



# An Overlooked Workforce

Colorado's Informal Caregivers of Color and  
Policies That Can Support Them

JUNE 2020

# On the evening of July 20, 2019,

Laura\*, a resident of suburban Denver, received a call that changed her life forever.

Laura's mother, who was the caregiver to her stepfather, had survived a massive stroke that would leave her unable to care for herself. Rather than put them in the care of strangers, Laura chose to move back into her California family home to care for her parents.

Jumping into the role of primary caregiver required learning how to care for her mother, who was paralyzed on her right side and unable to walk on her own. Her days consisted of three-hour morning grooming routines along with transfers to and from a wheelchair more than 20 times per day.

Due to the stroke, Laura's mother was unable to communicate using words, so every day was filled with questioning and guessing her mother's needs and desires. During this time, Laura also cared for her stepfather, who required dialysis three days a week and diabetic-approved meals.

Laura's story isn't a unique one. Across the state, many "informal caregivers" like Laura care for their loved ones without formal pay, training, or support.

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*\*Name has been changed to protect privacy.*



## Key Takeaways:

- Communities of color, many of which are growing populations in Colorado, are more likely to offer and use informal caregiving to support their loved ones.
- Informal caregivers who are people of color are less likely to be connected to formal support, making them more likely to experience emotional and financial strains.
- Policymakers should address caregiver needs using tailored, culturally competent approaches in health care systems, community-based organizations, and state legislation and regulation.

## Introduction

As Colorado's population ages, its demand for caregiving is growing. Colorado's population of people 65 years or older is expected to double from 2018 to 2050.<sup>1</sup>

And this population is increasingly diverse. For instance, the Colorado State Demography Office projects an 81% increase in Colorado's Hispanic/Latinx population ages 65 years or older from 2018 to 2030, compared to a projected 42% increase among white (non-Hispanic/Latinx) Coloradans.<sup>2</sup> That means that the number of caregivers and the type of care they provide will need to look different.

Though caregiving brings many benefits — from strengthening relationships to knowing that loved ones are well cared for — it's hard and costly work. Burdens range from loss of wages to poor physical and mental health. And informal caregivers often go without services and supports that could help them avoid these poor outcomes.

Informal caregiving has other costs. In 2017, Colorado's unpaid caregivers provided \$7.8 billion of uncompensated care. That's more than the state's entire education budget for FY 2020-21 (\$6.4 billion).<sup>3</sup> Colorado's Medicaid program, Health First Colorado, covers services for older adults who need formal long-

term care but can't afford it.<sup>4</sup> Informal caregivers help delay or avoid the need for costly formal care for others, but they still face many needs of their own that are not getting addressed.

Because many communities of color are growing in Colorado, and because informal caregiving is more common in many of these communities, policies affecting caregivers should be tailored to these communities' needs. This report analyzes the needs of informal caregivers, especially those from communities of color, and offers potential policy options to address those needs.

Various decision-makers in Colorado can use different approaches to address the needs of informal caregivers — including the growing number of informal caregivers who are people of color:

- **Health care providers** can proactively screen for and address caregiver physical and mental well-being in health care settings.
- Community-based organizations can adopt **evidence-based programs** that provide skill-building and supports such as respite care.
- **State legislators and regulators** can consider policies that reduce financial burden on informal caregivers.

## What Is Informal Caregiving?

Informal caregiving refers to the unpaid support people provide for a family member or loved one. Most informal caregivers are caring for older adults. As opposed to formal caregivers in a skilled nursing facility, informal caregivers can have a long-term commitment to a loved one and are not trained or paid for their support.

There are approximately 600,000 informal caregivers living in Colorado.<sup>5</sup>

Informal caregivers' work can vary in responsibility and intensity.

*Examples of Responsibilities Informal Caregivers Manage:*

- **Buying groceries**
- **Cooking**
- **Doing laundry**
- **Helping care recipient get showered and dressed**
- **Administering medications**
- **Making appointments**
- **Assisting with physical therapy**
- **Talking with doctors and care managers**

# Caregiving in Communities of Color

People of color are more likely than white people to be caregivers. Nationally, more than one in five informal caregivers identifies as Hispanic (21.0%), African American (20.3%), or Asian-American (19.7%), compared to 16.9% who identify as non-Hispanic white (see Figure 1).<sup>6</sup>

Coloradans needing care are becoming more diverse as well. In 2019, more than four in five (83.5%) Coloradans ages 65 and older were white (non-Hispanic/Latinx), compared to 10.7% Hispanic/Latinx, 2.7% Black (non-Hispanic/Latinx) and 2.4% Asian (non-Hispanic/Latinx)<sup>7</sup>. This will look different by 2050, however. State projections estimate the white (non-Hispanic/Latinx) population in older adults will decrease to 72.2%, and people of color will make up 27.8%.<sup>8</sup>

The burdens of caregiving disproportionately impact communities of color. That's partly because informal caregivers in communities of color are more likely to step into their role at an earlier age than white informal caregivers. For example, the average age of a non-Hispanic white caregiver is 52.5 years old, while caregivers of color are significantly younger (see Table 1).<sup>9</sup> African-American caregivers, for instance, are on average 44.2 years old.

This can negatively affect the careers of informal caregivers in communities of color. Starting caregiving at a younger age means these individuals will experience the burdens of caregiving — such as negative health outcomes and financial burdens — for longer than caregivers who start later in life.

## Impact of Caregiving in Communities of Color

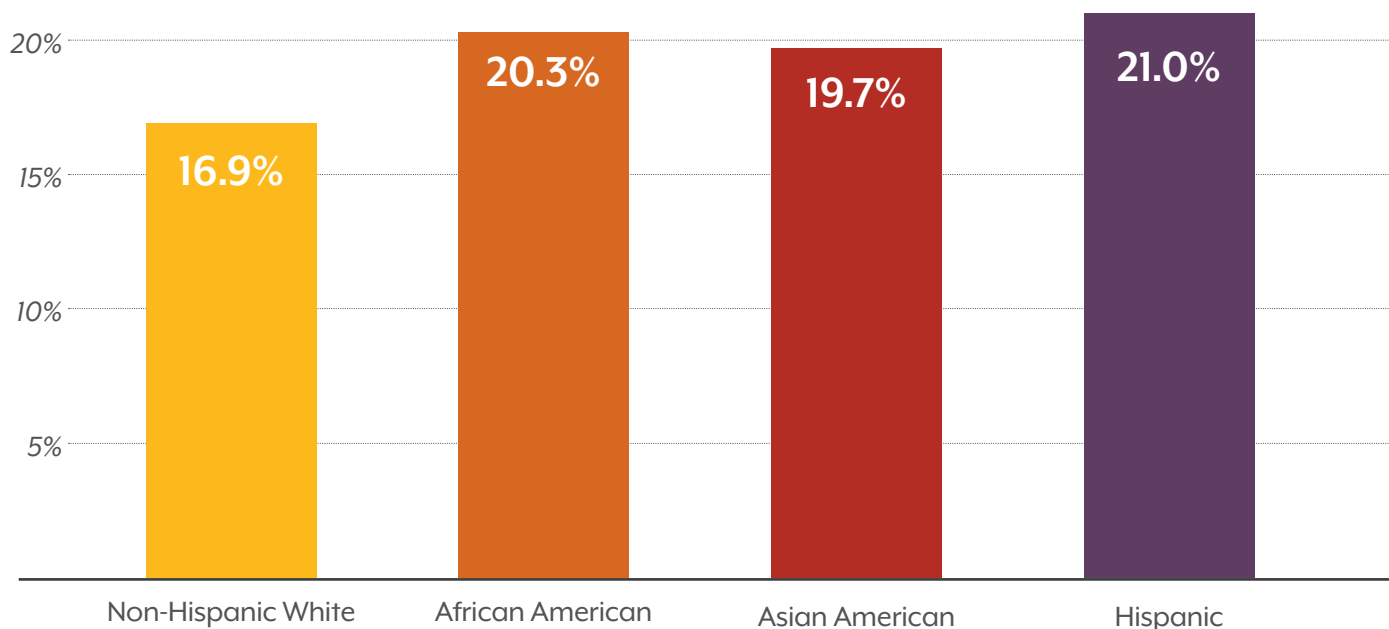
Informal caregiving is more common in many communities of color. That means the challenges of informal caregiving — such as poor health outcomes, a lack of formal support, and financial strain — disproportionately affect these communities.

**Table 1. Average Caregiver Age by Race/Ethnicity**

Race/Ethnicity	Average Caregiver Age (Years)
Non-Hispanic White	52.5
African American	44.2
Asian American	42.7
Hispanic	46.6

Source: National Alliance for Caregiving and the AARP Public Policy Institute, 2015

**Figure 1. Portion of Informal Caregivers Nationally by Race/Ethnicity**



Source: National Alliance for Caregiving and the AARP Public Policy Institute, 2015

## Informal Caregivers Need Health Supports

Informal caregivers need support staying healthy. Many report fair or poor general health. This may be no surprise given the physical demands of caregiving. Informal caregivers may transfer adults in their care multiple times per day, for example from bed to a car to a wheelchair and back again. They help them eat, dress, toilet, bathe, and travel.

People of color are more likely to report fair or poor health compared to the white population. Nationally, only 16.3% of the white (non-Hispanic/Latinx) population report their health is fair or poor, compared to 25.8% of Hispanic/Latinx, 21.2% of Black (non-Hispanic/Latinx), and 10.4% of Asian/Pacific Islanders.<sup>10</sup>

And compared to white caregivers, people of color report even higher burdens on their health due to caregiving. Nationally, around 23% of non-Hispanic white caregivers report their health is fair or poor, compared to 33% of Asian/Pacific Islanders, 31% of non-Hispanic Black/African Americans, and 30% of Hispanic caregivers (see Figure 2).<sup>11</sup>

Caregiving affects mental health, too. For example, informal caregivers are more likely to experience

## How This Report Talks About Race and Ethnicity

*This report uses data and information from a variety of sources. It employs the language used by each source in order to accurately reflect the content of its sources.*

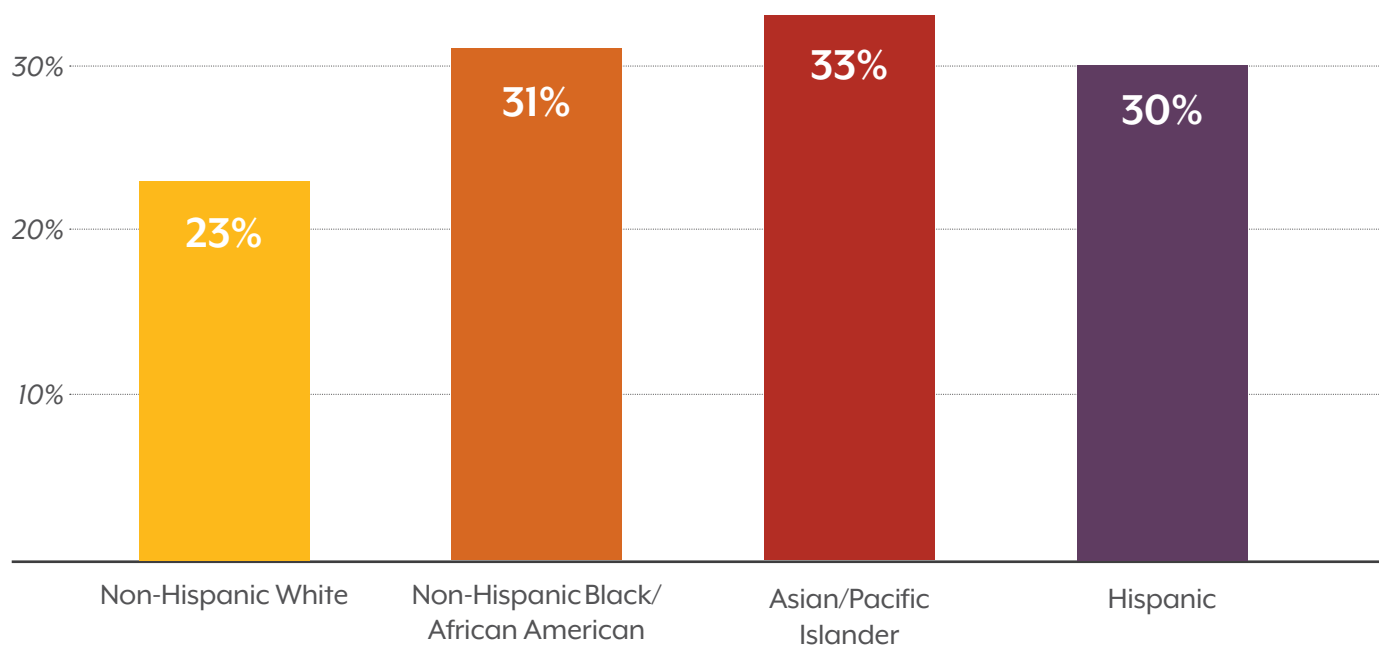
*Different sources use different language to describe different racial/ethnic groups. Such identifications are nuanced, and it is important to be specific when describing data sources.*

*Data on Hispanic and Latinx populations are not interchangeable: “Hispanic” typically refers to people who have Spanish-speaking ancestry, while “Latinx” refers to people with Latin American ancestry.*

*A survey may ask people to self-identify as Black or African American, and people may self-identify as one but not the other.*

depression than the general population.<sup>12</sup> Studies estimate 40-70% of caregivers have clinically significant symptoms of depression, compared to

**Figure 2. Portion of Informal Caregivers Reporting Fair or Poor General Health by Race/Ethnicity**



Source: National Alliance for Caregiving and the AARP Public Policy Institute, 2015



6.7% of the general population.<sup>13,14</sup>

Informal caregivers might not be getting the clinical care they need to address their health — perhaps due to a lack of access to care, stigma, or unwillingness to admit they need support. The underlying barriers to care that communities of color experience might also affect disparate access to care.

For example, findings from the 2019 Colorado Health Access Survey (CHAS) show that 79.2% of Black (non-Hispanic/Latinx) Coloradans have a usual source of care, compared to 87.9% of white (non-Hispanic/Latinx) Coloradans.<sup>15</sup>

Despite these concerning physical and mental health trends, only 16% of informal caregivers say a health care provider has asked them about their own needs while on a visit with the person in their care.<sup>16</sup> Health care providers can address the health needs of informal caregivers, but they may not know how and when to engage with them effectively.

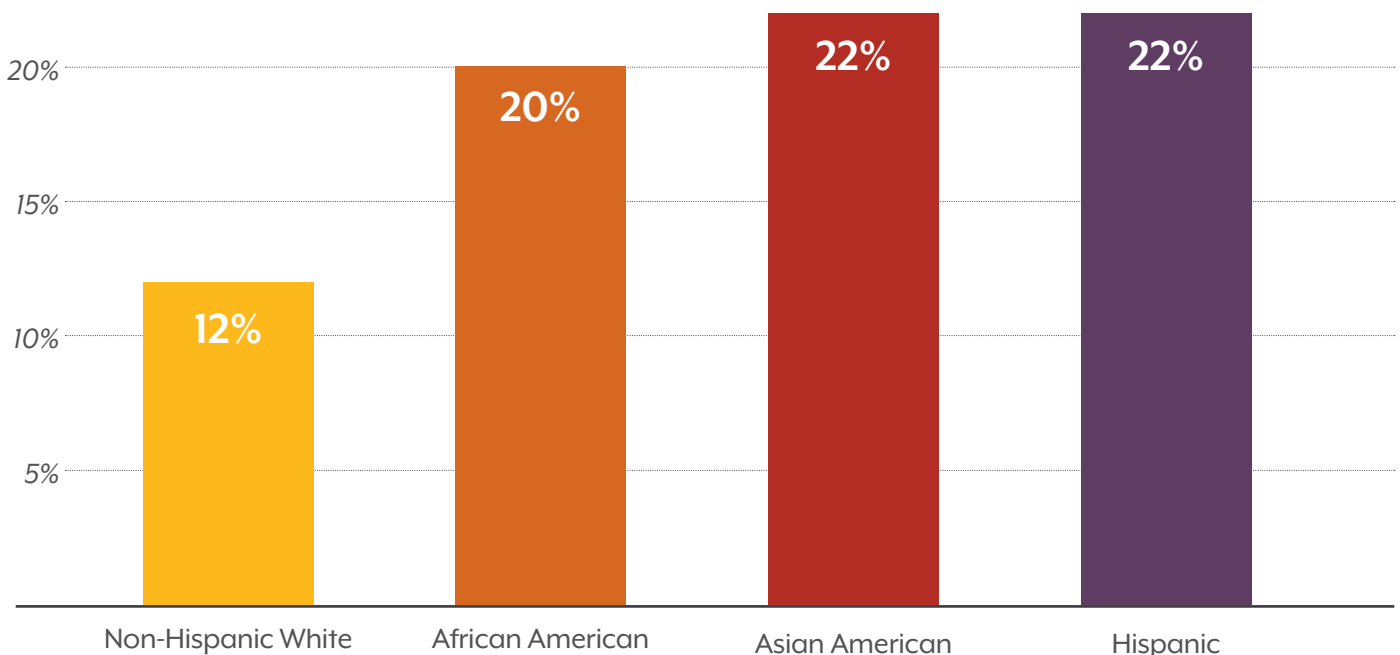
### Informal Caregivers Need Additional Formal Supports

Informal caregivers need formal supports, including respite care, training and education, and support materials available in multiple languages. And these supports should be tailored to the needs of caregivers from communities of color.

Respite care, for example, provides short-term relief for primary caregivers. Caregivers can use respite care to take time for themselves while ensuring the safety of the person in their care. Respite care is especially important for informal caregivers because the amount of time they spend providing care is linked to their self-reported levels of emotional distress.<sup>17</sup>

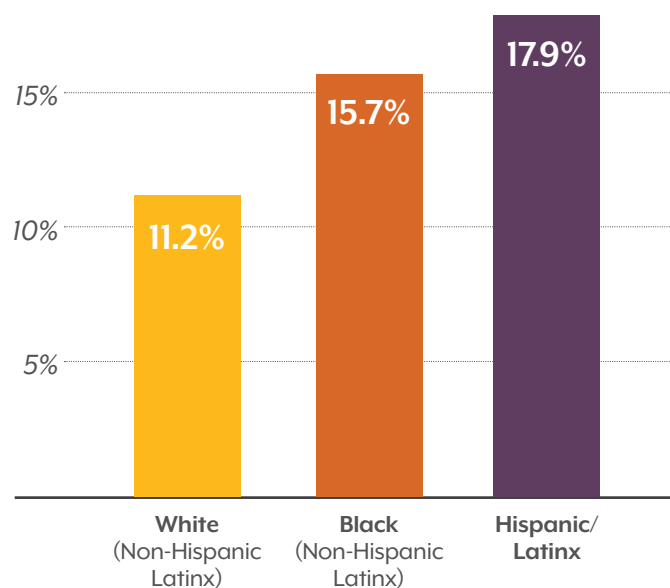
Communities of color are more likely to use respite care services than white caregivers.<sup>18</sup> For instance,

**Figure 3. Portion of Informal Caregivers Using Respite Care Services, by Race/Ethnicity**



Source: National Alliance for Caregiving and the AARP Public Policy Institute, 2015

**Figure 4. Portion of Coloradans Reporting Incomes Below the Federal Poverty Level, by Race/Ethnicity**



Source: 2019 Colorado Health Access Survey

while only 12% of non-Hispanic white caregivers report using respite care services, almost twice as many Hispanic caregivers (22%) report using these supports (see Figure 3).<sup>19</sup>

That said, respite care services are not available at the level many caregivers require. For example, payers including Health First Colorado, the state's Medicaid program, do not reimburse for respite care workers to provide more than seven hours of care in a day. Giving an informal caregiver a "weekend vacation," for example, is impossible in this model.

Coloradans report other barriers to respite care including confusion with Health First Colorado's enrollment waivers, difficulty accessing overnight, facility-based respite care, lack of availability in rural areas, and culturally competent providers.<sup>20</sup>

In addition to needing tailored respite care, informal caregivers also want and need training and education. Many health care providers equip caregivers with materials and instructions for home accommodations to prevent falls, how to manage medications, and trainings on caring for someone with physical or cognitive limitations. But these trainings are not always available in the caregiver's native language.

As Colorado gets more diverse, more caregivers are

requesting materials in a language other than English from health care providers or community-based organizations. Almost one in five (22% of Hispanic caregivers and 19% of Asian-American caregivers) report wanting materials in a language other than English, compared to 1% of non-Hispanic white and African-American caregivers.<sup>21</sup>

## Informal Caregivers Need Financial Supports

Informal caregivers are not paid for their time. Around 60% of caregivers report making some workplace accommodation to continue providing care, such as cutting back on their working hours or taking a leave of absence.<sup>22</sup> If informal caregivers are forgoing paid work, they lose income when providing care, which can create financial strain. It's not only individuals who are affected — communities are also impacted when workers are removed from the labor force.

In addition to foregone earnings, most caregivers incur out-of-pocket costs related to providing care, such as paying for medical care, medications, or housing. In 2016, unpaid caregivers spent almost \$7,000 yearly on out-of-pocket costs to support their loved one.<sup>23</sup>

This financial impact is especially acute among communities of color. There are significant wage disparities between white employees and people of color. For example, people of color are more likely to report incomes below the federal poverty level, or FPL (\$25,750 for a family of four) than white people. According to the 2019 CHAS, 17.9% of Hispanic/Latinx Coloradans reported earning at or below 100% FPL, compared with 11.2% of white (non-Hispanic/Latinx) Coloradans (see Figure 4).<sup>24</sup>

Wage disparities are important because they illustrate the tradeoff informal caregivers face when deciding whether to seek employment to support their families or to forego paid work to stay home and provide care.

While all informal caregivers experience this tradeoff, those in communities of color experience it differently. White caregivers, who are less likely to live in poverty, can more often afford to pay for formal care, making them less likely to forego paid work. But for many informal caregivers in communities of color, paying for care may be more expensive than their daily earnings. This may make them more likely to leave their jobs.

# Policy Considerations

Decision-makers can address needs within health care settings and community-based organizations and through legislative and regulatory action. Policy solutions should be co-created with caregivers and communities of color in order to be responsive to their needs.

## HEALTH SYSTEMS

Health administrators, clinicians, and other decision-makers within health care systems can address poor health outcomes and caregivers’ medical training needs by meeting them where they are — which is often in health care settings where they take their loved ones already receiving care. Potential policies could include implementing caregiver health assessment tools within health care settings and equipping caregivers to provide medical care.

**Policy Consideration: Assess caregiver health needs.**

Health care systems can mitigate negative health outcomes experienced by caregivers by assessing health needs either through caregivers’ appointments or when they bring care recipients in for care. This could mean implementing evidence-based assessment tools to measure mental health



The Rocky Mountain Regional VA Medical Center in Aurora, CO.

burdens specific to caregivers, such as the Tailored Caregiver Assessment and Referral tool. Increasing outreach to caregivers through telehealth also could mitigate negative health outcomes for caregivers by allowing care to happen at home during the caregiver’s “workday” — reducing the need for transportation or other supports, as well as the stigma associated with asking for help. Expanding these tools will require reimbursing health care providers for administering caregiver assessment tools, ensuring caregiver access to broadband and telehealth services, and offering services and assessments in multiple languages.

**Policy Consideration: Ensure caregivers are equipped to provide medical care to loved ones.**

Though caregivers are not medical professionals, they are often called upon to coordinate care for their loved ones and manage medications, injections, and wound care. Health systems can ensure caregivers are included throughout the care process and are also able to deliver care on their own after leaving the hospital. For example, health systems can equip communities of color by providing discharge plans, instruction manuals, and supports they need by providing materials in non-English languages. The CARE (Caregiver Advise, Record, Enable) Act of 2014 puts this best practice into federal law. It requires hospitals to keep the caregiver informed of their loved one’s discharge plans and provide education of post-discharge tasks such as medication management, injections, and wound care.<sup>25</sup>

Some hospitals and health care systems in Colorado, including the VA Eastern Colorado Health Care System, are complying with the CARE Act by, for example, providing comprehensive trainings on post-discharge tasks to informal caregivers of post-9/11 veterans. By integrating caregivers more in the transition from the health care system to their homes, caregivers can feel better prepared and supported to excel in their role providing medical care.



## COMMUNITY-BASED ORGANIZATIONS

Local organizations and leaders can address caregivers' needs by working with community-based organizations such as the Colorado Respite Coalition, community centers, or other service agencies. Potential policy options could include screening for respite care needs and offering workforce development programs.

### **Policy Consideration:**

#### **Screen caregivers for respite care needs.**

Respite care is underused even though it can provide temporary relief to informal caregivers. Community-based organizations and skilled nursing facilities can increase utilization by screening informal caregivers for respite care needs and connecting them to respite care services. A respite care screening should assess where respite care is needed (in home versus out of home), frequency (weekly versus monthly), and length of service (two hours versus eight hours). Organizations like the Colorado Respite Coalition provide a model for the state by improving care access and coordination for those who either do not know about respite care services or cannot find a formal support that meets their family's needs.

### **Policy Consideration: Build reimbursable skills in the caregiver workforce.**

Community-based organizations can empower informal caregivers to be paid to provide care. For example, through Personal Assistance Services of Colorado (PASCO), the Family Caregiver Program started in 2001 to train caregivers to become Certified Nursing Assistants. The program equips otherwise unpaid caregivers with licensure and training necessary to get reimbursed for certain caregiving services. Outreach to caregivers in communities of color can ensure they have the skills to get reimbursed for the care they provide.

Latino Age Wave Colorado ([LAWC](#)) is an example of a workforce development program that trains and reimburses four informal



## Profile of a Conectora

**The Conectoras de Montbello are informal caregivers who have been trained by LAWC to support the well-being of the growing Hispanic/Latinx adult population in their community.**

They work alongside care networks and policy partners to host monthly social activities for Hispanic/Latinx older adults and their family and friends, and to connect older adults to health care providers and local resources. They make warm handoffs between service providers — such as respite and health care workers — and older adults and their caregivers.

The Conectoras model not only supports the well-being of older adults of color in Denver, but it also equips the caregivers of those adults with the skills and resources they need to serve their loved ones. Conectoras are unique in that three of the four live in this community and all four culturally reflect the population they serve.

caregivers in communities of color to provide caregiving services. Policymakers should consider implementing this model in other communities across the state.



## STATE LEGISLATIVE AND REGULATORY ACTIONS

The state's legislators and regulators can address caregivers' financial strain. Sample policies could include expanding the state's long-term services and supports program and the state's definition of paid family medical leave.

### **Policy Consideration: Expand the long-term services and supports (LTSS) program.**

State legislators and regulators can address financial strain that caregivers experience by directing limited resources through Health First Colorado's long-term services and supports (LTSS) program, which currently offers training, counseling, support groups, and respite care. Informal caregivers, especially those within communities of color, experience barriers like cost, geographic availability, and restrictions on the types and amounts of services that are covered when they try to use services like respite care. Because of this, Health First Colorado should consider expanding the types of services that are covered and the amount of time that is reimbursable. Informal caregivers from communities of color are more likely than white caregivers to lack documentation — making them ineligible for Health First Colorado. Policymakers should consider making them eligible for the LTSS program. A tight state budget will make this option difficult in the short-term, but the LTSS program will remain a key component of the state's strategies to care for its aging population.

### **Policy Consideration: Expand the state's definition of "family" used to determine paid family medical leave.**

State legislators and regulators can expand paid family leave for informal caregivers to provide benefits to many working caregivers and their families. In Colorado, that means expanding the definition of "family." Currently, Colorado relies on the federal Family and Medical Leave Act (FMLA) definition, which limits family to a spouse, child, or parent. Policymakers in Colorado could expand the definition to include whomever a caregiver is taking long-term care of. The Family and Medical Leave Insurance (FAMLI) Program, a ballot initiative expected in 2020, would provide an opportunity for policymakers to adopt a new definition of family.<sup>26</sup> Oregon's family medical leave law definition of a family member can serve as a model. It states that "any individual related by blood or affinity whose close association with a covered individual is the equivalent of a family relationship."

Expanding the definition of "family" would likely require employers to allow their staff to take additional family leave. This expansion also would increase state spending on regulating employers. It would help ensure caregivers are getting paid for their time, both at work and with their family. People in communities of color are especially in need of an expanded definition of "family," as they are more likely to take care of extended family.

## Conclusion

Informal caregivers are getting left behind. Compared to the general population, informal caregivers — especially those from communities of color — experience worse health outcomes, a lack of formal support, and financial strain. And often, programs and interventions are not tailored to meet the specific needs of these communities.

Some organizations have started addressing those specific needs. For example, the [Latino Age Wave Colorado](#) trains Conectoras to support the growing Hispanic/Latinx population, and the Colorado Respite Coalition connects caregivers to respite care services.

As the state's population ages, policymakers will need to address the needs of both the growing older adult population and those taking care of them.



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# Endnotes

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# Notes

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