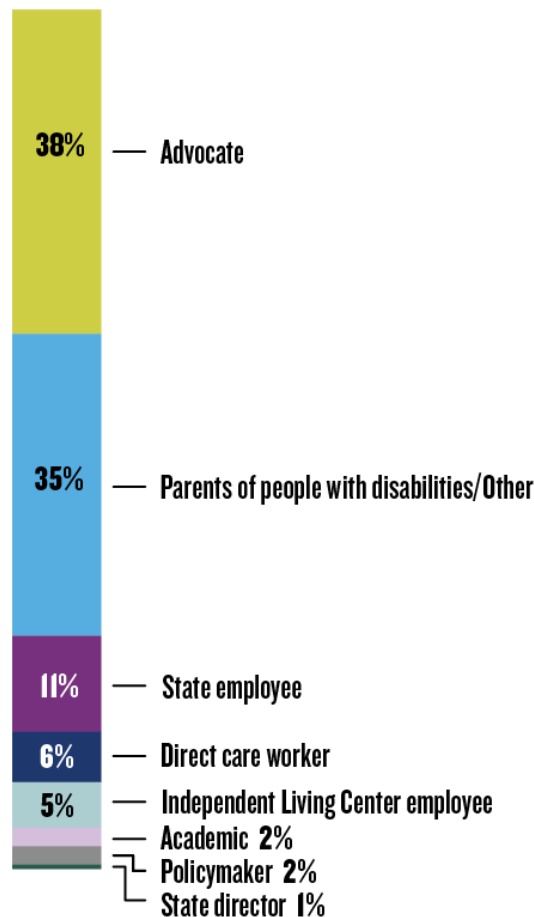
In addition to collaborating with these entities, CLPC partners suggested other individuals to invite. CLPC Policy Director, Henry Claypool, conducted outreach. A total of 31 individuals participated in the roundtables. A summary of the four roundtables and list of participants is included at the end of this report.

The CLPC team developed a Roundtable Discussion Guide with input from CLPC partners to facilitate open ended discussion about needs, opportunities, and priorities for future community living policy research, focused on priorities over the next five years. Roundtable discussions were co-facilitated by Henry Claypool and Kimberly The, Brandeis Senior Research Associate, Greg Robinson, Deputy Director of Public Policy at the Autistic Self Advocacy Network (ASAN), and Ruby Siegel, Undergraduate Research Fellow at the Lurie Institute for Disability Policy. Three roundtables were conducted virtually and one hybrid. Roundtable discussions were recorded with permission of participants and transcribed. The facilitators also took notes during the roundtables. The CLPC team listened to recordings, reviewed transcripts and notes multiple times and developed coding of major themes. The team met regularly to revise themes and develop the summary report.

Community Living Policy Survey

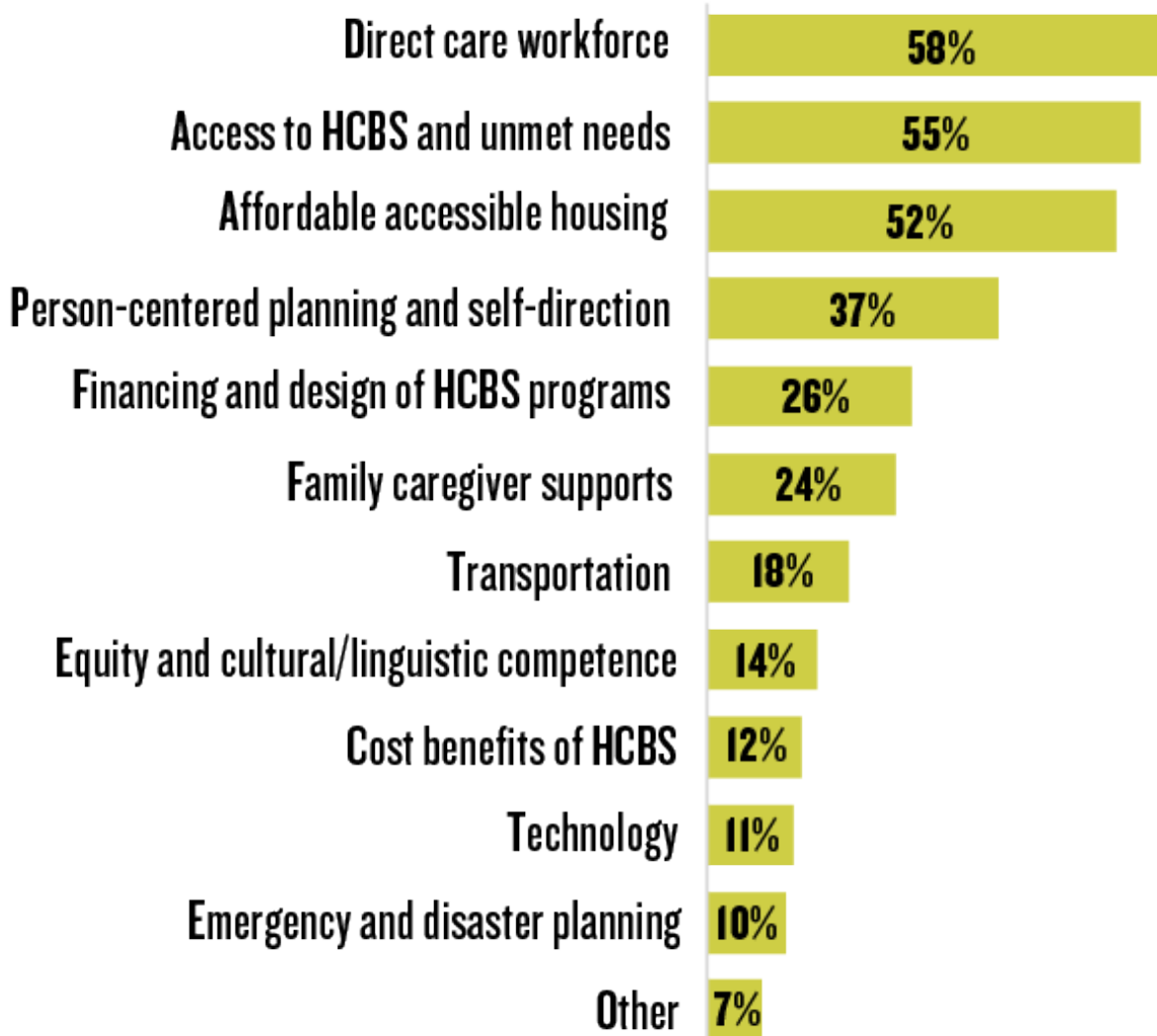
The Community Living Policy Survey was distributed during the CLPC’s virtual State of the Science conference throughout June 2023. The conference consisted of a series of three webinars highlighting key community living policy issues and the current state of research and knowledge. In conjunction with the webinar series, we developed an electronic survey to distribute during the webinar series to solicit broad input on the State of Science in community living policy, gaps in knowledge, and recommendations for future research. The survey garnered over 200 responses and consisted of 4 questions related to community living research including top research priorities, greatest barriers to community living, and additional policy recommendations. The survey also included 2 demographic questions related to stakeholder type and geographic location. The highest percentages of respondents were advocates, parents of people with disabilities, and state employees located in the Southeast, Midwest, and West, respectively (Figure 1). The themes that emerged from the survey were substantially aligned with the themes developed during the stakeholder roundtables in the Fall. Figures 2 and 3 below illustrate themes that were similar across both modalities.

Figure 1: Survey Respondent Categories



Themes are organized into two main sections: 1) Programs, Policies, and Practices Related to the Delivery of Home and Community-Based Services; and 2) Barriers and Facilitators to Community Living and Outcomes.

Figure 2: HCBS Research Priorities from the Community Living Policy Survey



Programs, Policies, And Practices Related To Delivery Of HCBS

Access to HCBS and Unmet Needs

- **Lack of data on access to HCBS** was a major theme. Available HCBS participant and expenditure data is not disaggregated by race/ethnicity, age, sex, gender identity, sexual orientation, disability type, and other characteristics to allow advocates and policymakers to understand disparities and advance equity. This data is critical to tracking the extent to which states have rebalanced their systems from institutional to HCBS and for which populations.
- **Improved data on HCBS waiting lists** is needed, including characteristics of individuals on waiting lists, length of time on waiting lists, and how waiting lists are managed.
- Stakeholders also raised issues about the **inadequacies of HCBS waiting list data** and the need for better, population level data on LTSS needs and unmet needs at state and national levels.
- Additional research is also needed that examines the **impacts of unmet needs for HCBS on community living and health outcomes**.
- Additional research is needed on **eligibility for HCBS**, including individuals near Medicaid eligible and presumptive eligibility.

Cost Benefits of HCBS

- Stakeholders wanted additional research that demonstrates **cost benefits and savings of expanding access to HCBS**, including reduced nursing home and institutional placements. This type of research is particularly useful to state and national policymakers trying to expand access to HCBS.
- Stakeholders also recommended **assessing how funding from the American Rescue Plan Act (ARPA) has been used** and impacts on expanding access to HCBS and strengthen the direct care workforce.

Equity and Culturally and Linguistically Competency

- Related to access, additional research is needed on **culturally and linguistically appropriate information** about HCBS and systemic barriers in eligibility and application processes of (i.e. “getting in the front door”). Participatory research is needed to better understand and reduce these disparities with underrepresented communities.
- **What does community living mean to people from different racial/ethnic and other cultural backgrounds?** What do people from underrepresented groups consider as culturally acceptable services? How are processes such as person-centered planning

facilitating culturally and linguistically appropriate and acceptable services and supports?

- Additional research is needed on **individuals who identify as LGBTQ+ needing HCBS**. There currently is very little research on this population. What data limitations exist? What barriers and disparities do individuals experience? How can services and supports be more culturally competent?
- Additional research is needed on **HCBS for tribal nations**. How does Indian Health Services interact or not interact with Medicaid? What is the quality of care provided through Indian Health Services? What is the state of access to services and supports for Indigenous people, specifically those living on reservations?

Financing and Design of HCBS Programs

- Research is needed on **state adoption of HCBS authorities**. In particular, some participants recommended additional research on adoption of the 1915(i) HCBS State Plan Option. While this option has a lot of potential for individuals with serious mental illness and behavioral health needs, not many states have adopted it. Why is the case? Are their particular barriers or incentives that could improve state adoption and usage?
- Stakeholders discussed the long-standing “institutional bias” within Medicaid where nursing home and institutional services are mandatory while most HCBS are optional for states. In particular, some stakeholders suggested research and policy development of **recommendations for a mandatory, core Medicaid HCBS benefit**.
- More research is needed on **programs that integrate acute, LTSS, and behavioral health** (i.e. MLTSS, integrated programs for individuals dually eligible for Medicare and Medicaid). What are promising practices? How do programs improve health and community living outcomes? How can value based purchasing influence desired outcomes?
- Additional research is needed on **state programs that are serving individuals with lower level of care needs** and the extent to which these programs are preventing or delaying institutional placements.
- Policy analysis, research, and development is needed on **financing of LTSS outside of Medicaid** through social insurance models, such as the recent mandatory long-term care insurance benefit in Washington state.

Person-Centered Planning and Self-Direction

- Stakeholders recommended additional research on **implementation of person-centered thinking, policy, and practices**. Person-centered planning is required within Medicaid HCBS, but implementation varies widely. Additional research is needed on state and provider compliance with implementation, promising practices, and cultural context of person-centered planning and care coordination.
- Self-direction is a delivery model in which consumers have greater control over their HCBS, such as hiring authority and budget authority. Additional research is needed on

expansion of self-direction during COVID-19 and impacts. Has this expansion continued, including the ability to hire family members? What are the impacts on community living outcomes and costs?

Emergency and Disaster Planning

- Additional research is needed to understand the **impacts of COVID-19 on individuals receiving HCBS**. What have been the impacts on mortality, health and community living outcomes? What were racial/ethnic disparities in impacts? What are the impacts of individuals living with long COVID on needs for HCBS? What policy changes and innovations should continue after the public health emergency?
- COVID-19 highlighted the importance of disaster planning for people receiving HCBS. However, people with disabilities, including people of color, LGBTQ+ individuals, socio-economically disadvantaged communities, and older adults, have been disproportionately left behind during disasters as a matter of course. Research and policy development are needed **to ensure adequate disaster planning within Medicaid HCBS programs**.

Barriers And Facilitators To Community Living Access And Outcomes

Direct Care Workforce Crisis

- The direct care workforce crisis was the highest priority barrier discussed during roundtables. Roundtable participants were concerned that inability to recruit and retain workers may lead to HCBS recipients being forced back into more institutionalized settings. They discussed that the majority of workers live in poverty, need better wages for basic daily living expenses, and often experience bad working conditions. Many indicated that **continued expansion of HCBS is not possible without strengthening the workforce.**
- Wages and rate setting were viewed as the most important issue related to the direct care workforce crisis. Wages of direct care workers have not kept pace with wages of similar industries competing for workers, contributing to difficulties with recruitment, retention, gaps in care, and turnover. Research is needed to **document the direct care workforce crisis and associations with wages.** Research is also needed on rate setting processes in states, what data is being used, and whether this is adequate to monitor and ensure access to direct care workers and HCBS.
- Additional research is also needed on **strategies to improve recruitment and retention of the workforce,** including the role of supervisory relationships, career paths and advancement, and pipelines for new workers.
- **Improving direct care worker knowledge and understanding of how to live with and support individuals receiving HCBS services based on HCBS beneficiaries' rights** was also identified as a research area.

Affordable Accessible Housing

- Additional research is needed on **promising practices and policies in at the local level to expand access to affordable, accessible housing.** How are HCBS service providers and systems interacting with housing providers and systems (i.e. housing authorities and HUD)? What promising practices and laws exist at the local level?
- Stakeholders suggested additional research on **Medicaid coverage of housing.** In general, direct housing costs are not covered by Medicaid. A range of housing supports are allowable and CMS has recently issued guidance expanding allowable expenses in 1115 waivers, such as transitional costs. Some participants suggested research on usage and impacts of this coverage.
- More research is needed on analysis on the type of housing states are developing and for whom. **How many permanent, accessible units are available in any given area? Who gets access to these accessible units? Which disability types are underrepresented?**
- More research on the **unhoused and homeless population** is needed. In particular, research is needed on the relationship between housing and institutional placements in

nursing homes for younger individuals under 65 years of age. Who does or does not have housing after a hospital or nursing home stay and why?

- Additional research is needed on **increasing access to and knowledge of home modification programs and improving rental assistance programs** for HCBS applicants and beneficiaries on fixed incomes.

Transportation

- Accessible transportation continues to be a major barrier to community living. In particular, stakeholders discussed **significant barriers in rural areas related to transportation**, technology, and other issues. Additional research could identify promising practices and models at the local level.
- Research is also needed on **Medicaid payment of transportation** and how states are using additional federal funding through ARPA and recent infrastructure packages to improve accessible transportation infrastructure.

Technology

- Roundtable members discussed the rise in technology usage and its impact on healthcare services. They also discussed **how technology can act as both a way to access information and a barrier to information** if consumers are not able or comfortable with using the technology.
- Stakeholders recommended additional research on **expansion of technology first practices**, telehealth services as compared to in-person services, and Medicaid coverage.
- Survey participants identified research needs related to **barriers to accessing technology** including social isolation and employment barriers related to limited internet access.
- Additional research is needed to explore how technology, specifically how AI and robotics can be used to increase access to HCBS services. In the alternative, **research on bias in algorithms resulting in discrimination** was also recommended.

Family Caregiver Supports

- Stakeholders recommended additional research on **supports for family caregivers**, including impacts of family caregiving and the extent to which self-direction allows hiring family members, including legally responsible relatives.
- Additional research is also needed on the use of family caregiver assessments within Medicaid HCBS programs. **Assessing unmet needs of caregivers and the extent to which Medicaid HCBS programs are providing respite** and other family supports and services was identified as important.

Food and Economic Security

- Survey responses indicated a need to **bolster access to healthy food**. Meals on Wheels was provided as an example in need of increased nutritional options.
- Research is also needed in the areas of Social Security benefits, **increasing Supplemental Security Income**, and ways to maintain benefits while working.
- Additional research is needed on **access to competitive integrated employment** and how to provide effective services to obtain these types of jobs and enjoy career advancement.

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Kimberly The, Senior Research Associate at the Lurie Institute for Disability Policy
Ruby Siegel, Undergraduate Research Fellow at the Lurie Institute for Disability Policy

Roundtable Participants:

Roundtable 1: National Aging and Disability Organizations

- Michael Atkins, Senior Policy Associate at The Arc of the United States
- Howard Bedlin, Vice President for Public Policy and Advocacy at the National Council on Aging (NCOA)
- Dan Berland, Director of Federal Policy at the National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- Alice Dembner, Director of Community Catalyst's Substance Use Disorders Project
- Amy Hewitt, Director, Institute on Community Integration at University of Minnesota
- Jennifer Lav, Senior Attorney at National Health Law Program
- David Machledt, Senior Policy Analyst at National Health Law Program
- Mike Oxford, Interim Executive Director at Atlantis Community Inc.
- Gelila Selassie, Senior Attorney at Justice in Aging

Roundtable 2: States and State Associations

- Curtis Cunningham, Assistant Administrator of Medicaid Benefits and Service Delivery at the Wisconsin Department of Health Services
- Bonnie Silva, Director of the Office of Community Living at Colorado Department of Healthcare, Policy, and Financing

- Laura Vegas, Director of National Core Indicators for the National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Roundtable 3: Individuals with Disabilities and Intersecting Identities

- Tyree Brown, Disability Advocate and Visual Artist
- Juliana Huereña, National Advisor and project support to Self-Advocates Becoming Empowered (SABE)
- Teresa Moore, Self-Advocates Becoming, Project Director of the Go Voter Project Self-Advocacy Resource Technical Assistance Center (SARTAC) at Self Advocates Becoming Empowered (SABE)
- Germán Parodi, Co-Executive Director at The Partnership for Inclusive Disaster Strategies

Roundtable 4: Providers, Health Plans, and Other Stakeholders

- Sharon Alexander, President, LTSS Solutions for AmeriHealth Caritas
- Carrie Blakeway Amero, Director of Long-Term Services and Supports at AARP Public Policy Institute
- Michelle Bentzien-Purrington, Sr. Vice President of MTLSS for Molina Healthcare
- Camille Dobson, Deputy Executive Director at ADvancing States
- Wendy Fox-Grage, Project Director at National Academy for State Health Policy
- Claire Jensen, Policy and Communication Manager of Long-Term Quality Alliance
- Mary Kaschak, Chief Executive Officer of the Long-Term Quality Alliance
- Michael Monson, Chief Executive Officer and President of Altarum
- Krissy Azeem, Senior Director, Delivery System Transformation, Altarum
- Terrance O'Malley, Instructor at Harvard Medical School
- Carol Raphael, Senior Advisor at Manatt Health
- Katie Smith Sloan, President and Chief Executive Officer of LeadingAge
- Nora Super, Senior-Fellow of the Long-Term Quality Alliance
- John Tschida, Executive Director at Association of University Centers on Disabilities (AUCD)
- Christina Wu, Vice President of Policy and Research of the Long-Term Quality Alliance

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