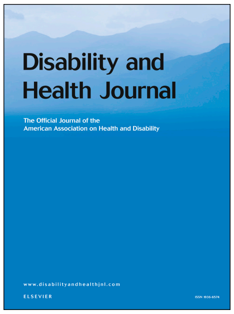

Community Living Policy: Progress, Uncertainty, and Research to Inform Paths Forward

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PII: S1936-6574(25)00115-3

DOI: https://doi.org/10.1016/j.dhjo.2025.101886

Reference: DHJO 101886

To appear in: *Disability and Health Journal*

Received Date: 1 May 2025

Revised Date: 20 May 2025

Accepted Date: 20 May 2025

Please cite this article as: Caldwell J, Ne'eman A, Community Living Policy: Progress, Uncertainty, and Research to Inform Paths Forward, *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2025.101886.

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Keywords: Medicaid, Home and Community-Based Services, Long-Term Services and Supports

This work was supported by The Community Living Policy Center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (Research grant ##90RTCP0004). The authors have no financial conflicts of interest to disclose. This study and the findings have not been submitted for any other publication or journal and are not under consideration for publication elsewhere. The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding agencies.

Word count for abstract:
Word count for complete manuscript: 2,593
Number of tables: 0
Number of references: 0

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The twenty-first century has seen a dramatic shift in the long-term services and supports (LTSS) ecosystem, defined by the dramatic expansion of Home and Community-Based Services (HCBS) as an alternative to institutional care. The promotion of community living represents an important paradigm shift with implications for the design, administration and monitoring of LTSS. A variety of factors have facilitated the transition towards HCBS, including consumer preference, quality and cost advantages, and enforcement of the Supreme Court's 1999 landmark decision in *Olmstead v. L.C.*, which mandates states provide services in the most integrated setting.[1]

Medicaid is the primary payer of LTSS in the U.S. In 2022, approximately 7.8 million Medicaid beneficiaries received HCBS, while 1.5 million received services in nursing homes and other institutional settings.[2] However, Medicaid forces individuals to become impoverished and remain poor to receive needed LTSS. Moreover, even as state Medicaid agencies have been responsive to calls from advocates to transition resources and people from institutional settings to community-based ones, the policy environment surrounding HCBS continues to be oriented primarily towards institutional settings. Advocates and policymakers have sought to facilitate a change in that policy environment through a variety of mechanisms. Federal policymakers have incorporated most integrated setting requirements in regulations implementing the Section 1557 and Section 504 final rules.[3,4] The Centers for Medicare and Medicaid Services (CMS) issued regulations in 2014 setting minimum standards for HCBS (known as the 'Settings Rule') focusing on the settings in which HCBS should be delivered as well as the rights that people receiving HCBS should have, which came into full effect in 2023.[5,6] In 2024, CMS also issued regulations called the Medicaid Access Rule, requiring new data collection and reporting on HCBS as well as setting a requirement that at least 80 percent of all Medicaid payments for homemaker services, home health aide services, and personal care services go towards compensation for direct care workers.[7]

These shifts are important, as they each address policy issues that interfere with the quality and integrity of community-based supports for people with disabilities. Incorporating *Olmstead* obligations into Section 1557 and Section 504 acknowledge that people with disabilities have a right to services in the most integrated setting in contexts beyond the application of the ADA's Title II, which applies only to state and local governments, under which most prior *Olmstead* litigation has focused. By acknowledging a most integrated setting requirement in Section 1557's regulations and reinforcing it within Section 504's, the Department of Health and Human Services recognized an obligation to serve people in the most integrated setting that applied broadly to all entities receiving federal financial assistance, including providers, health plans (such as under Medicare Advantage), and other entities.

The Settings Rule addressed serious and ongoing problems in the program integrity of HCBS, whereby many providers replicated the dynamic of institutional settings within congregate residential programs that were only nominally community-based. These programs failed to respect the rights of people with disabilities to make basic decisions about their own lives, such as when to get up in the morning, who gets to visit them in their own homes, and how to spend their time. The Settings Rule provided crucial protections to address these denials of rights, and established an important expectation that services should be delivered in settings integrated into the broader community in order to be financed as HCBS. The Medicaid Access rule represents an important step forward in both tracking HCBS quality and implementation, while also addressing the inadequate compensation of direct care workers. Its minimum requirements for direct care worker compensation are also particularly important given the proliferation of private equity acquisitions in the HCBS space.[8]

Unfortunately, these advances are now under serious risk. Recent actions to deconstruct the Administration on Community Living (ACL), the primary operation division within HHS addressing the needs of people with disabilities and older adults, may deprive the federal government of vital administrative leadership in efforts to promote HCBS. Rollbacks in civil rights enforcement and ongoing litigation raise questions as to whether the most integrated setting language in Section 1557 and Section 504 will be retained as-is and whether they will be enforced even if they are.[9] Regulations such as the Settings Rule and Medicaid Access Rule could be weakened or eliminated.[10] [11] In addition, broader Medicaid cuts could seriously harm people with disabilities and the HCBS program as a whole as states are forced to cut back in response to more limited federal financing.[12] We are thus in a moment of deep concern and uncertainty regarding the future of the ongoing shift towards community living in LTSS policy.

In this moment of precarity, scholarship can play a crucial role in highlighting the importance of careful policymaking and service-provision to protect and advance the rights of people with disabilities. As such, it feels especially appropriate to share an important body of research in this special issue supplement focused on Community Living Policy. The supplement examines the issue of community living policy, considering how state Medicaid agencies and accompanying policymakers in adjoining areas, such as housing, can effectively support the continued transition towards the community. How can the policy environment in which LTSS exists be modified to better reflect the values of the transition to community-based services. This topic has long been at the center of disability policy debates, most particularly with respect to Medicaid’s ‘institutional bias’ - the fact that Medicaid requires coverage of nursing home services without waiting lists but permits states to cap enrollment for HCBS. Advocates have long pointed out that Medicaid’s institutional bias creates a policy environment in which it is easier to access nursing home services than HCBS in much of the country. However, evolving the LTSS policy environment to reflect the shift towards community living requires a broader perspective, looking not only at the underlying mechanism of Medicaid law but also the broad range of policy choices made by states to facilitate community living for people with disabilities.

Overview of Articles in Supplemental Issue

Supporting people in the community necessitates access to housing. For many people with disabilities who do not reside in family homes, this can be difficult. Multiple articles examine the issue of housing. **Goddard, Hall, Greiman, Koon & Gray** evaluated the impacts of an innovative home modification intervention for people with mobility disabilities. The Home Usability Program (HUP) trained staff from Centers for Independent Living (CILs) to conduct comprehensive assessments and evaluations of the home environments of individuals with mobility impairments. Based on the assessment, an individualized plan was developed and modifications were made, including architectural changes, assistive devices, and adaptations to specific areas such as the bathroom, kitchen, or bedroom. Through pre-post surveys and participant interviews, the authors found the intervention resulted in decreased exertion. Decreased exertion led to positive outcomes, including increased time for other activities, improved socialization, enhanced independence, and the potential for engaging in activities outside the home. Additionally, the HUP intervention contributed to increased safety, which positively affected mental well-being and independence. **Park, Haseeb & Namkung** used longitudinal fixed effects models on data from the Disability and Life Dynamic Panel, a nationally representative study of people with disabilities in South Korea, and found that poor housing conditions were associated with increased depressive symptoms among adults with disabilities, an effect that was mediated by access to community services. **Trivedi, Pickern & Nguyen** analyzed data from the American Housing Survey and found that households in which persons have LTSS needs faced greater housing instability than households without person with LTSS needs.

Similarly, the transition to HCBS frequently necessitates types of services that are atypical in institutional settings, such as transportation and employment supports. **Friedman** analyzed data from state 1915(c) HCBS waivers and found that people with Intellectual and Developmental Disabilities (I/DD) often make use of Medicaid-financed transportation services embedded within residential habilitation, supported employment, and day habilitation benefits. She also found that a total of $781.78 million in spending was projected for stand-alone transportation services for 261,109 people with I/DD, approximately one-third of HCBS waiver recipients. **DuBois, Bradley & Isvan** analyzed data from the National Core Indicators Intellectual and Developmental Disabilities (NCI-IDD), a person-reported survey of individuals receiving I/DD services in the U.S., to explore characteristics associated with participation in competitive, integrated employment. They found several demographic and service-related characteristics significantly associated with employment. Of particular note, having an employment-related goal in one's service plan was a high predictor of competitive integrated employment, underscoring the importance of person-centered planning.

Recognizing that the delivery of service-provision in community-based settings requires a greater degree of individualization and planning, ACL and CMS have worked over the last decade to promote greater clarity and consistency to advance person-centered planning within HCBS programs. Regulations now require person-centered planning within all Medicaid HCBS programs as well as within other federally funded HCBS programs. Research supports positive community living outcomes associated with person-centered planning.[13] However, implementation and service delivery in line with person-centered planning drives outcomes. **Tennety, Schram, Kish, Sadler, Kaine, Kaufman, Lutzky & Heinemann** explored the perspectives of HCBS professionals and users on systematic barriers that affect receiving person-centered HCBS. Through qualitative analysis they identified three overarching themes:

(1) Workforce considerations; (2) Resources and service access; and (3) Infrastructure for feedback. These themes tap into many current policy barriers facing individuals and providers, including access to services and the direct care workforce crisis.

As policymakers work to align the policy environment with the goal of community living, larger considerations of equity are important to take account of. **Levine, Cole, Michals, Wang & Rubenstein** analyzed Medicaid administrative claims data and found that racial and ethnic minorities with I/DD had 3.66 to 12 percentage point less likelihood of enrolling in HCBS waiver programs as compared to white non-Hispanic Medicaid beneficiaries with I/DD. **Caldwell, Daniels & Stober** utilized data from the Behavioral Risk Factor Surveillance System core survey and a state supplement on LTSS in Texas. They found that among persons with LTSS needs, persons were more likely to have unmet needs if they were under age 65, female, had higher educational attainment and were of non-straight sexual orientation. After controlling for socio-demographic variables, having unmet needs for LTSS was significantly associated with poorer physical and mental health outcomes and suicide ideation. These findings suggest that additional work is needed to ensure that all persons with LTSS needs have access to the services necessary to support them.

In a commentary, **Basnet, Killick, Diaz & Felteau** discussed the role of Ombudsman programs in assisting people with disabilities in the Medicare-Medicaid dual eligible demonstrations authorized by the Affordable Care Act, and their continued importance as these demonstrations shift to the Dual-Eligible Special Needs Plans model (D-SNP). **The, Sheets, Acevedo, Almeda-Lopez, Garr-Colzie, Hu & Heaphy** explored the role of LTSS Coordinators in Massachusetts' OneCare dual eligible demonstration using qualitative methods, and found that such coordinators played an important role in filling care gaps related to social determinants of health, but that consumer stakeholders had mixed understandings and definitions of their role.

LaPierre, Wednel, Babitzke, Sullivan, Schwartzendruber & Olds used a mixed-methods design to examine the role of care coordination and backup plans in HCBS in Kansas's Medicaid Managed Care program; they found that one-third of survey respondents did not have a backup plan for their HCBS provider and 39% went without formal services for at least 2 consecutive weeks.

Finally, the continued evolution of the HCBS service system requires quality measures in order to hold providers, health plans and state government accountable for outcomes. This is particularly the case given the rapid expansion of Managed Long Term Services and Supports over the course of the last decade, under which states contract out the operation of their Medicaid program to private health plans in exchange for capitated payments. The use of standardized person-centered outcome measures is essential to allow individuals, advocates, providers, and state and federal policymakers to compare quality within and across programs, explore disparities, and set benchmarks and incentives for improvement. However, significant gaps exist in HCBS measure development. **Nyce, Roberts, Tichá, & Abery** pilot tested new measures in six domains: meaningful activities, social connectedness, choice and control, employment, transportation, and freedom from abuse and neglect. These measures were piloted with a wide range of HCBS recipients, including individuals with IDD, physical disabilities, age-related disabilities, traumatic/acquired brain injury, and serious mental health conditions. They found very strong psychometric evidence for the measures across populations. This pilot testing contributed to broader field testing to advance the availability of these new measures. **Karon, Tennety, Schram, DuBois, Lutzky, Heinemann & Deutsch** engaged a Participant Council representing HCBS recipients to identify aspects of HCBS quality that mattered to them. They then identified gaps in current instruments and measures, selecting nine concepts for additional measure development, consisting of: (1) dignity of risk, (2) community engagement, (3) living arrangement, (4) how time is spent, (5) money, (6) important relationships, (7) personal expression, (8) food and nutrition, and (9) healthcare and health.

Ultimately, the shift from institutional care towards HCBS represents one of the most significant transitions in the history of the Medicaid program. The continued sustainability of this transition is dependent not only on shifting people and resources but also on the evolution of the larger policy context in which LTSS is delivered. Research from this supplemental issue can help inform bi-partisan policies and practices that continue momentum in shifting towards community-based supports, achieve potential savings and efficiencies in overall spending, and improve health, community living, and employment outcomes for individuals with disabilities.

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