

Systemic Barriers to Community Living Experienced by People of Color in Institutional Settings

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Definitions

United States Supreme Court 1999 *Olmstead v. L.C. case* – The Olmstead decision clarified that unjustified segregation of persons with disabilities is discrimination and violates the Americans with Disabilities Act (ADA).¹

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.²

Institutional settings – Nursing homes and other settings where substantial amounts of care or 24-hour care are provided.³ Settings include residential care for older adults (i.e., nursing homes), 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

Participatory Action Research (PAR) – Conducting research with people rather than for people to address issues important to a community. This approach requires that group members respect the expertise and knowledge of all individuals in said community, and calls for reflexivity from academic researchers, people who usually reside within privileged institutions.⁵

Ableism – Discrimination and social prejudice against people with disabilities based on the belief that nondisabled people are superior.⁶

Note on language: The term “people of color” is a term developed that highlights coalitional alliances between racial groups such as Black/African Americans, Indigenous people, Asian Americans, and Latino/a/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 the experiences of all racial minorities are the same.⁷ 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

- We found people of color with disabilities experience systemic barriers that contribute to institutional placements and pose challenges in transitions from institutional settings back to the community.
- Barriers include unmet health and disability support needs, economic and housing barriers, administrative burden, inadequate peer and case management support to navigate complex systems, lack of information about Home and Community-Based Services (HCBS), and discrimination based on the intersection of race and disability.
- The results of systemic discrimination (i.e., racial/ethnic disparities in social determinants of health, in home ownership, and in wealth attainment) may inform and/or exacerbate barriers to community living for disabled people of color.
- The findings inform recommendations for improving transition services and access to HCBS through improved outpatient medical services, rent and homeownership support, better supported and informed social workers, and making HCBS mandatory for states to provide.



Background

- Monumental shifts from institutional to community-based services have occurred across the U.S. over the past several decades yet people of color face significant disparities in accessing HCBS and other community living supports.
- The full promise of the U.S. Supreme Court's *Olmstead* decision, which ruled that people with disabilities have a right to receive services in the community versus institutions, has not been realized.⁸
- Growing literature documents the significant barriers to transitioning from nursing homes to the community, such as informational, financial, and geographical barriers,^{9, 10, 11, 12} as well as housing availability and accessibility.^{13, 14} These barriers can slow or prevent disabled people of color from transitioning from institutional settings to the community.
- In nursing homes, residents with a higher proportion of people of color report lower overall quality of life than residents of facilities with lower proportions of people of color.¹⁵
- Studies show people of color have lower rates of HCBS access and utilization than White individuals.^{16, 17} When disabled people of color receive HCBS, they are more likely to have higher unmet needs and lower HCBS expenditures than their White counterparts.^{18, 19}
- There is little research that centers the experiences of people of color with disabilities who have lived in institutional settings and the barriers they experience while transitioning back to the community.

Purpose

The purpose of this study is to explore systemic barriers to community living that contribute to institutional placements and heightened challenges to transitioning back to the community for disabled people of color.

How Was This Study Done?

This study is unique because of its Participatory Action Research (PAR) design. For this study, a PAR approach meant that people with disabilities were included at each step of the research process.

This project hired 5 disabled people of color to serve as peer researchers, some of whom had experience living in nursing homes. For the study, peer researchers developed the interview guide, conducted interviews, completed data analysis, assisted with manuscript writing, and supported the dissemination of findings. All peer researchers received training on research ethics, interviewing, and qualitative data analysis.



Participants were disabled people of color with experience living in an institutional setting. Participants were interviewed through video conference or phone. They were compensated with a \$50 gift card for their participation in the study.

Who Participated in the Study?

Twenty-six individuals participated in this study. Participants were 23 to 76 years old and majority Black/African American (73%). The sample was close to an even split across cisgender males (58%) and cisgender females (42%). Most individuals identified as having a physical disability (69%) followed by both physical and psychiatric or mental disability (23%), psychiatric or mental disability alone (4%), and intellectual or developmental disability (4%).

All participants had experience living in a nursing home or rehabilitation facility, with 62% of individuals currently living in their own home, 31% of people 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. Participants' median length of institutional stay was 20 months with a range of 418 months (34.8 years) (minimum stay: 2 months; maximum stay: 420 months) in nursing homes and other institutional settings. This brief uses pseudonyms to maintain participant confidentiality.



What Did We Find?

We found six major systemic barriers to community living experienced by disabled people of color. These barriers contributed to individuals being placed in institutional settings and posed challenges to transitioning back to the community. Themes included: 1) unmet health and disability needs, 2) economic and housing barriers, 3) significant administrative burden and complex organizational processes, 4) inadequate case management/social work support for community living, 5) insufficient informational support and peer guides to complete transitions, and 6) discrimination based on race and disability status (racism/ableism). These themes often occurred simultaneously or in succession.

1. Unmet health and disability needs

Unmet physical, mental health and disability needs contributed to institutional placements and lengthy stays. Physical and mental health crises, accidents and injuries, and lack of daily supports in the community led participants into institutional settings, often for prolonged periods of time. Once inside institutional settings, illness, infections, worsening mental health, unmet support needs, and a lack of durable medical equipment contributed to extended or returning stays.



"It's a convoluted thing. Several years ago, I fell down some stairs. I injured my neck and have been in and out of nursing homes ever since. So, I'll get better. I'll get out. I'll get back to my home, and then I'll have some weird setback. I'll get sick or something will happen, and I'll end up back. Then, the last stint, I got some random infection. I ended up back in the nursing home. I wasn't actually progressing that well, medium well, and then I got COVID...The fall is what kind of started me down that slippery slope if that makes any sense." Serenity²⁰, 14 months

People of color with disabilities also experienced discrimination at the intersection of racism and ableism through delayed diagnoses and/or insufficient care that prolonged their stays. The experiences of diagnostic delay are a consistent occurrence cited in racial health disparities.²¹

Often, placement in an institutional setting came down to safety, accessibility of services, and availability of services. Unmet disability and health needs were a foundational barrier to community living. Many participants could have received supports in their homes or in the community had they been informed about HCBS programs.

2. Economic and housing barriers

Most participants did not have the financial resources to move out of institutions or to an otherwise less restrictive setting. More than 70% of participants utilized or were obtaining Supplemental Security Income (SSI) and nearly half (46%) identified using Medicaid or not having insurance. Several participants emphasized the complicated application processes and noted lengthy waiting periods to obtain benefits and publicly subsidized housing. These supports were crucial to mitigating barriers to transitioning for those with low incomes.



Maintaining benefit eligibility meant that participants could not save for renting or buying a home, monthly bills, durable medical equipment, home modifications, and other supports needed to transition back to the community. This left participants to rely on family or friends to get out of institutional settings; however, many of their interpersonal ties faced similar financial and economic hardships and were unable to provide support for community living. Access to affordable and accessible housing was among the most significant barriers. Barriers related to benefits and subsidies created further housing disparities for disabled people of color in this study.



"I was hoping I can find a place that's Section 8 or subsidized, but it didn't happen. It takes years and years though. That's not easy. So, my only option is assisted living or at a nursing home." Aaliyah, 15 months

Our findings are consistent with existing research that documents the enduring impacts of housing segregation as a result of discrimination in the U.S.²² Moreover, past research highlights how the challenges associated with transitioning from institutional settings may intensify housing discrimination experienced by people of color with disabilities.^{23, 24}

3. Significant administrative burden and complex organizational processes

Institutional settings, hospitals, organizations, government agencies, and property managers often had long and complex processes which delayed or inhibited participants transition from institutions to the community. Waiting times, lengthy and repetitive paperwork, and unclear services all delayed the transition to the community. These administrative barriers connect to recent research that stresses the importance of shifting administrative burden from the individual to the state.^{25, 26}



The process often intensified as participants moved closer to making a transition with individuals having to coordinate among multiple service providers such as property managers, disability service organizations, transportation services, and government benefit offices. For participants with greater financial means, bureaucratic and complex processes inhibited transition into the community for disabled people of color.



"We filled out some paperwork...I had to do that, so my goddaughter's mother took me to do that. Every day I had to go pick something and take it back to them. I think I faxed it back to the rehab, and I had a social worker fax it. They called me back to sign the lease. This time, I had my girlfriend's niece. She came and got me from the rehab and took me to sign the lease, and I had to have \$50. I paid her \$50. My girlfriend said to call her...youngest daughter...I get to the place. I said, 'Do y'all take the money off the card, or I [inaudible] have cash?' I didn't know this. She said, 'We don't do cash. We don't take it off your card. You have to get a money order.'...I'm sitting here, like, I don't even have enough [money] for a money order. This guy that was in the rehab with me, he gave me some extra money...I went back, signed my lease, because then they gave me one set of keys...to get in the front door. To get in the apartment, I had to bring the \$50 back so I could get my actual key. I got the money order. I brought it back. I gave it to her. She gave me the key." Leah, 9 months

4. Inadequate case management/social work support for community living

Participants continually mentioned the shortcomings of social workers, case managers, and other professionals that should assist with providing transition support. Some participants faced increased challenges due to racist and ableist beliefs from staff about their ability to successfully transition into the community. For example, some individuals noted how they were viewed as incompetent—or not possessing enough independent living skills to transition.



Almost half (46%) of participants reported that nursing home social workers were unhelpful and/or rebuffed consumers request to support them in their transition process. These shortcomings may stem from an overburdened and underpaid provider workforce. Individuals shared how social workers would refuse to help in various tasks such as completing paperwork, finding housing, and securing care workers. The inaction from social workers left many participants to rely on their own knowledge, self-advocacy efforts, and peer circles. Lack of support significantly contributed to delayed transition from institutional settings to the community.



"The social worker came in and she sat in the chair in my room. She didn't introduce herself or anything. She just sat down and said, 'You know you can't stay here, right?' And I said, 'Oh, okay. I didn't know that.' And then she said, 'You need to work on where you're going to go because you can't be here.' And then she just walked out." Sophia, 42 months

5. Insufficient informational support and peer guides to complete transitions

Transitions from institution to community exist within a complex organizational process in which participants must navigate numerous organizations, services, and providers. Lack of available information about HCBS and community living supports not only contributed to institutional placements but also a lack of awareness of alternatives. Information was difficult to obtain, and peer-to-peer support and guidance were rarely available. Without information, participants were unsure what services and supports were available. Our findings, along with other research,^{27, 28} further demonstrate information barriers that exist for people of color.

Participants who left institutions and returned often had better understanding of the transition process. This suggests a difficulty for persons of color with disabilities transitioning for the first time and indicates the potential power of peer guides and robust information during the transition process.



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“When I was young, I was soft-spoken. I really didn’t ask about something until I saw somebody else with it. I was like, ‘How did you get that?’ They were like, ‘Oh, such-and-such. Somebody told me about it.’ I guess it is because I didn’t ask many questions. I just assumed that all this stuff was going to fall into my lap. They were like, ‘No, you gotta ask for it.’ I was like, ‘Okay.’ I did not know – you don’t get offered – things are not offered to you... You have to know about [Program #4] and apply for it. You have to know about the [Program #3] services. I don’t think it happened because it was anything because of race. I think it was more of the wealth side...It is just what you knew and what you didn’t know. If you did not know something, and you did not ask the questions, you would not know.”
Madison, 18 months

6. Discrimination based on race and disability status (racism/ableism)

Most participants described instances of interpersonal discrimination and prejudice, that which occurred in everyday interactions between people, as contributing to delayed transitions from institutions to the community. This included anti-Asian, anti-Black, and Islamophobic sentiments from staff and perceived lower quality of care in institutional settings. These experiences connect with the unmet health and disability needs stated above as these interpersonal interactions often resulted in delays in diagnoses and care. A few participants also connected their individual treatment to structural racism in areas such as housing discrimination, medical racism, and criminalization on the basis of race.



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“I am very convinced that when I went to [Transportation service] it was absolutely clear to me that she looked at me, and she saw just another lazy Black person, too lazy to get up and walk. He’s rolling around in this expensive chair that he should not have...it was just like I said, you get finely tuned to it. It is just so clear that your color is influencing how they feel.”
Mason, 48 months

What Did We Learn?

The systemic barriers experienced by disabled people of color undermine the promises of Olmstead which calls for community living as a civil right.²⁹ These issues, while personally experienced by 26 participants, suggest systemic problems that delay or prevent people of color with disabilities from entering the community.

The findings make considerable contributions to the literature on institutional transitions and HCBS access, particularly as it relates to the community living barriers of disabled people of color. Past research has yet to explore both institutional transition and HCBS access for disabled people of color, has explored barriers from the perspective of staff, or has been quantitative in nature. This study helps elevate the voices of people of color with disabilities who have experience living in institutional settings and faced considerable barriers in returning to the community. The findings confirm barriers that were previously known (i.e., informational, financial, and racial discrimination), and offers new insights (inadequate care coordination, lack of peer guides, unmet health and disability support needs) on the barriers affecting community living and access to HCBS for disabled people of color.

While participants were more likely to discuss interpersonal examples of racism and ableism, the findings suggest the pervasiveness of systemic discrimination. Illness and disabling conditions, which are most prevalent among Black and Native people,^{30, 31} may occur due to inaccessibility of outpatient and provider care, food sources, medical racism, and housing segregation among other social determinants of health.³² ³³ Individuals' low-income status, and that of many of their families cannot be separated from inequitable opportunities for education, employment, and homeownership, factors which build generational wealth and for which disabled people of color, particularly Black people, face greater obstacles to accessing.^{34, 35} The findings reveal opportunities for improving transition services and access to HCBS through services and programs such as rent and homeownership support, outpatient medical services, job training and employment support, and care-coordination post-transition.



What are some policy recommendations based on findings?

We shared findings with participants, the Community Living Equity Center advisory committee, which consists of a diverse group of disabled people of color, and partners, including disability-led community-based organizations. While not exhaustive, below is a list of policy recommendations developed to eliminate barriers and facilitate transitions back to the community for people of color with disabilities.

- Reduce health disparities and address social determinants of health that contribute to higher rates of LTSS needs and secondary conditions among disabled people of color.
- Improve outreach and information about HCBS to communities of color, particularly during periods of transitions from hospitals to institutional settings.
- Rebalance LTSS systems away from reliance on institutional settings and improve access to HCBS.
 - Eliminate the institutional bias with the Medicaid program, where nursing homes are mandatory for states to provide while HCBS are optional.
- Enforce Olmstead and the Americans with Disabilities Act (ADA) through oversight of institutions and inclusion of Ombudsman programs.
- Address the direct workforce crisis which disproportionately impacts women of color and poses barriers to community living for consumers.^{36, 37}
- Improve supports to transition individuals from institutional settings back to the community.
 - Require and enforce that education is offered to institutional residents about their rights and aid with navigating access to HCBS and community-based supports.
 - Make the Money Follows the Person (MFP) program permanent and strengthen state adoption and utilization of the program.
 - Enhance funding for Centers for Independent Living (CILs) and other community-based organizations serving people of color to provide peer-to-peer support with transitions.
- Address the national housing crisis, which effects housing availability, affordability, and accessibility, particularly for people of color with disabilities.
 - Expand Medicaid coverage, access to Durable Medical Equipment, and improve access to housing modifications to increase safe and accessible housing options.
 - Increase funding for federal Housing Choice Vouchers, expand the availability of state-funded vouchers,³⁸ and create lifts on zoning practices which restrict the building of affordable multi-family units.
 - Develop and expand Social Housing Programs that utilize public financing options at the state level to create sustainable, long term mixed-income housing developments that are permanently affordable, and resident controlled.³⁹
 - Expand and create additional home ownership programs that fund down payments and security deposits.



Endnotes

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