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LONG-TERM
QUALITY ALLIANCE

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Literature Review of Home- and Community-Based Services in Diverse Communities: Utilization

LITERATURE REVIEW

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Introduction

Long-Term Quality Alliance (LTQA) in partnership with O'Leary Management Associates worked with the Minnesota Department of Human Services (DHS) to explore the feasibility of programs that would assist older adults to stay in their homes as they age and their long-term care needs increase. As part of this work, LTQA conducted literature reviews on home- and community-based services (HCBS) in diverse communities with special consideration given to **trends in diverse communities' utilization of HCBS**, **diverse caregivers**, and **rural communities**. This literature review examines trends in diverse communities' utilization of HCBS.

Overall, minority individuals are less likely than White individuals to use formal services for their home care needs and more likely to rely on family, friends, and other community members as informal caregivers. For those who do receive Medicaid long-term services and supports (LTSS), minority individuals are proportionally much more likely to receive their services via HCBS rather than institutional care compared to White individuals. Among HCBS users, minority groups spend less and have worse levels of self-reported health, while Black HCBS users also have higher rates of hospitalization. There are indications that significant levels of unmet need for HCBS may be present among diverse communities. Barriers to formal service use include lack of awareness of services and how to get them, cultural factors which lead to hesitance to use formal services, and language barriers faced primarily by Hispanic and Asian older adults.

Methods

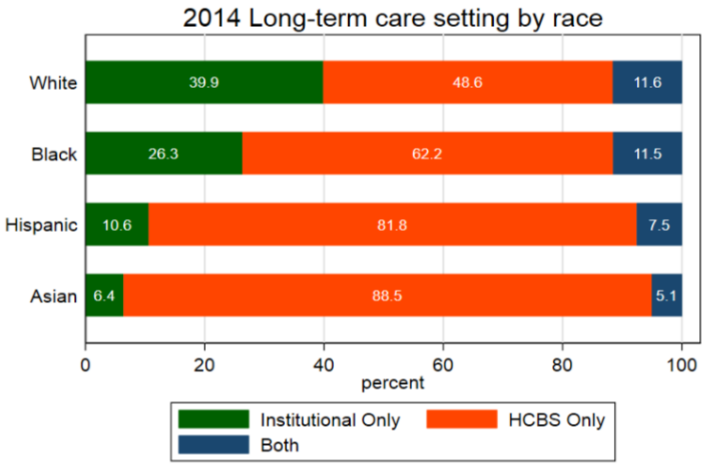
The process for this literature review involved a scan of databases for relevant literature related to LTSS and the population groups of interest, as well as the targeted outreach to and investigation of the websites of relevant advocacy groups. Promising programs were identified from existing lists of innovative HCBS programs as well as via general web searches and from the sites of relevant advocacy organizations. The identified relevant literature was then examined in detail in order to identify key findings, which are summarized in this document. A full list of the literature and programs identified can be found in the **Appendix**.

HCBS Utilization Among Diverse Communities

In order to address the HCBS needs of diverse communities, we need to understand the unique trends in these communities' utilization of HCBS and LTSS in general. Much of the prior research on racial disparities in LTSS have focused on nursing home care or Medicare home health rather than HCBS, in part due to the variation in HCBS service provision across states. Furthermore, studies of the utilization of HCBS/home health care among different racial/ethnic groups have often produced inconsistent results depending on the data used (Fabius et al 2019).

Utilization of HCBS Verses Institutional Care

There are some clear trends which emerge when comparing the relative rates of utilization of HCBS compared to institutional care. Of those receiving LTSS, Black and Hispanic individuals have historically utilized HCBS at higher rates and institutional care at lower rates compared to non-Hispanic White individuals. A 2019 study of Medicaid and Medicare claims data from 2012 found that among elderly LTSS users who are dually eligible for Medicare and Medicaid, Asian, Hispanic, and Black individuals all receive a higher proportion of their paid services via HCBS only compared to White individuals; 48.6% of White LTSS users received only HCBS in 2012, compared to 62.2% of Black LTSS users, 81.8% of Hispanic LTSS users, and 88.5% of Asian LTSS users (Gorges et al 2019).



Data source: 2014 MAX, elderly, duals. Adjusted for age and sex.

Informal Care

Among those who receive care at home, minorities have been found to utilize unpaid, informal care from family and friends more and formal care less compared to Whites. These differences may be due to different cultural values around caregiving, differences in health needs, economic factors, awareness of the availability of formal care, or whether individuals live with or near informal caregivers (Kirby and Lau 2010). A 2001 AARP survey found that Asian, Black, and Hispanic respondents were all more likely to have three generations or other extended family living in a household than White respondents (Pandya 2005). One paper from 2010 sought to determine whether older adults living in communities with a high proportion sharing their racial/ethnic background would be more likely to utilize home care, either formal or informal, compared to older adults living in communities with a lower proportion of others sharing their race.

Communities with a high proportion of a specific racial/ethnic group may be more likely to have an accessible supply of home care providers who specialize in meeting the needs of older adults of that race/ethnicity. Black and Hispanic older adults had worse health, were more likely to have indicators of cognitive impairment, and were less likely to have private supplemental insurance compared to White older adults. Black older adults were more likely than White older adults to live alone, while more Asian and Hispanic older adults lived with their adult children. No differences were found for formal home health care, but Asian and Hispanic older adults living in block groups with ≥25 percent of residents being Asian or Hispanic, respectively, were more likely to use informal home health care than their counterparts in other block groups. This relationship was not seen for White or Black older adults using informal care. This may be because Hispanics and Asian older adults face different barriers to care than Black older adults, specifically language barriers and immigration/citizenship status (Kirby and Lau 2010).

Paid HCBS

Some studies have also investigated patterns of specific service usage within paid HCBS, although there is not yet evidence of clear, consistent trends. One 2006 study using data from the 1994 Second Longitudinal Study of Aging to investigate patterns in the use of different HCBS services from any source by Black, Hispanic, and White men and women, without controlling for level of need. Although they were not more likely to use paid services, among those who did, Black HCBS users used the largest number of different services, followed by Hispanics, then Whites. Compared to White women, Black women had higher odds of using Personal Care Aides, Transportation, Adult Day Centers, and Information and Referral services. Hispanic women had higher odds of using Adult Day Centers and Transportation services. Hispanic men were more likely to use homemaker services. White men were less likely to use Personal Care Aides, Senior Centers, and Transportation than White women. Some of these differences in utilization may be due to the fact that minority respondents were more likely to be dually eligible for Medicare and Medicaid and Black women were more likely to have three or more Activities of Daily Living (ADL) impairments than were individuals in other groups, both of which were traits associated with higher levels of service use (Laditka et al. 2006).

Dually eligible Black HCBS users with multiple sclerosis were less likely than their White counterparts to use case management, equipment, technology, and modification services, and nursing services.

Another study of adults with multiple sclerosis who are dually eligible for Medicare and Medicaid examined disparities in the utilization of specific Medicaid HCBS services based on claims data. After controlling for age, sex, comorbidities, state, and months of eligibility, Black HCBS users were less likely than White HCBS users to use case management, equipment, technology, and modification services, and nursing services. The study also found differences in expenditure by race for equipment, technology, and modifications, non-emergency transportation, participant direction, and total expenditures, with White users having higher expenditures compared to Black users. Notably, Black men had the highest rates of mobility impairment, which is typically associated with greater need for HCBS. Several of these findings align with those of previous studies, one of which found that Black HCBS recipients who wanted more control over home care workers were likely to prefer a cash and counseling or negotiated care management model over more traditional care management services. The disparity in the equipment, technology, and modification services category may also be due to the fact that the majority of spending in this category was on home modifications, and Black HCBS recipients may be more likely to be living in apartments, which are more likely to have been built with wheelchair accessibility, and are less likely to be homeowners, meaning they may not have the ability to modify their home (Fabius et al 2018).

Paid HCBS Trends Among People with Intellectual/Developmental Disabilities (I/DD)

Overall, Black men had the lowest average HCBS expenditures ($56,088.17), followed by Black women ($56,335.60), and White women ($59,783.15), while White men had the highest total Medicaid HCBS expenditures ($70,002.33).

Racial disparities in formal HCBS service use and expenditures also exist among people with I/DD. A 2004 study showed that Black adults with developmental disabilities are more likely to have unmet needs for services, while another from 1997 showed that they use fewer paid services than White adults. Disparities may be related to insurance status but have been found to still be present even when insurance status is controlled for. Income may be a more important driver, as members of families with higher incomes, which typically also have higher education, could have an advantage in navigating the service system and in identifying unmet needs due to greater knowledge about how to obtain services and ability to advocate for services. Minorities may be less willing to challenge professional opinions regarding service allocations, and language barriers could again be an issue. Although Medicaid eligibility is linked to lower incomes, it could also provide greater access to services (Harrington and Kang 2016).

2013 data from California showed that 24% of people with I/DD did not receive any kind of paid services via Medicaid or other sources, with people in younger age groups receiving less services. All racial and ethnic minority groups were less likely to receive any services compared to White people, and they also had significantly lower expenditures when they did receive services, even when controlling for client need. The difference in expenditures was found to have increased between 2005 and 2013. Individuals with I/DD who were on Medicaid had higher odds of receiving services than those not on Medicaid and also had higher expenditures. Factors which were deemed by the researchers to be “non-allowable” with regard to having an effect on utilization, such as race and gender, were concerningly found to be more than twice as influential on access to services as client need (Harrington and Kang 2016).

Paid HCBS State HCBS Policy and Utilization

In 2013, spending for Hispanic individuals was $4,480 less per person compared to White individuals, while Asian and Pacific Islander individuals spent $2,530 less, Black individuals spent $2,120 less, and other races spent $1,560 less.

Variations in state policy regarding the implementation of HCBS may also play a role in differences in HCBS utilization by race. A second study of adults with multiple sclerosis who were dually eligible for Medicare and Medicaid examined disparities in the context of state HCBS policy, with the hypothesis that the relative priority which states place on HCBS compared to institutional care might influence disparities in HCBS utilization. Using Medicare and Medicaid data, the researchers found that HCBS users in high-priority states were younger and more likely to be male and White; disparities in the percent HCBS utilization between White and Black and Hispanic individuals were in fact greater in states which were classified as placing a high priority on HCBS compared to states in which HCBS was a lower priority. These disparities may be due to differences in the populations covered by high-priority and low-priority states, with high-priority states being more likely to extend services via waivers to groups like technology-dependent children, people with AIDS, people with I/DD, and people living with traumatic brain injuries. Furthermore, Medicaid LTSS expenditures for older adults and the disabled are lower than for younger individuals, such that states serving more young people may serve fewer older adults with higher needs. (Fabius et al. 2019).

Another study based on national survey data found that increased generosity of Medicaid waivers has been found to reduce disparities in unmet need among children with autism spectrum disorder (ASD). About 27% surveyed White children with ASD reported unmet need, compared to about 18% of Black children and 27% of Hispanic children with ASD, and Black children with ASD were more likely to have Medicaid as their primary insurance. The presence of a waiver in a state alone did not have any association with rates of unmet need, but increased waiver generosity was associated with significantly reduced odds of having unmet need for Black children with ASD compared to White children with ASD, although there was no significant association between waiver generosity and unmet need for Hispanic children with ASD. This lack of decrease in disparity for Hispanic children may be because they experience barriers which waiver generosity is less likely to address, such as cultural and language barriers (LaClair et al. 2019).

Health Outcomes

Some studies have also investigated health outcomes for diverse HCBS users, the findings of which parallel some known broader trends in healthcare. In general, White older Americans consistently rate their health more positively than Black, Asian, and Hispanic older adults, even after adjusting for social demographic factors, socioeconomic status, and health factors. Black and Asian adults also consistently report a lower sense of control than White older adults. A study using data from the 2015 NCI-AD survey in Minnesota found that racial/ethnic minority users of publicly funded HCBS reported lower self-rated health and sense of control than White participants. These differences in self-rated health and sense of control remained statistically significant for Asian and Hispanic older adults after controlling for sociodemographic characteristics.

62.5% of Black older adults, 57.69% of Asian older adults, and 55.33% of Hispanic older adults rated their health as poor or fair, compared with 42% of White older adults.

More than 80% of Black and White older adults reported they often felt in control of life, compared with 61.9% of Asian and 72.7% of Hispanic older adults.

While functional impairment was a common explanatory factor for the racial/ethnic differences, and the study did find higher levels of functional impairment among minority older adults compared to White older adults, negative mood and financial strain were mediators for Asian and Hispanic participants, respectively. The notably high disparities seen for Asian participants in this study may be driven in part by the demographics of Minnesota, as about 60% of the Asian older adults who took the survey were low-income, non-English-speaking Hmong refugees. Previous studies have documented a higher prevalence of depressive symptoms and mental distress among immigrant and refugee community-dwelling Asian older adults, including Hmong older adults, coupled with low health literacy and low use of mental health services (Shippee et al. 2020).

Hospitalization Rates and Spending

HCBS users also saw disparities in hospitalization and spending. The previously mentioned 2019 study of 2012 Medicaid claims data for individuals dually eligible for Medicare and Medicaid found that Black HCBS users had the highest rates of hospitalization, followed by White, then Hispanic, then Asian HCBS users. Racial disparities in hospitalizations were exacerbated by the presence of dementia. Overall spending (including spending on both HCBS and hospital care) was highest for White HCBS users, followed by Black, then Hispanic, then Asian HCBS users. However, Black HCBS users led in spending on hospital care, followed by Hispanic HCBS users, then White HCBS users, then Asian HCBS users. This study suggests that the disparities in outcomes which have been documented in nursing homes may persist in HCBS as well. Further research is needed to determine if the observed high rates of hospitalization are driven by access barriers or inadequacy of the offered HCBS services themselves. The authors specifically noted caregiver support as an opportunity to support minority HCBS recipients (Gorges at al. 2019).

Case Study: Access Barriers Among Korean Americans

While it is commonly believed that Asian Americans do not seek outside help due to cultural beliefs around saving face and family responsibility for caregiving for older adults, studies have shown that Korean Americans may be more willing to use formal services than previously believed, leading to a gap in services desired and services received (Casado and Lee 2012). Although one survey in South Korea found that only 19% of older Koreans were willing to enter a long-term care facility, 45% of sampled Korean American older adults in a 2008 study were willing to use a nursing home, with poorer self-perceived health and having someone close to them using a nursing home being associated with increased willingness. The lack of available ethnically oriented nursing homes was a greater barrier to use than willingness (Jang et al. 2008). An early study from 1998 also reported far lower awareness and utilization of HCBS among Korean Americans compared to Whites. However, utilization among those who were aware of services was higher for Koreans than Whites, indicating that lack of awareness was the main barrier to utilization. Additional barriers may include personal pride, hesitance of having outsiders come in, perceived unavailability of the service, and the complexity of bureaucracy.

In a 2012 study, Korean American older adults and their caregivers reported high rates of access barriers for all six HCBS services included in the survey, with the most common barriers reported being knowledge-related; an especially high percentage of caregivers did not know about or did not know how to get respite care, home health care, housekeeping, and transportation. Care recipient refusal was the second most common and reported mainly for respite care, adult day care, and personal care, although caregivers demonstrated little reluctance to use services. System-related barriers, such as complex bureaucracy, were noted for respite care, adult day care, and personal care as well, while eligibility barriers also prevented access to adult day care, personal care, and housekeeping. System-related barriers may be underestimated, as individuals could not report difficulty in accessing services which they were not previously aware of. Access to all types of HCBS was impacted by language and cultural barriers. Notably, those with Medicaid coverage had greater unmet need for respite care compared to those without, despite respite being a key component of HCBS waivers, indicating a serious gap in service delivery (Casado and Lee 2012).

Long-Term Quality Alliance

Long-Term Quality Alliance (LTQA) is a 501(c)3 membership organization aimed at improving outcomes and quality of life for people who need long-term services and supports (LTSS), and their families. LTQA advances person- and family-centered, integrated LTSS through research, education, and advocacy. For more information, visit **ltqa.org.**

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