

Circles of Care: Home and Community-Based Services Supports for People of Color with Disabilities Leaving Institutional Settings

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May 2026



Definitions

Ableism – Discrimination and social prejudice against people with disabilities based on the belief that nondisabled people are superior.¹

Centers for Independent Living – Local organizations, designed and operated by people with disabilities, that provide independent living services and supports for integrating people with disabilities meaningfully into their communities.²

Home and Community-Based Services (HCBS) – Services and supports that assist individuals with disabilities and older adults to live in their own homes or in community-based settings. HCBS consists of a wide range of services, including case management, homemaker, personal care, day services, employment supports, transportation, home modifications, adaptive equipment, and family supports.³

Institutional settings – Nursing homes and other settings where substantial amounts of care or 24-hour care are provided. Settings include residential care for older adults (e.g., nursing homes or supported living facilities), psychiatric facilities, and intermediate care facilities for individuals with intellectual disabilities. These settings are often restrictive and have little or limited integration with the larger community.⁴

Money Follows the Person (MFP) – MFP supports states to transition people residing in nursing homes and other institutional settings back to the community. It assists states with “rebalancing” their long-term services and supports (LTSS) systems by advancing access to HCBS and improving community living outcomes.⁵

Participatory Action Research (PAR) – Conducting research with people rather than for people to address issues important to a community.⁶ This approach requires that group members respect the expertise and knowledge of all individuals, and calls for reflexivity from academic researchers, people who usually reside within privileged institutions.⁷



A Note on Language

The term “people of color” was developed to highlight coalitional alliances between racial groups such as Black/African Americans, Indigenous people, Asian Americans, and Latino/a/e/x people. The term “people of color” aims to draw attention to sometimes shared histories of oppression, including but not limited to discrimination, war, slavery, and colonialism. It does not aim to homogenize racial minorities under one term, nor does it claim that the experiences of all racial minorities are the same.⁸ While this brief uses the term “people of color”, we recognize that different individuals or groups may use different terms to refer to themselves.

Summary

- Culturally responsive and disability-led models are critical for moving toward community living and fulfilling the promise of *Olmstead*.
- People of color with disabilities need multiple types of coordinated supports to transition out of institutional settings and access Home and Community-Based Services (HCBS).
- Supports include interpersonal relationships and the disability community, ongoing societal-level assistance through policies and programs, and informational resources.
- Adequate support networks, culturally validating programs, community resources, and access to HCBS all aided transitions and sustained community living for people of color with disabilities.

Background

- The U.S. Supreme Court 1999 *Olmstead v. L.C.* decision declared that unnecessary institutionalization constitutes discrimination under the Americans with Disabilities Act (ADA) and affirmed the right of persons with disabilities to live in the most integrated setting possible.⁹
 - Despite the promise of *Olmstead*, and the reallocation of Medicaid funding to HCBS,¹⁰ people with disabilities still encounter barriers to access HCBS.
- People of color using Medicaid HCBS experience higher unmet need than their White counterparts, even after adjusting for socioeconomic and health factors.^{11,12,13}
- Evidence suggests that culturally responsive and peer-based supports can strengthen pathways to independent living.^{14,15}
- Few studies address supports that help people of color with disabilities transition out of institutions and sustain community living.



Purpose

The purpose of this study is to explore the types of supports that help people of color with disabilities transition from institutional to community settings and remain integrated in the community.

How Was This Study Done?

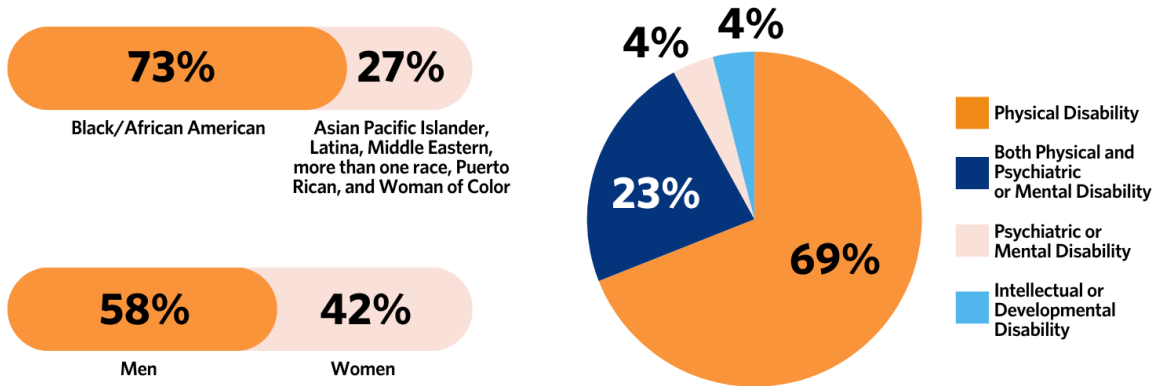
This study uses a Participatory Action Research (PAR) approach with semi-structured, open-ended interviews. Using PAR, people with disabilities were included at each step of the research process. This project hired five disabled people of color to serve as peer researchers, some of whom had experience living in a nursing home. Peer researchers contributed to interview guide development, conducted interviews, completed data analysis, assisted with paper writing, and supported the sharing of findings. All peer researchers received training in research ethics, interviewing, and data analysis.



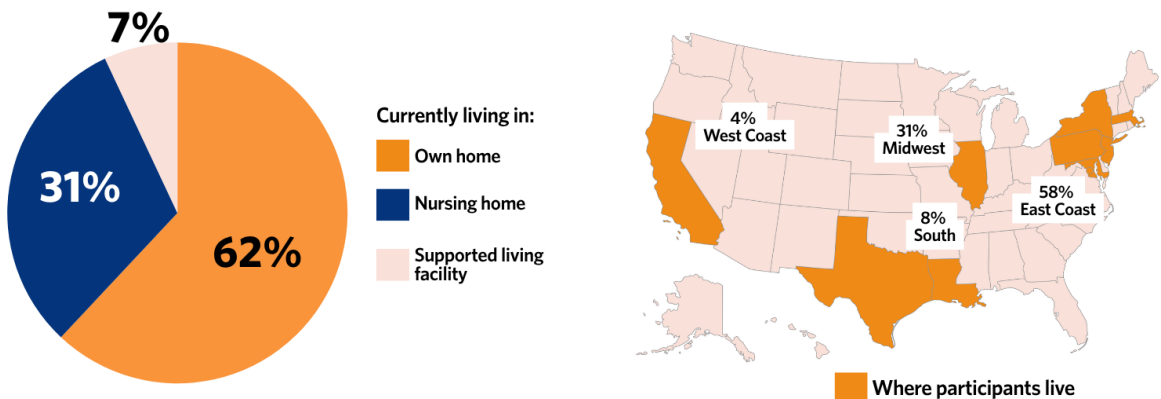
Participants were disabled people of color, primarily Black individuals, with experience living in an institutional setting. Participants were interviewed through Zoom or phone. They received a \$50 gift card for participation in the study.

Participant Characteristics

Twenty-six individuals participated in this study. Participants were 23 to 76 years of age and majority Black/African American (73%). The remaining 27% of participants identified as Asian Pacific Islander, Latina, Middle Eastern, more than one race, Puerto Rican, and Woman of Color. The sample was 58% cisgender men and 42% cisgender women. Most individuals identified as having a physical disability (69%), followed by both physical and psychiatric or mental disability (23%), psychiatric or mental disability (4%), and intellectual or developmental disability (4%).



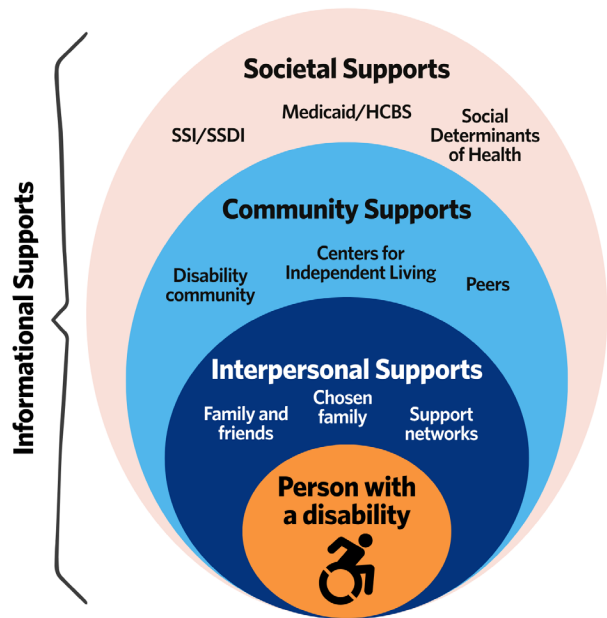
Most participants had some college education (38%) or a bachelor's degree or beyond (27%), with 23% of participants having a high school diploma or GED, and 12% having not completed high school. All participants had experience living in an institutional setting, with 62% of individuals currently living in their own home, 31% of participants living in nursing homes, and 7% living in supported living facilities. Most of the participants (58%) came from the East Coast, 31% from the Midwest, 8% from the South, and 4% from the West Coast.



What Did We Find?

We found **four primary themes** that enabled disabled people of color to transition from institutional settings to sustained community living:

- 1. Interpersonal-level supports** from family, friends, chosen kin, and support networks;
- 2. Community-level supports** through the disability community;
- 3. Ongoing societal-level supports** from public benefit programs; and
- 4. Informational supports**, a stand alone and interrelated theme through every level of support.



1. Interpersonal Supports

Participants identified family members, friends, and chosen kin as central to their transition process. These trusted figures remained engaged before, during, and after participants' transition into the community. Participants described family and friends as those who frequently took charge of important tasks like helping with discharge procedures, organizing logistics, and arranging housing accommodations. Some participants who lacked strong family ties developed meaningful relationships with staff beyond the employee's formal responsibilities; several of whom remained in contact after the participant's discharge.

Informal social networks, such as neighbors, faith-based or religious groups, and other members of the community, were described by participants as important for their transition and integration into the community. Informal networks provided companionship, emotional support, and help with daily activities like personal care, shopping, and housekeeping.



My best friend visited me regularly. One day she took me to look at an apartment. On the drive back I shared my desire to live there. She said, 'Good, because next month we are coming back to sign the lease, you're going to live there!' I had no money. My net worth was about 78 cents. She made sure I had furniture, food, and everything I needed. All I had to do was roll in. (P24)



The only reason I got out of there was because my siblings got together, gathered money, organized everything and convinced my mother I should move. They decided I would fare better moving out-of-state because the rehabilitative services and technology were better where they were in the [location]. I could live with my sister and be closer to family. (P8)

2. Community Supports

Participants identified the disability community, particularly Centers for Independent Living (CILs) and peer support networks, as critical for facilitating transitions into the community. CILs were described as trusted sources, offering training and information related to self-advocacy, resource navigation, and independent living skills.

Formal peer support, provided by trained specialists, offered structured guidance with discharge planning, service navigation, and preparation for independent living. Informal peer support occurred through engagement with fellow disabled residents. Through both formal and informal supports, peers drew on lived experience to offer practical advice, clarify procedures and options during transition, and share perspectives on life post-discharge.





The independent living center developed a structured training program featuring weekly topics such as transportation, Medicaid, and Social Security. Subject matter experts were invited to provide detailed explanations of relevant processes and assist with the necessary documentation to facilitate a successful transition. (P5)



The support groups for people with disabilities are great for having real discussions with people who just get it. I love the support from my family and friends but chatting with others who know what it's like living with a disability is invaluable. (P18)

3. Societal Supports

Participants consistently identified Medicaid, HCBS, Social Security, the Supplemental Nutrition Assistance Program (SNAP), and Section 8 Housing Choice Vouchers, a federal program that provides rental assistance to eligible low-income individuals, as supports necessary for transitioning and sustaining community living. Participants emphasized that Medicaid HCBS enabled them to receive services in their own home and facilitated access to care management, attendant services, transportation, home modifications, and assistive technology. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), federal programs that provide cash assistance to eligible low-income individuals, were frequently cited as the primary sources of income that supported participants' basic needs in the community after discharge. Similarly, food assistance through SNAP supported nutritional needs and Section 8 supported housing needs. However, delays in SSI/SSDI enrollment and limited availability of public housing hindered transitions.



The key to remaining in the community is home and community-based services, including medical insurance, adequate housing, transportation, resources, and attendant care. Unfortunately, these do not exist the way they should, and most people don't even know what they are. People of color are living and dying in nursing homes more than others, and there must be a better way. Having relevant information and education is key. (P8)



My housing authority, they actually came to my bedside because being that I had my stroke, I couldn't work. I was living in a shelter at the time. Not having a stable home can affect your health in a big way. For me, having the support of housing [Section 8] enabled me to manage my disability, manage how I operate. Housing is very important, especially for people who are disabled. Because a lot of people who are disabled don't have a stable home. And to have housing for the disabled, it's important because some people that get disabled don't have family support. (P5)

4. Informational Supports

Informational support served as a distinct and overlapping theme across interpersonal-, community-, and societal-level supports. Two compounding aspects stood out. First, the need for relevant information and, second, the knowledge on how to apply this information. Participants stressed the importance of receiving clear discharge instructions and awareness of community resources. Reliable information from institutional staff was often absent or deficient, causing participants to look toward the disability community, family, friends, and other supports for accurate information and guidance that facilitated transitions. Timely access to relevant, practical information directly affected participants' ability to locate, access, and maintain resources and supports for community living.



I understood how to use the information and developed a system that worked for me and helped my transition. Most residents in institutions do not understand the paperwork, process and information, even when it is available. Nobody explains it, so they fall through the cracks. (P2)



I got involved with a local non-profit organization called [name], which is an independent living center here in [location]. They taught me everything. They taught me that I had civil rights, that I should live in the community, and that this issue wasn't a me issue. It was something that had impacted thousands of people per year even before me. I learned about different laws that were in place—the Olmstead decision of 1999, things like that—which really helped me advocate for myself. (P26)

What Did We Learn?

Consistent with prior research on transitions from acute and institutional care settings, our findings indicate that individuals with complex needs, including co-occurring psychiatric and physical disabilities, require multiple, coordinated supports for community reintegration.^{16,17,18} Our study extends prior research by demonstrating that supports do not operate in isolation, but are interrelated and compounded (e.g., elements of a circle of care).

We find that strong interpersonal relationships are the foundation by which participants can transition. Similar to past literature, people of color rely on biological^{19,20} and chosen family,²¹ close friends,²² religious congregations,^{23,24} and other support networks^{25,26} to provide advocacy, emotional support, and/or tangible assistance during times of hardship.

Despite individuals who have close relationships willing to support transitions, the delays in enrollment for Medicaid, SSI, and SSDI, and long waitlists for Section 8 can impede participants' access to HCBS and housing, often stalling access to community living. These findings agree with previous research on structural barriers to Medicaid and related programs.^{11,17,16} The accounts of participants underscore the importance of access to public benefit programs for transition opportunities and sustained community living.

Insufficient or inaccessible information delays or complicates integration.^{16,27,28} To address gaps in informational support, one participant proposes involving a peer navigator; someone with a disability to connect transitioning individuals, support programs and resources, the facility, and the disability community. Staff also have a responsibility during the transition process. Research on a state transition program found that trained counselors who provided information to nursing home residents effectively supported the decision-making and transition process.¹¹

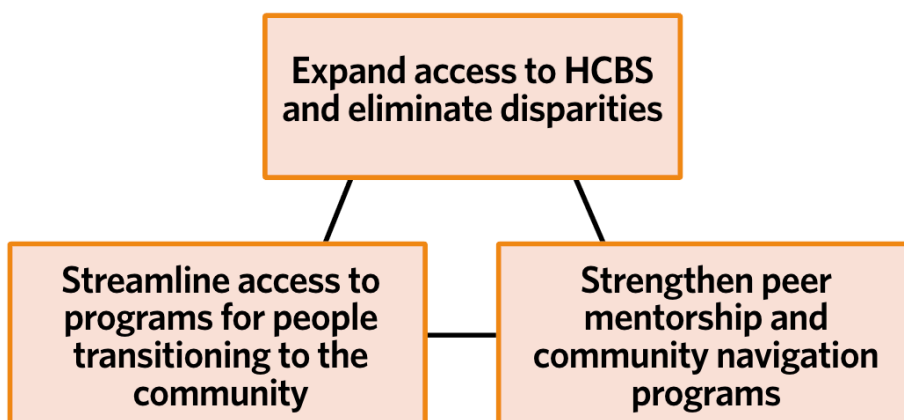
The findings of this PAR study reveal opportunities for improving transitions to the community and access to HCBS through investment in government programs (HCBS, SNAP, Money Follows the Person, etc.) and the community, namely Centers for Independent Living, peer-support programs, and biological and chosen family supports. In addition, more information, a greater awareness of resource availability, and skill-building opportunities on how to apply the provided information are needed.

Recommendations offered in this brief, to support sustained community living for disabled people of color, suggest investments at the interpersonal-, community-, policy-, and informational- levels. Such actions can fulfill the promise of *Olmstead*, a decision that calls for community living as a civil right.²⁹

What Are Some Policy Recommendations Based on the Findings?

While not exhaustive, below is a list of policy recommendations developed to elevate supports that facilitate transitions back to the community for people of color with disabilities.

- Expand access to Medicaid HCBS and eliminate disparities by state, type of disability, and demographics, including race and ethnicity.
 - Bills like the HCBS Access Act of 2023 (S.762)³⁰ which would make HCBS a mandatory Medicaid benefit, and the Better Care Better Jobs Act (H.R.547)³¹ which would strengthen the direct care workforce and improve service delivery, offer a potential pathway to reducing these disparities by ensuring more consistent service availability across states.
- Streamline access to Medicaid HCBS and safety-net programs for individuals transitioning from institutional care.
 - States can more fully utilize the Money Follows the Person program to support transitions from nursing homes and other institutional settings back into the community.
 - States can also establish strong state partnerships with non-profit healthcare providers and use regulatory state authorities to protect and support consumers of Medicaid HCBS and other healthcare services.
- Strengthen peer mentorship and community-based navigation programs, such as those provided through CILs, by increasing funding and expanding access to peer supports.
 - Support mentorship programs and fund non-profits that aid in the transition process.



Funding Statement

Support for the development of this brief was provided by the Robert Wood Johnson Foundation (Grant Number 49624) and the National Institute on Disability, Independent Living, and Rehabilitation Research (Grant Number 90RTCP0006). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief's contents reflect the views of the authors and not of the National Institute on Disability, Independent Living, and Rehabilitation Research.

How to Cite This Brief

Gomes, A., Novack, V. J., The, K. J., Hu, L. A., Siegel, R., Lee-Rambharose, J., Nguyen, T., & Caldwell, J. (2026, May). *Circles of care: Home and community-based services for people of color with disabilities leaving institutional settings* [Research Brief]. Community Living Equity Center, Lurie Institute for Disability Policy, Brandeis University.

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