

# Equity in Home and Community- Based Services (HCBS)

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*A Review of the Literature*

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**COLORADO**  
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## I. Introduction

The Department of Health Care Policy and Financing (HCPF) was afforded the opportunity to research health equity within the population of Health First Colorado (Colorado's Medicaid program) members receiving home and community-based services (HCBS), thanks to funding from [American Rescue Plan Act](#). This project has three parts: (1) this literature review; (2) [a Colorado HCBS equity data analysis](#); and (3) interviews with community groups to dive deeper into barriers and solutions (results are forthcoming). The culmination of all this work will be an HCBS equity implementation plan that features action steps for addressing disparities and how to track disparities over time.

HCPF developed this literature review to identify the existing evidence of health disparities within HCBS. This review also served as a starting point for steps two and three above. Often, people with disabilities are considered a stand-alone population for health equity with little research available on how people with various identities, especially racial/ethnic identities, differ in their access and use of services. This review focuses on race/ethnicity within HCBS but also touches on other populations including LGBTQ+ individuals, American Indian/Alaska Native members and members experiencing housing insecurity, among others.

This literature review is separated into two sections: representation in HCBS and utilization of HCBS. Representation refers to the underlying reasons that certain populations may be less likely to enroll in HCBS, including a lack of awareness of services as well as challenges navigating the health system. When populations are underrepresented in HCBS, people may go without the care they need and for which they are eligible. Less research is available on equity as it pertains to the utilization of HCBS, but this review highlights the research as it exists today. When people underutilize HCBS for which they have been authorized based on needs assessments, their health and quality of life may suffer as a result.

Due to the limited research available on this topic, we included articles about other payers and related services such as Medicare and home health. Whenever possible, these distinctions are noted. Additionally, relevant Health First Colorado information is included in the boxes throughout the text to provide state-specific context for the

reader. Box 1 below offers an overview of HCBS to orient the reader to the services available and how individuals access care in Colorado.

Lastly, to learn more about representation and utilization disparities among HCBS members in Colorado, please refer to HCPF's data analysis [report](#).

**Box 1: What Are Home and Community-Based Services (HCBS) and How Are They Accessed?**

Individuals seeking health care and support for functional limitations and/or disabilities through Health First Colorado must first apply. Individuals have to meet specific financial criteria and meet an institutional level of care regardless of whether or not they prefer to live at home. A high-level overview of criteria is available on HCPF's [website](#). Once enrolled, members have access to supports for functional limitations that they qualify for as well as medical and behavioral health services, just like any Health First Colorado member.

Individuals seeking services for their disability or functional limitation can choose between facility-based services, such as nursing facilities, and home and community-based services (HCBS) which are offered by waivers. Regardless of the setting of care (facility or HCBS), members are part of Health First Colorado's long-term care system, also called "Long-term Services and Supports" or LTSS. In other words, HCBS is a subset of LTSS services within Colorado's broader Health First Colorado program. Other programs for this population, such as the Program of All-Inclusive Care for the Elderly (PACE), also are considered LTSS but are not discussed in this report.

There are currently six adult HCBS waivers and four children's HCBS waivers. [Chart comparisons](#) published on HCPF's website outline the services available, who is eligible, and basic steps in accessing care. Examples of services include personal care, homemaker services, certified nursing assistants, home modifications, respite care, assistive technology, case management, therapeutic services, among many others. Service options vary by waiver even though some services are available across multiple waivers.

At the Case Management Agency, staff conduct a level of care assessment and service planning process with the member and/or caregiver to determine the number of service hours or units that can be authorized. The services outlined go through a Prior Authorization Request (PAR) process and are documented in the service plan. Members can then use up to the amount of care authorized via the PAR on a weekly basis. There are sometimes differences in the quantity of services authorized versus the quantity of services used. Reasons can include challenges in finding providers or other issues, but differences can also be the result of normal variation in utilization, such as not needing as many services one week or having fluctuating needs.

## II. Issues that Impact Representation in HCBS

The extent to which people are aware of and able to navigate enrollment in Health First Colorado HCBS influences whether certain groups are underrepresented in the program. This section will summarize available research on awareness of services, cultural norms and preferences for care, health literacy, and issues of trust and stigma.

### A. Knowing the Options Available for Care

Some individuals may not know that HCBS is an option and, therefore, be less likely to seek support in the first place (see Box 2). A study<sup>i</sup> from 2011 analyzed national survey responses of Medicare enrollees and their caregivers to explore unmet HCBS needs. The most common reason for unmet needs was a reported lack of awareness of HCBS services among caregivers.

#### Box 2: Health First Colorado Outreach Efforts

Health First Colorado relies primarily on case management agencies (CMAs) to outreach communities to make residents aware that they may qualify for HCBS. These outreach strategies vary by region. HCPF conducts limited outreach to individuals who are not yet members, focusing instead on outreach to existing members on topics such as how to use and navigate benefits.

Because a majority of caregiving is unpaid, meaning relatives and friends provide the care,<sup>ii</sup> outreaching families and communities is important, particularly among those who may be less likely to seek support or have awareness of HCBS options. Other reasons include the unavailability, or perceived unavailability, of services and a reluctance to invite outsiders into the home.<sup>iii</sup> Black/African American caregivers were more likely to report not needing services or being unaware of services, which may contribute to greater unmet needs.<sup>iv</sup> This study also found that unmet needs were higher for recipients whose caregivers lacked supplemental supports and for recipients with a higher number of challenges with instrumental activities of daily living (IADLs) and behavioral issues.<sup>v</sup> A more recent study set outside of the United States found that people with lower incomes had less access to information about HCBS.<sup>vi</sup>

How do caregivers and future care recipients find out that HCBS may be an option? Ideally, one referral pathway is through medical providers. However, according to research, medical providers are not consistently having these conversations with individuals and families. A national AARP survey<sup>vii</sup> of adults ages 50 and older found that less than three in 10 caregivers report that a health care provider asked them what they needed to ensure the person they support receives adequate care. Caregivers are very interested in having these conversations, especially those supporting higher acuity individuals.<sup>viii</sup>

Those with lower incomes and education levels were even less likely to have these conversations with providers.<sup>ix</sup> Additionally, some groups were more likely to have an interest in these conversations, including caregivers who feel alone, African American caregivers, LGBTQ+ caregivers, and those caring for someone with memory loss or emotional challenges.<sup>x</sup>

Conversations with and referrals from medical providers may be even less accessible for Medicaid members who are less likely to have a regular source of care or receive preventive visits, which one study found especially impacts Black/African American and Hispanic/Latino Medicaid recipients.<sup>xi</sup>

## **B. Cultural Norms and Preferences**

A majority of people prefer to age in place, meaning they would rather utilize HCBS instead of institutional care.<sup>xii xiii</sup> However, there are some notable ways in which cultural norms can influence decisions about whether families select HCBS care or rely on unpaid care, or some combination of both.

A qualitative study<sup>xiv</sup> of caregiving preferences found that Hispanic/Latino, Asian, and Black/African American families tend to view caregiving as an ingrained part of their culture, so much so that alternative options for care are not even necessarily recognized or considered. Cultures with a more collectivism orientation, such as some Asian cultures, possess a sense of duty when it comes to providing care. The caregiving role is often expected and encouraged depending on gender and hierarchy within a family. In fact, a survey found that Asian and Native Hawaiian/Other Pacific Islander families are nearly twice as likely as the general population to care for elders and are less likely to consider institutional facilities when compared to other racial/ethnic groups.<sup>xv</sup> On the other hand, the qualitative study mentioned above also

found that for people of European and American ethnicity, one's personal responsibility to care for a family member is more of a decision and less a culturally embedded expectation.<sup>xvi</sup>

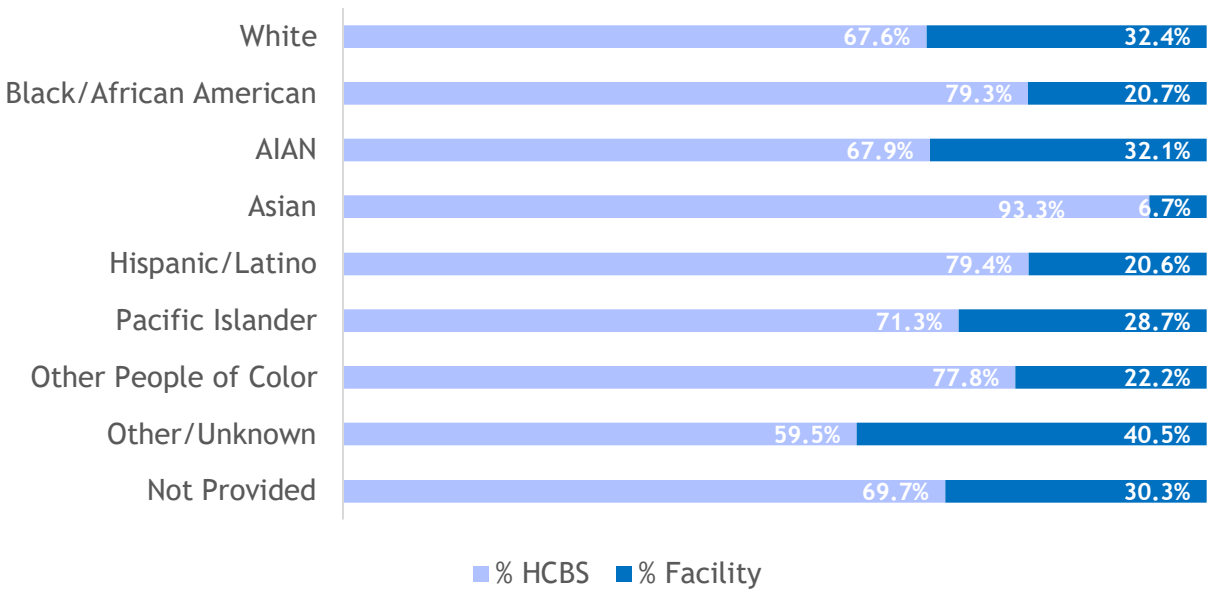
Additionally, whether someone is born in the United States (U.S.) or immigrates here can have an impact on preferences for paid versus unpaid care. One study<sup>xvii</sup> found that individuals residing in the U.S. who were born in other countries, particularly those with stronger family connections, are more likely to prefer unpaid family caregiving rather than individuals born in the U.S. Moreover, the longer an immigrant family lives in the U.S., the less likely they are to exclusively use family care.

To some extent, underrepresentation in Medicaid may be explained by preferences held by certain groups for caregiving. However, it is extremely difficult to tease out these cultural preferences in data as an explanation for why certain groups may be less likely to access services. For example, while it may be the case that caregivers provide unpaid care because they prefer to, it may also be because the providers they want are not available, are not culturally competent, do not realize consumer-directed options are available, or for any other number of reasons.

When looking at Colorado's long-term care population (HCBS recipients as well as members in nursing facilities), most older adults (ages 65+) prefer HCBS over nursing facilities, and some member groups are more likely to use HCBS than others (Figure 1). This is likely a function of preferences but also other factors such as service availability. Asian, Black/African American, and Hispanic/Latino older adults are the most likely to use HCBS over nursing facilities. Alternately, white and American Indian/Alaska Native older adults have higher rates of nursing facility use.

**Figure 1. LTSS Setting of Care by Race/Ethnicity, Ages 65+**

## Percentage of LTSS Members Ages 65+ Who Are Using HCBS Waivers versus Nursing Facilities, Colorado



*Source: Health First Colorado enrollment data, April 2021-March 2022*

*Note: Assisted living is considered HCBS in the graph. Only adults ages 65 and older are included in the graph because this age group is the primary user of facility-based services (i.e., nursing facilities).*

### C. Trust of Health Care Providers and Systems

There are various reasons a care recipient is hesitant or reluctant to enroll in and accept services, particularly in their own home. People in need of services may struggle with feelings of being a burden, a lack of trust in others, and the loss of control and independence.<sup>xviii</sup> Caregivers also may be reluctant to let outsiders into their home to care for their family members.<sup>xix xx</sup>

Additionally, people’s lived experiences matter greatly in terms of their interactions with a health care system impacted by institutional racism and interpersonal discrimination. These experiences and perceptions sow mistrust of medical providers and result in people avoiding care altogether.<sup>xxi xxii</sup> One recent study looked specifically at Black/African American and Hispanic/Latino individuals (this study was not specific to LTSS or Medicaid) and found that their experiences of racism when seeking health care led to lower levels of trust in providers and lower perceived quality of care.<sup>xxiii</sup> There is a substantial amount of research documenting institutional



racism in the health care system. Existing health disparities also influence care decisions families make. For instance, research finds that Black and Hispanic home health patients have less access to high quality agencies than white patients living in the same neighborhoods.<sup>xxiv</sup> Residential segregation may also impact options available to people of color seeking HCBS or nursing facilities.<sup>xxv xxvi</sup>

Trust is also compromised when low-income people experience stigma during health care interactions because of their socioeconomic status and/or health insurance type. The Colorado Health Access Survey found that of adults who reported that they experienced lower levels of respect, 58% said it was due to their income or financial situation.<sup>xxvii</sup> Additionally, Coloradans with public insurance were more likely to report discrimination than those with commercial insurance. A qualitative study featuring Oregon's Medicaid program found that members who experienced stigma from interactions with providers were less likely to rate their health as good or excellent.<sup>xxviii</sup> Negative interactions with providers also can result in members being less likely to seek care in the future.

One Arkansas program<sup>xxix</sup> sought to address trust and HCBS enrollment by increasing awareness of services via community health workers. These workers were members of the same communities they were outreaching to, with the goal of building trust and linking individuals to services. Outcomes indicated that people who engaged with the community health workers were less likely to enter a nursing facility than those who did not.

#### **D. Health Literacy and Support Systems**

Health literacy can impact an individual's ability to understand and use health care services and navigate systems. Income, wealth, and educational attainment are all positively correlated with health literacy,<sup>xxx</sup> and most Medicaid members are low-income. The long-term care system is difficult to navigate for many people, regardless of income or literacy level. One national survey<sup>xxxi</sup> of adults ages 40 to 70 (not Medicaid specific) found that knowledge of long-term care is low. Additionally, more than a quarter of caregivers say it is challenging to coordinate care for those whom they support.<sup>xxxii</sup> Beyond knowledge, the time it takes to navigate the system can be taxing.

However, it is imperative that health systems also are health literate. Organizational health literacy is defined as the “degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”<sup>xxxiii</sup> This distinction means that organizations or systems - like Health First Colorado - have a responsibility to make it easier to access care and to meet the diverse literacy needs of its members.<sup>xxxiv</sup> This might look like reducing lengthy forms and replacing complex language; minimizing the time required to produce documents; streamlining processes; and tailoring outreach and communication to specific communities.<sup>xxxv</sup>

Beyond individual and organizational literacy, social networks and supports can be particularly advantageous for navigating HCBS. Multiple studies find that people who live alone are at a higher risk of nursing home entry than those who live with others.<sup>xxxvi xxxvii xxxviii</sup> People who live alone are also three times more likely to use any HCBS services than people who do not live alone.<sup>xxxix</sup> Other research suggests that there is a lower chance of the HCBS recipient experiencing unmet needs when their caregiver also has support, meaning there is at least someone else to help out.<sup>xl</sup> These social support limitations matter more than ever because the need for caregivers is growing as the supply is diminishing. This means the long-term care system will need to adapt to provide paid caregivers and to provide more culturally diverse care when families are not present.<sup>xli xlii</sup>

### **III. Issues that Impact Utilization in HCBS**

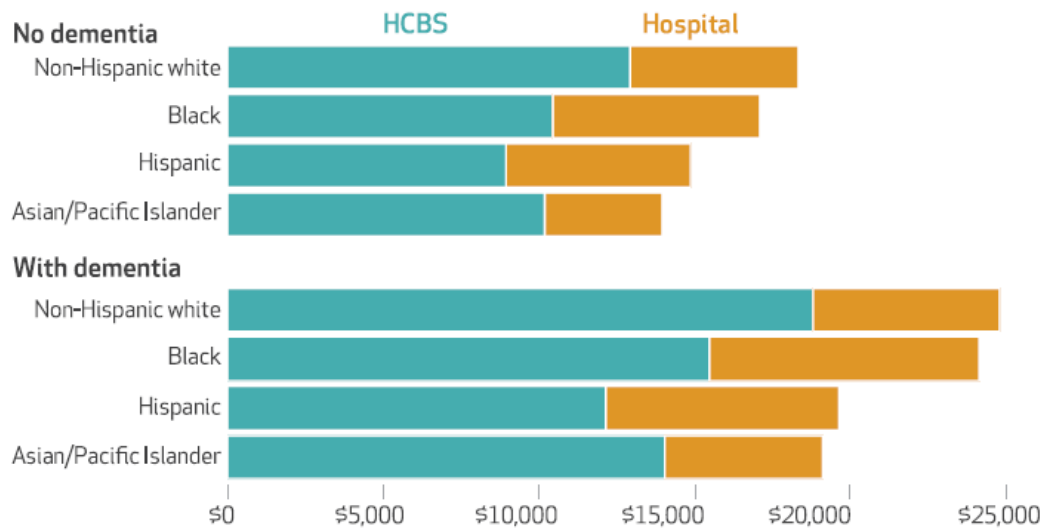
Health First Colorado members’ health and wellbeing can be at risk if they are not approved for the correct type and quantity of services or if they are unable to access those services. Underutilization of services can occur for a number of reasons, including low availability of services and access barriers, which are explored further in this section. While it is expected that there will be some degree of normal fluctuation in service utilization, the focus here is on persistent patterns of underutilization for specific groups of members due to inadequate access to care.

This section first reviews existing research that has explored racial and ethnic disparities in HCBS utilization. Then, it covers issues of prevalence, supply of services, and access barriers for specific populations.

### A. Research on the Underutilization of Services among Older Adults

One national study<sup>xliii</sup> in particular stands out for its analysis of utilization for different racial/ethnic groups with a focus on those who are eligible for both Medicaid and Medicare. Researchers found that people of color were more likely to be enrolled in HCBS than white individuals (who are more represented in institutional settings), but that people of color had lower HCBS spending or utilization (Figure 2). In particular, white individuals had the highest HCBS spending levels, then Black/African American individuals, followed by Asian/Pacific Islander<sup>1</sup> individuals, and lastly, Hispanic/Latino individuals.

**Figure 2. Average HCBS and Hospital Spending by Race/Ethnicity and Dementia Status among Dually Eligible Members in the U.S. (2012)**



Source: *A National Examination of Long-Term Care Setting, Outcomes, and Disparities among Elderly Dual Eligibles* (2019)

Note: This graph is shown as it was published in the academic journal article. HCPF was unable to recreate this figure with data from the article.

This study also found that hospitalization expenditures were greater for people of color - who also used fewer HCBS services - than white individuals, suggesting worse health outcomes. As shown in Figure 2 above, dementia was analyzed as a factor too,

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<sup>1</sup> This term is used by the authors of the report.

showing higher spending or utilization for individuals with dementia, although the relative changes in racial/ethnic disparities remain the same.

This study suggests that people of color may be underserved in HCBS despite being represented more in HCBS as compared to nursing facilities. Moreover, because hospitalization rates are higher for people of color, these disparities in service utilization are not easily explained by hypotheses that people of color may be in better health or have more support. Researchers theorize that disparities could be the result of multiple causes, such as inadequate supply of providers, low-quality providers, or people not obtaining the right amount or type of services.

Another Medicaid HCBS utilization study<sup>xliv</sup> focused on adults with multiple sclerosis (MS) also found that racial disparities exist. The research suggests that Black/African American members, though disproportionately more likely to experience MS, use fewer services than white members, especially case management, nursing services, and home modifications. The precise reasons for these disparities are not definitively known, but researchers suggest that underutilization of home modifications, for instance, could be due to Black/African American individuals having lower rates of homeownership which may limit their eligibility for services.

Finally, a Medicare study<sup>xlv</sup> of adults with Type 2 diabetes who needed home health care found that Black/African American individuals received fewer skilled nursing visits per week and fewer visits of any clinical type combined than white individuals even after controlling for socioeconomic and health variables. Hispanic/Latino individuals were less likely than white individuals to receive physical therapy or home health aide services.

#### **B. Research on the Underutilization of Services for Individuals with IDD**

Disparities in utilization have also been documented for the IDD population. For example, Medicaid-enrolled children with autism spectrum disorder (ASD) who identify as Black/African American, Asian American, or Native American/Pacific Islander<sup>2</sup> are less likely to obtain ASD services than white children.<sup>xlvi</sup> This is despite

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<sup>2</sup> This language is used by the authors of the report.

recent data which suggest trends are changing, and children who do not identify as white have higher rates of ASD.<sup>xlvi</sup> <sup>3</sup>

A study<sup>xlvi</sup> based in California examined IDD community services, including but not limited to Medicaid-funded services, offered at regional centers.<sup>xlvi</sup> Researchers found that people of color and children/youth (ages 3-21) underutilize community-based IDD services after controlling for acuity and Medicaid status when compared to older adults and white individuals. The researchers hypothesized that some groups have less knowledge about the disability system and how to access services, and that some may be less comfortable challenging authority figures (such as providers) to advocate for their needs. They also mention that institutional racism in the areas of housing, education, and financial investments is also likely a factor for why groups that are not white have consistently lower utilization. California now publicly reports these data to track progress on disparity reduction over time.<sup>4</sup>

### **C. Factors that Impact Underutilization**

Many factors contribute to why certain groups may underutilize HCBS services. Below two factors in particular are highlighted: (1) the availability of services, and (2) access barriers for specific populations.

#### **Availability of Services**

An equitable HCBS system must ensure that there are adequate providers available to give members options for selecting care. If there are provider shortages in geographic areas or at certain levels of care that are especially used by certain member groups, then members may struggle to access any services at all or to receive the appropriate amount of services.<sup>li</sup> Moreover, it is important that the right services are available, not just the right quantity. Providers should be culturally competent (see Box 3) to ensure services provided meet the needs of individuals and families.

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<sup>3</sup> Autism spectrum disorder services are covered through Health First Colorado, but children who use these services do not receive them through HCBS waivers. Instead, these services are offered by pediatric behavioral therapy providers.

<sup>4</sup> The ongoing reporting does not appear to control for Medicaid status, age, or acuity.

### Box 3. Specifying What We Mean by “Cultural Competence”

Cultural competence is a widely used term that benefits from a clear definition. The U.S. Department of Health and Human Services Office of Minority Health defines it as “care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.” National standards for culturally and linguistically appropriate services are available [here](#) and include specific examples including, but not limited to, providing language assistance and recruiting a workforce that reflects the patient population. The Office of Minority Health has stated that culturally and linguistic appropriate services can improve the quality care. Competence could also involve disability specific training of health providers.

Rural and frontier communities are particularly at risk of not having access to the community-based long term care services they need as compared with individuals in more urban areas.<sup>lii liii</sup> This disparity may be due to a combination of poorer health and greater functional limitations of rural residents along with factors such as provider shortages and longer distances to travel with limited transportation options.<sup>liv</sup> As “rebalancing” efforts aim to shift services away from institutions, which are more heavily relied upon in rural areas, there must be adequate HCBS replacement options.<sup>lv lvi</sup> One study of Maine older-adult Medicaid members found that rural members had lower rates of HCBS use and higher rates of nursing facility use when compared to urban members.<sup>lvii</sup> Furthermore, these geographic differences could not be fully attributed to member characteristics, such as age; instead, system factors are likely at play including policies that impact the supply or availability of providers.<sup>lviii</sup>

A 2016 Colorado-specific study<sup>lix</sup> examined the availability of respite services and found that caregivers were only able to utilize 22% of the respite hours they had been authorized. Underutilization was particularly influenced by provider shortages in rural communities as well as not enough trained providers for higher acuity individuals. The National Academy for State Health Policy (NASHP) has documented that respite care spending is small for most states, including in Colorado.<sup>lx</sup> Because respite services allow for short-term relief for caregivers, it could be particularly beneficial in rural provider shortage areas as well as for reinforcing culturally competent care for communities that take on a larger share of unpaid caregiving.

Considerations of availability also must include giving members access to the *right* providers. One national survey<sup>lxi</sup> of Hispanic/Latino adults ages 40 and older (not Medicaid specific) found that about 60% of people reported difficulty communicating

with a health provider because of a cultural or language barrier. They felt that this discordance sometimes led to delays in getting care or low-quality care. Beyond language, a portion of this community did not feel confident that providers would understand and meet their cultural needs. For instance, about 30% of Hispanic/Latino people surveyed were concerned about finding providers that could offer the types of food they prefer and others worried that nursing homes would not respect their religious beliefs.

Colorado's participant-directed programs such as Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) - perhaps more than other areas of HCBS - are positioned to increase culturally competent care and health equity.<sup>lxii</sup> This program allows members on various HCBS waivers to hire and manage their own attendants - sometimes with the support of an agency - for personal care, homemaker services, and health maintenance services. Consumer-directed services can be an important Medicaid service offering for members who seek more culturally concordant care, who wish to have greater control over their care, who face barriers finding a provider (e.g., due to inadequate supply), or for those with family members who are already providing uncompensated care.<sup>lxiii</sup> <sup>lxiv</sup> In Connecticut, Medicaid enrollees can specify languages they prefer in job descriptions.<sup>lxv</sup> This is also true in Colorado. In California, researchers found that the option to hire a family member was particularly popular among Asian and Hispanic/Latino Medicaid members.<sup>lxvi</sup> The California study also discovered that people who selected "consumer-direction" with family members were less likely to change their provider, which can help promote continuity of care.

### **Access Barriers for Specific Populations**

Although this report focuses on racial and ethnic disparities among people with disabilities, there are additional ways members identify that are important to acknowledge, particularly because they can compound barriers to receiving care. We briefly highlight these additional identities below to encourage a broader conversation about intersectional identities and how HCPF's future equity plan can be inclusive of them.

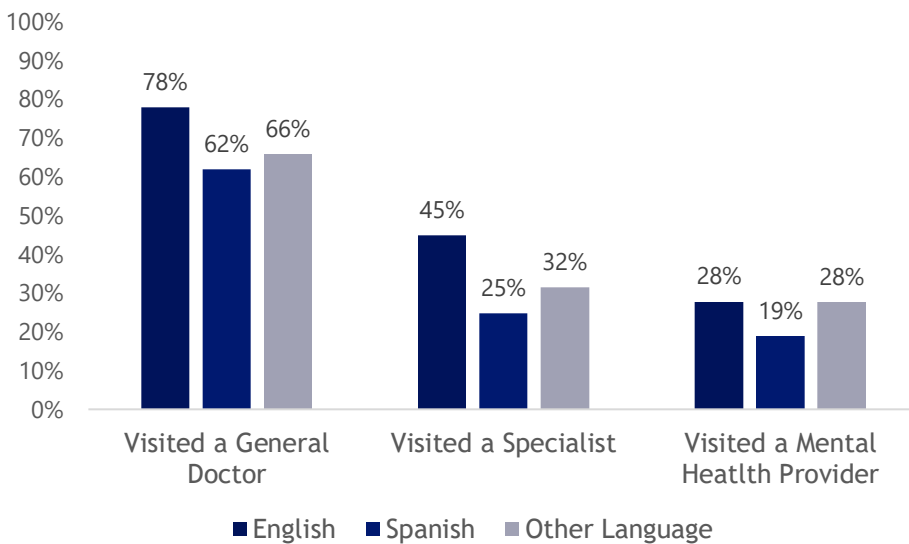
### **People Who Speak Languages Other than English**

When patients and providers do not speak the same language or lack professional translators, quality of care can be negatively impacted.<sup>lxvii</sup> Evidence suggests that

language barriers reduce patient and provider satisfaction, decrease patient understanding of their diagnoses, and increase adverse events that contribute to poor health outcomes.<sup>lxxviii lxxix lxxx lxxxi</sup> For example, one study of children in a hospital setting (not Medicaid-specific) found that when parents were not proficient in speaking English, their children received fewer home health referrals and stayed in the hospital longer.<sup>lxxii</sup> A small, descriptive study in New York found that language concordance, which included the use of translators, occurred a small percentage of the time for home health services.<sup>lxxiii</sup> Additionally, a lack of language concordance and/or translation has been shown to be associated with increased length of hospital stays and higher 30-day readmission rates.<sup>lxxiv</sup>

In Colorado, survey data suggest that people who primarily speak a language other than English at home were less likely to visit a general doctor or specialist.<sup>lxxv</sup> In fact, those who speak Spanish at home were substantially less likely than English speakers to attend an appointment with a general doctor, specialist, or mental health provider.<sup>lxxvi</sup> Figure 3 below is sourced from the Colorado Health Institute’s biannual survey and shows health care access by language for Coloradans (not limited to Health First Colorado).

**Figure 3. Coloradans’ Access to Health Care in the Last 12 Months by Language (2021)**





Source: Colorado Health Institute, Colorado Health Access Survey, 2021.

Note: Graph recreated from the Colorado Health Institutes 2022 research brief, [“Language and Culturally Responsive Care in Colorado”](#)

Federal statute requires that language services are available to anyone with limited English proficiency. However, providers are typically responsible for financing translation and language support services, meaning they are not directly reimbursed for it.<sup>lxxvii</sup> It is possible for state Medicaid programs to reimburse for translation services, but Colorado has not taken this step, which would require a state plan amendment.<sup>lxxviii</sup> In practice, this can mean a lack of or limited formal translation services.<sup>lxxix</sup>

### **Individuals with Disabilities and Behavioral Health Conditions**

Individuals living with IDD are as likely, and potentially more likely, than people living without IDD to have a co-occurring mental health disorder.<sup>lxxx lxxxi</sup> Although limited research has been conducted on mental health within the IDD population, there are multiple hypotheses for why the need is greater. In general, there is a lack of service funding, awareness, and treatment options for mental health conditions experienced by this population.<sup>lxxxii</sup> The experience of adverse psychosocial factors, such as abuse, low social support, stress, and social and economic disadvantages which correlate with depression, and are not unique to this population alone, can also play a role.<sup>lxxxiii</sup>

<sup>lxxxiv</sup>

Despite having potentially greater mental health needs, the IDD population is often poorly served by mental health providers, who tend to lack population-specific training and may focus too heavily on disability while overlooking other health conditions.<sup>lxxxv lxxxvi lxxxvii</sup> People with IDD also are less likely to refer themselves to mental health services, which puts more onus on caregivers to recognize and act on this need.<sup>lxxxviii</sup> Not only might individuals with IDD be underdiagnosed and have access to fewer health care services, but in some instances, they can be over-diagnosed or overprescribed. In particular, individuals with IDD are disproportionately prescribed psychotropic drugs for behavioral issues that may not be necessary.<sup>lxxxix xc</sup> Other evidence suggests Medicaid members with IDD may have greater use of or access to the ED and inpatient hospitalizations than the general population, often driven by unmet behavioral health needs.<sup>xc</sup>

When considering substance use disorders (SUD), there is some evidence that people with disabilities (which in this study<sup>xcii</sup> are defined more broadly than IDD) have higher rates of certain types of SUD. The authors of the study found chronic pain was associated with drug use. Additionally, for non-IDD disabilities, mental distress is higher for people with more ADL limitations than those without.<sup>xciii</sup> In short, addressing behavioral health appropriately is critically important when considering health disparities for people with disabilities.

### **American Indian/Alaska Native Populations**

There is a substantial lack of utilization of HCBS for American Indian and Alaska Native (AIAN) communities, including in Colorado.<sup>xciv xcv</sup> This is despite HCBS being preferred to institutions with native culture's emphasis on caring for elders and relatively high rates of disability. Finding available and high-quality providers that are culturally competent and in close proximity is particularly challenging for AIAN communities that reside on tribal lands.<sup>xcvi xcvii</sup> When HCBS is not locally available, AIAN elders are left with few options, which often include transitioning to far-away nursing home facilities that disconnect them from their community and may not be culturally competent.<sup>xcviii xcix</sup> When long-term care is offered on tribal lands and administered by the tribes themselves, services are more likely to be utilized and to meet individuals' needs.<sup>c</sup> However, this practice is not common.<sup>ci</sup> The Oneida Nation in Wisconsin is one example of a tribe that administers HCBS using a 1915(c) Medicaid waiver, and because services are provided to AIAN individuals, the tribe receives a 100% federal matching rate.<sup>cii</sup> There are two federally recognized Tribes (Ute Mountain Ute and Southern Ute) in Colorado but limited Health First Colorado -funded HCBS services are provided to the individuals who live here. Additionally, approximately 1% of Health First Colorado members identify as AIAN, most of whom do not live on tribal lands. These individuals also encounter barriers to accessing HCBS services.<sup>5</sup>

### **LGBTQ+ Individuals**

Unlike some other states, the state of Colorado and its Health First Colorado program explicitly prohibit discrimination on the basis of gender identity, gender expression,

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<sup>5</sup> Information source is Health First Colorado claims data (April 2021-March 2022) and conversations with community stakeholders in 2023.

and sexual orientation as well as disability.<sup>ciii civ</sup> Despite this protection, LGBTQ+ individuals still face discrimination and negative experiences in accessing health care in Colorado.<sup>cv</sup> For example, LGBTQ+ Health First Colorado members are more likely to report mental health concerns and lack of confidence that they can make medical decisions for their partners.<sup>cvi</sup>

Health First Colorado does not collect information on members' sexual orientation or gender identity, so it is difficult to assess how LGBTQ+ members are utilizing HCBS. More often, this information is exchanged at the provider level, if at all. However, national research and advocates' work generally supports efforts to improve the cultural competency of long-term care staff by instituting more inclusive policies. For example, SAGE and the Human Rights Campaign Foundation have developed a Long-Term Care Equality Index (LEI) which long-term care facilities can use as a self-assessment tool to identify areas to improve LGBTQ+ equity.<sup>cvi</sup> This can be particularly beneficial because research has shown that older LGBTQ+ adults fear discrimination and stigma especially when it comes time to consider their long-term care options.<sup>cvi</sup> LGBTQ+ older adults in need of long-term care may be especially vulnerable to underutilizing services if they do not feel they have safe, inclusive options for care, and they may have fewer social supports and less trust in health providers due to past negative experiences.<sup>cxi cxii</sup> These concerns of discrimination and unfair treatment are also present in HCBS settings. An older Denver study using focus groups found that LGBTQ+ older adults worried their health care worker would be uncomfortable helping them if they had gender affirming surgery, for instance.<sup>cxiii</sup> Others mentioned concerns of isolation and lacking traditional social support with a greater reliance on a combination of friends, partners, and neighbors. Housing concerns also came up, with older LGBTQ+ adults voicing concerns about leaving their neighborhoods and communities to live in residences that may not be LGBTQ+ affirming.

### **People Facing Housing Challenges**

Affordable, accessible, and stable housing remains a barrier for many HCBS enrollees, although it is difficult to provide accurate estimates.<sup>cxiv</sup> Most HCBS is delivered in a home environment, so when housing is unaffordable or inaccessible, one's ability to access and remain in HCBS is at risk. In Colorado, extremely low-income adults are the most likely to be cost-burdened by housing and have the most barriers to finding

an available unit.<sup>cxv</sup> Housing vouchers are limited, as is permanent supportive housing, which can limit options for people with disabilities who seek affordable places to live as well as wrap-around supportive services. (See Box 4 for Colorado-specific information on housing.)

#### **Box 4. Challenges Enrolling Unhoused Members into HCBS**

It is difficult to enroll someone into HCBS if they do not have a place to live. When an individual enrolls, there is a short window of time to connect them to housing supports before services are approved. Finding adequate housing can take much longer. Currently, HCPF does not have a way of tracking individuals who could utilize HCBS services if not for housing barriers identified during the initial enrollment process.

Housing instability is likely even greater for Medicaid members who have a disability and are people of color, due to long-standing systemic racism in housing policy.<sup>cxvi</sup> One adverse outcome of inadequate housing for HCBS enrollees is potentially higher rates of institutionalization. One Medicaid study in California found that individuals with three or more activities of daily living limitations who were also unhoused had more than 400% higher odds of entering a nursing facility.<sup>cxvii</sup> However, it is important to note that per Medicaid policies, housing status is not supposed to be associated with nursing home admission.

Housing challenges can also be considered from the opposite end of the long-term care spectrum, that is, when members are already in institutions either temporarily or longer term. Members entering skilled nursing facilities for a short-term rehabilitation stay can sometimes lose their housing when they end up staying for longer than they expected.<sup>cxviii</sup> It can also be challenging to transition out of nursing facilities back to living in the community when there is a shortage of affordable and accessible housing.<sup>cxix</sup> Landlords and building managers may be less tolerant of people with severe and persistent mental illness, and other housing options may not be accessible to meet the individuals' needs (e.g., no wheel chair ramps).<sup>cxx</sup> Health First Colorado's transitions program and related services is one avenue for assisting members in institutions transition back to the community; however, a shortage of housing options remains a limitation.

It is important to mention that Colorado HCBS does offer home modifications services through several HCBS waivers. Health First Colorado members with physical disabilities have access to up to \$14,000 to modify their home, such as widening

doorways, installing ramps, and more. However, a small percentage of waiver recipients are using this service.

#### IV. Conclusion

HCPF developed this literature review to aggregate the available evidence on health disparities *within* the population of people using HCBS and to better understand the factors that contribute to these disparities. As mentioned throughout this review, HCPF decided to focus on HCBS representation and utilization. Many of the issues that impact representation in Health First Colorado - such as the lack of awareness of services, low trust of health systems, and prior negative experience - are not unique to members with disabilities, but they may impact subgroups differently and contribute to disparate levels of HCBS enrollment. Similarly, reasons for underutilization - such as too few providers or not enough culturally competent providers - may disproportionately impact some members with disabilities than others. Solutions that further equity will need to be both broad and targeted.

HCPF leveraged this literature review to inform a data analysis of representation and utilization among HCBS Health First Colorado members. That [report](#) is available and highlights key findings with a focus on disparities by race/ethnicity, age, language, and geography. Because of data limitations, the data analysis cannot speak to inequities faced by some important HCBS members, such as LGBTQ+ individuals and housing insecure individuals. This literature review fills that gap to some extent, but HCPF recognizes that community engagement will offer the most insight. The results of this project, including feedback from community meetings, will be posted to the HCPF [website](#) as they are completed.

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