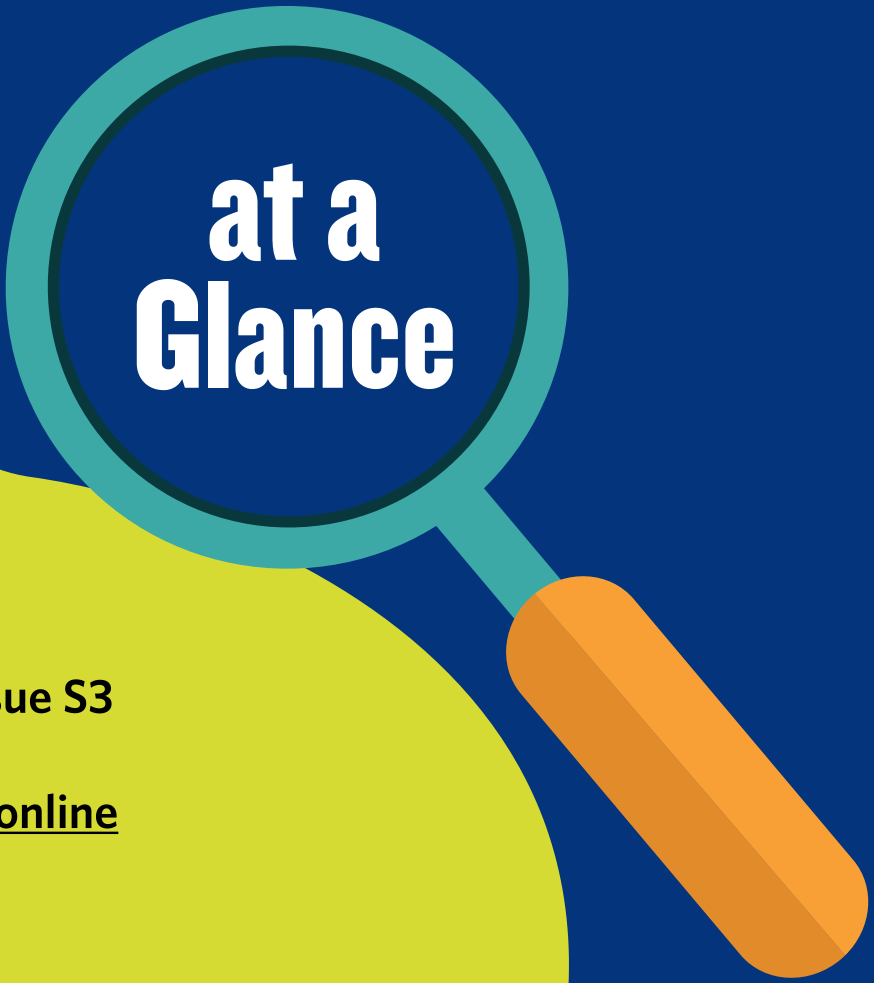
Disability and Health Journal Special Issue on Community Living Policy



at a Glance

Volume 18
Supplement Issue S3
July 2025
[View full issue online]

CLPC
Community Living
Policy Center

First Special Issue on Community Living Policy

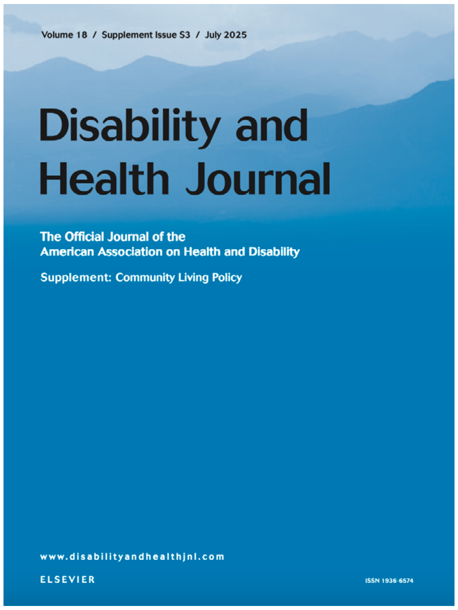
This Special Issue of the Disability and Health Journal is the first issue of this journal to f**ocus specifically on Community Living Policy**. The supplement highlights the importance of careful policymaking and service provision to protect and advance the rights of people with disabilities and illustrates the crucial role research plays in advancing community living policy. A number of the articles included in the Special Issue were developed by research centers funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

What is Community Living Policy?

Community living policy refers to the set of laws, regulations, and practices that support people with disabilities and older adults to live in the community rather than in institutions. It emphasizes person-centered services fostering individual autonomy and independence. Community living policy is fundamental to positive health outcomes and to ensure the promise of community integration founded in the disability civil rights movement.

What's in this Special Issue?

- 13 articles cover a wide range of current issues and populations needing Long-Term Services and Supports (LTSS), including topics of housing, transportation, integrated employment and person-centered planning.
- The articles comprise a mix of quantitative and qualitative methods and commentary.
- The articles cover four major themes in community living policy:
    - Housing and Transportation Supports,
    - Access to Home and Community-Based Services (HCBS) and Unmet Needs,
    - System Design and Delivery, and
    - HCBS Outcome Measures.



Volume 18 / Supplement Issue S3 / July 2025

Disability and Health Journal

The Official Journal of the American Association on Health and Disability

Supplement: Community Living Policy

www.disabilityandhealthjnl.com

ELSEVIER

ISSN 1936-6574

This document provides brief summaries of the 13 articles included in the Special Issue, broken down into the four major themes listed above.

View the full special issue on the Disability and Health Journal's website.

Housing and Transportation Supports

Examining the Effects of Home Modifications on Perceptions of Exertion and Safety Among People with Mobility Disabilities, *by Kelsey S. Goddard, Jean P. Hall, Lillie Greiman, Lyndsie M. Koon, and Randi C. Gray*

The purpose of this study was to examine the effects of home modifications on exertion and safety among people with mobility disabilities. Findings highlight the need for usable living environments that minimize physical strain and reduce exertion. Policy recommendations include prioritizing accessibility standards for housing, implementing individualized assessments for funding home modifications, providing financial assistance options, and allocating research funding for innovative solutions and technologies.

Housing Stability for Households with LTSS Needs in America: Contrasting Pre-pandemic Housing Data from 2017 with Data from 2021, *by Kartik Trivedi, Syd Pickern, and Teresa Nguyen*

This study analyzed data from the American Housing Survey and found that households in which persons have LTSS needs faced greater housing instability in the form of mortgage, rent delinquency, or missing utility payments than households without persons with LTSS needs. Sustained policy interventions, like those employed during the COVID-19 crisis at both federal and state levels, helped reduce housing instability for LTSS households.

The Effects of Poor Housing Conditions on Depressive Symptoms in Persons with Disabilities: Do Neighborhood Resources and Residence Type Matter?, *by Gum-Ryeong Park, Saud Haseeb, and Eun Ha Namkung*

Researchers 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. They found that poor housing conditions including structural inadequacies, poor ventilation, lighting, and noise protection, were associated with increased depressive symptoms among adults with disabilities. The negative impact of poor housing conditions on mental health was mitigated by access to community services.

Transportation for People with Intellectual and Developmental Disabilities in Home and Community-Based Services, *by Carli Friedman*

Transportation can help improve the health, quality of life, and community integration of people with disabilities including people with intellectual and developmental disabilities (I/DD). Yet, transportation is one of the most common unmet needs for this population. The aim of this study was to examine how states provide non-medical transportation to people with I/DD in their Medicaid HCBS 1915(c) waivers. Findings indicate that although HCBS waivers are an important resource for providing transportation for people with I/DD, significant variation in how states implement waivers may result in unmet transportation needs.

Access to HCBS and Unmet Needs

An Observational Investigation of Unemployment, Underemployment, and Competitive Integrated Employment of People with Intellectual and Developmental Disabilities in 2021- 2022, *by Lindsay A. DuBois, Valerie Bradley, and Nilüfer Isvan*

Researchers 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.

Measuring Nonmedical, Person-Centered Outcomes for Home and Community-Based Service Participants: Selecting and Defining Concepts, *by Sarita L. Karon, Niveda Tennety, Bridgette M. Schram, Steven Lutzky, Allen Heinemann, and Anne Deutsch*

Quality measures can monitor whether HCBS are delivered effectively and support positive health outcomes. Researchers 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.

Inequities in Medicaid Home- and Community-Based Services Waiver Enrollment Among People with Intellectual and/or Developmental Disabilities: A Nationwide Claims-Based Analysis, *by A. Alex Levine, Megan B. Cole, Amy Lynn Michals, Na Wang, and Eric Rubenstein*

Disabled POC are
3.66-12%
less likely to enroll in HCBS waiver programs than non-Hispanic white disabled people

States use Medicaid 1915(c) waiver programs to enable access to HCBS for disabled people including people with intellectual and/or developmental disabilities (I/DD). However, there is little data about waiver enrollment for disabled people of color. Researchers 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.

Unmet Needs for Long-Term Services and Supports and Associations with Health Outcomes, *by Joseph Caldwell, Elad Daniels, and Kaitlin Stober*

Researchers utilized data from the Behavioral Risk Factor Surveillance System (BRFSS) core survey and a state supplement on LTSS in Texas. They found that among persons with LTSS needs, those who were under age 65, female, had higher educational attainment and were of non-straight sexual orientation were more likely to have unmet needs. Additionally, 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.

System Design and Delivery

The Importance of Ombudsman Programs in Supporting the Transition from Medicare-Medicaid Plans to Dual Special Needs Plans, *by Falguni Basnet, Colin Killick, Leslie Diaz, and Sabrina Felteau*

In this commentary, authors 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). Findings emphasize the importance of maintaining and potentially expanding Ombudsman programs during and after the transition to ensure person-centric, high-quality care for dual-eligible members.

Experiences with Care Coordination and Backup Plans in Home and Community Based Services during the COVID-19 Pandemic in Kansas, *by Tracey A. LaPierre, Carrie L. Wendel, Jennifer Babitzke, Darcy L. Sullivan, Lora Swartzendruber, and Danielle M. Olds*

The COVID-19 pandemic was an emergency event during which backup plans for home care worker coverage became widely relevant. Although backup plans are required for Medicaid-funded HCBS, little is known about their implementation. Researchers used a mixed-methods design to examine the role of care coordination and backup plans in HCBS in Kansas's Medicaid Managed Care program during COVID-19. 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. Findings indicate that improvements are needed in care coordination to support the development and maintenance of backup home care worker plans that can be successfully drawn on to avoid interruptions to care.

Explorations of the Long-Term Supports Coordinator Role in Managed Care for People Who Are Dually Eligible for Medicare and Medicaid: A Participatory Action Research-Informed Study, *by Kimberly J. The, Maggie Sheets, Shulamith Acevedo, Emily Almeda-Lopez, Nancy Garr-Colzie, Luanjiao Aggie Hu, and Dennis Heaphy*

Long-Term Supports (LTS) Coordinators help people navigate healthcare and services. The study 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. The LTS Coordinator feature of One Care can serve as a model for other integrated care programs.

HCBS Outcome Measures

The Design and Methodology for a Pilot Study of Home and Community-Based Services Outcome Measures, *by Alec Nyce, Matthew A Roberts, Renáta Tichá, and Brian H Abery*

The use of standardized person-centered outcome measures is essential to compare quality within and across programs, explore disparities, and set benchmarks and incentives for improvement. However, significant gaps exist in HCBS measure development. This study 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 and findings indicate very strong psychometric evidence for the measures across populations, contributing to broader field testing to advance the availability of these new measures.

Systemic Barriers Hinder Person-Centered Home and Community Based Services (HCBS): Perspectives of Service Users and Professionals, *by Niveda Tennety, Bridgette M. Schram, Jacqueline Kish, Tonie Sadler, Ross Kaine, Katie Kaufman, Steve Lutzky, and Allen Heinemann*

Researchers 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.

Funding Statement

Funding for this special issue was provided by the National Institute on Disability, Independent Living, and Rehabilitation Research, through grant number 90RTCP0009. NIDILRR is a center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). This special issues' contents reflect the findings of the researchers and not of the National Institute on Disability, Independent Living, and Rehabilitation Research.