

Uncovering Community-Driven Strategies and Solutions for Increasing Equity in Awareness and Enrollment in Home and Community-Based Services (HCBS)

> June 2023

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Land Acknowledgement

We would like to acknowledge the Indigenous Peoples of what is now Colorado and includes the lands of the Ute, Arapaho, Cheyenne, Diné (di-NAY), Lakota, Apache, Puebloan nations, and many other Tribes. Indigenous communities live today with the trauma of genocide, ethnic cleansing stolen land, and forced removal. We acknowledge a commitment and responsibility to Nation rebuilding, to improving relationships among Nations, and to improving our understanding of Indigenous Peoples, their cultures, and unique contributions in art, language, architecture, and food in our communities.

Participant Acknowledgement

We would like to express our heartfelt gratitude to the organizations and individuals who actively participated in the various aspects of this project. Their valuable insights, contributions, and dedication were instrumental in shaping the design of this project and the findings and recommendations in this report. We extend our thanks to the Colorado Department of Health Care Policy & Financing and the Office of Community Living staff for their continuous support, guidance, and collaboration throughout the process. We are grateful for the passionate providers, agency representatives, advocates, members, and caregivers who attended the Summits and responded to the initial survey. Finally, we are most appreciative of the staff of the community-driven organizations that met with us to share their knowledge and experiences. Their expertise and commitment to realizing equitable outcomes with their communities have been invaluable in achieving our shared goals. We deeply appreciate the time and effort invested by everyone involved and look forward to continued collaboration and success together.

Organization Acknowledgement

<u>Compañeros</u> serves immigrants and families in southwest Colorado.

<u>CREA Results</u> serves the immigrant community in Colorado through their Promotores de Salud model.

<u>Denver Indian Center</u> serves the American Indian and Alaska Native population in the Denver metropolitan area and beyond.

<u>El Grupo Vida</u> serves immigrants with disabilities and their families statewide. <u>Integrated Community | Comunidad Integrada</u> serves the immigrant population primarily in Routt and Moffat counties of northwest Colorado.

<u>It Takes A Village</u> serves people of color, particularly African Americans, in the Denver metropolitan area.

Jewish Family Services serves anyone in need with an emphasis on refugees, older adults, and those with disabilities in Colorado.

La Puente Home, Inc. serves the unhoused, housing insecure, and community members in crisis in the San Luis Valley.

<u>Project Worthmore</u> serves the refugee community in the Denver metropolitan area to foster self-sufficiency and increase quality of life.

<u>Rural Communities Resource Center</u> serves the Northeast Colorado region promoting physical, emotional and economic health.

Southern Colorado Harm Reduction An Overview of HCBS

<u>The Center on Colfax</u> serves LGBTQIA+ community in Denver, Colorado, and the Rocky Mountain Region.

Project Team 🎯

The project was overseen by The Colorado Department of Health Care Policy & Financing and the Office of Community Living and was implemented in partnership with the Civic Consulting Collaborative and **CREA Results.**

- The Colorado Department of Health Care Policy & Financing (HCPF): HCPF oversees and operates Health First Colorado (Colorado's Medicaid program), <u>Child Health Plan Plus</u> (CHP+), and other public health care programs for Coloradans who qualify.
- Office of Community Living (OCL): The goal of OCL is to provide strategic direction on the redesign of all aspects of the long-term services and supports delivery system, including service models, payment structures and data systems to create efficient and person-centered community-based care.
- Civic Consulting Collaborative (Collaborative): The Collaborative is a unique member-owned cooperative of consultants helping navigate challenging social and environmental issues by ensuring community is at the center of systems change. The Collaborative works across a range of issues, including conservation, education, behavioral health, and housing. This project was spearheaded by Amy Engelman, Jack Becker, and Roshan Bliss.
- CREA Results (CREA): CREA is a cultural broker, building the assets of the immigrant community in Colorado by increasing health equity and economic security. Their work is driven by a team of Promotores de Salud/Community Health Workers, passionate cultural and linguistic liaisons that advocate on behalf of the community and build trust among community members and local service agencies. Project participation was led by CEO and Founder, Fernando Pineda-Reyes.

Project Citation:

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Executive Summary 🎯

More than 52,000 Coloradans are enrolled in Medicaid Home and Community-Based Services (HCBS); however, disparities exist with a higher representation of white and English-speaking individuals compared to the general Medicaid population. The ARPA 3.01 HCBS Equity Study conducted by the Colorado Department of Health Care Policy & Financing (HCPF) and the project team aims to identify these disparities, understand their root causes, and develop strategies for greater equity in HCBS through a focus on developing community-driven solutions for greater awareness and enrollment. The project was conducted in partnership with the Civic Consulting Collaborative, CREA Results, and staff from HCPF with the following guiding questions:

- How do people with long-term disabilities become aware of HCBS and get successfully enrolled?
- Why are members in communities of color not enrolling?
- What can HCPF do to encourage communities of color to enroll?

Overview of Engagement

The heart of the HCBS Equity Study focused on engaging external stakeholders to understand the dynamics behind the internal data analysis findings and to develop meaningful solutions for HCPF to more equitably serve members and eligible Coloradans with disabilities. This included a survey, two virtual summits, nine learning exchanges with community-driven organizations, and four key informant interviews. The agency/provider and member/caregiver survey gathered responses from 349 agency and provider respondents and 136 member and caregiver respondents, and more than 200 highly engaged participants attended across the summits. Learning exchanges were conducted with nine trusted community-driven organizations specializing in working with underrepresented populations to foster a mutually beneficial experience. HCPF shared their expertise on HCBS and how the system works and the community-driven organizations shared their expertise on their communities and how to navigate them to greater services to support their health and wellbeing goals. The core questions for the learning exchanges were:

- What level of awareness, if any, do trusted community navigators working with marginalized populations have about HCBS?
- What barriers exist for their population in accessing health services and how do they navigate them?
- How does HCBS fit, or not, with the community's cultural needs and what would need to be in place to be a better fit?
- What would navigators need to know and be able to do to support their community in accessing HCBS and how can HCPF support them in building their capacity?

Overview of Community-Driven Strategies and Solutions for Increasing Equity in Awareness and Enrollment in HCBS

These recommendations are derived from the strategies, ideas, and solutions that stakeholders provided throughout the project and are addressed to HCPF's Office of Community Living (OCL) as recommendations for addressing inequities in HCBS awareness and enrollment.

- Continue to elevate trust and relationship building
 - Utilize its statewide reach to highlight community-driven organizations, develop a community-centered newsletter, and create a memberfacing website to improve information dissemination and promote equitable access to HCBS.
 - Convene collaborative meetings to address specific access and enrollment challenges, facilitate problem-solving, and promote collaboration among RAEs, CMAs, community navigators, and advocates.
 - Facilitate warm handoffs by providing community-driven organizations with up-to-date contact information and introductions for key stakeholders, improving collaboration and support for individuals navigating the system, and developing increased local/regional relationships.
 - Prioritize capacity building through ongoing learning exchanges with navigators and trusted community-driven organizations with populations experiencing the greatest disparities in HCBS. These exchanges should be co-designed for a mutually beneficial exchange of knowledge. Community organizations identified this as a productive venue to invite RAEs, CMAs, and potentially other stakeholders.

Integrate HCBS throughout the system

 Explore opportunities to integrate HCBS more thoroughly within statewide training and certification programs, such as within the desk aid for Certified Application Assistance Sites. Develop HCBS content for training materials, such as recorded webinars on program benefits and enrollment basics for eligible Coloradans.

- Collaborate with RAEs and CMAs to identify additional opportunities and for effective integration across other training and certification programs.
- Prioritize increasing integration of HCBS within government agencies, for example, CDHS manages MINDSOURCE - Colorado's Brain Injury Network - and the Colorado Refugee Services Program, two statewide networks of providers and community organizations and advocates that would benefit from greater knowledge and access to HCBS.
- Partner with community-driven organizations to disseminate HCBS materials effectively, utilizing resource fairs, cultural events, and other platforms to raise awareness and increase enrollment. Offer incentives, training opportunities, and recognition to build strong relationships and lasting capacity in the dissemination process.
- Seize the opportunity presented by new community health worker legislation to capitalize on existing work by HCPF to integrate HCBS into the healthcare system's rulemaking and procedures, aligning with the training and hiring of community health workers. Collaborate with the Colorado Department of Public Health & Environment to incorporate HCBS into their partners' credentialing programs through the Health Navigator Workforce Development Initiative.

• Develop accountability structures with continuous support

- Share local or regional data with demographic breakdowns, support communities in creating targeted outreach plans, and regularly analyze enrollment data to identify barriers and disparities in the enrollment process and ensure effective equity interventions are being implemented. Provide tailored support for Indian and tribal communities.
- Establish requirements for agencies to foster relationships with community-driven organizations, including locating on premises to support enrollment.

- Regularly audit the HCBS process to ensure it is as simple and straightforward as possible to minimize barriers and inequities.
- Ensure all critical documentation is in Spanish and commonly used languages, and that all forms also include a place for preferred name and pronouns and should consider removing sex, if the data isn't used, and move toward gender identity with multiple options, at least nonbinary and/or the option of "other".
- Implement a process for CMAs to prioritize calls and inquiries from community-driven organizations, ensuring timely resolution of complex situations and application status updates.
- Develop a standard agreement or pathway for community-driven organizations to check-in or receive relevant updates without violating HIPAA regulations.
- Ensure consistency in training and competence levels for CMA case managers to provide uniform quality care and support to individuals regardless of the organization or personnel involved.
- Mandate regular training and evaluation for case managers and agency representatives on culturally responsive, person-centered practices, as well as language and cultural justice, including assessments.

Engage users in materials design

 Adopt a co-creation approach, involving the intended audience in developing communication materials with a designer and content expert from HCPF's team in all future efforts. Plan for ongoing engagement, compensation for community members, and that internal staff can lead co-creation processes.

- Adopt a transcreation approach by involving diverse users from the start to create materials that are relevant and accessible to Coloradoans with different languages and cultural backgrounds. Plan for ongoing engagement, compensation for community members, and that internal staff can lead co-creation and transcreation processes.
- Develop user-driven outreach materials for HCBS to increase awareness and support enrollment based on an ongoing set of community-driven design principles which include: being straightforward, emphasizing individual choice, using simple and plain language, and including descriptive visuals. Actionable details, such as points of contact and timelines, should be included to build trust. Design principles should continually guide the development and quality control processes of member-facing materials.
- User-designed materials should prioritize addressing various aspects related to financial eligibility, level of care eligibility, the enrollment process, services and utilization, participant-directed programs, the redetermination process, and the accountability process. Specific recommendations include using exact income thresholds, clarifying eligibility for undocumented individuals, providing clarity on asset limits, ensuring clarity on eligibility criteria for different waivers, and creating a person-centered enrollment process map.

Introduction

More than 52,000 Coloradans are enrolled in Medicaid home and community-based services (HCBS). However, individuals receiving HCBS in Colorado are more likely to be white and English-speaking than the general Medicaid population. The purpose of the American Rescue Plan Act (ARPA) 3.01 Equity Study was for the Colorado Department of Health Care Policy & Financing (HCPF) to identify the disparities within the program, under more about what is driving those disparities, and how to create more equity in HCBS (for more information and regular updates, refer to:

> https://hcpf.colorado.gov/arpa/project-directory/improveaccess-for-underserved-populations/equity-study

The project had three distinct phases:

- 1. Internal data analysis: Department staff developed a report that identifies disparities across the system detailing findings from internal data analysis and literature review.
- 2. External stakeholder feedback and key learnings: Supported by external consultant teams composed of the Civic Consulting Collaborative and CREA Results, the project team conducted stakeholder engagement to illuminate community-driven solutions for the Department to more fully and more equitably serve members and eligible Coloradans with disabilities.
- 3. Project recommendations and implementation plan: This report includes the key learnings and recommendations from the project, which the Office of Community Living within HCPF will use to put together an implementation plan to foster more equity in HCBS.

Phase 1: Internal Data Analysis

Through the ARPA 3.01 Equity Study, the Colorado Department of Health Care Policy & Financing (HCPF) Research and Analysis Team and the Data Analytics Team aimed to identify disparities among populations that may be underrepresented in HCBS and accessing fewer services for which they are authorized. This study began with an internal data <u>analysis</u>, which focused on race/ethnicity, language, age, and geography due to data availability, to identify disparities in HCBS by analyzing Colorado Medicaid data and a <u>literature review</u>. HCPF framed their analysis of the data to examine equity in HCBS through the following levels (see Figure 1):

- 1. Prevalence of disability among the general population
- 2. Enrollment in HCBS programs overall
- 3. Enrollment in specific waivers
- 4. Amount of services authorized for people on waivers
- 5. Amount of services actually utilized
- 6. Outcomes

Figure 1: Guiding Framework for HCBS Equity Analysis

Guiding Logic for Identifying Compounding Disparities in HCBS

In order from outermost ring to innermost:

Prevalence Enrollment in HCBS Enrollment by Waiver Authorized Hours Utilized Hours Outcomes



Source: Health First Colorado. Notes: The Department also utilized the Conceptual Framework of Access to Healthcare developed by <u>Levesque et al, 2013.</u> The National Council on Disability has published a broader <u>equity framework</u> that includes strategies and concepts not included in this diagram, such as requiring disability clinical-care curricula in medical schools.

Disparities have a compounding effect. For example, American Indian/Alaska Native people report higher disability rates in Colorado, but they are under-enrolled in HCBS HCPF decided to focus the majority of the analysis on issues of representation, whether certain populations are under-enrolled in HCBS as compared to overall Medicaid enrollment. The reasons and limitations for this comparison point are described in the <u>report</u>. Some of the findings include (see Tables 1 and 2):

- Hispanic/Latino members are underrepresented in HCBS across all age groups, but this is particularly true for children (ages 0-17);
- Members, whose preferred language is Spanish, are underrepresented across all age groups; and
- Smaller populations, particularly Black, American Indian/Alaska Native, and Native Hawaiian/Other Pacific Islander, are underrepresented in HCBS, for adults but especially children.
- White and Asian populations tend to be overrepresented in HCBS, which means that they are more likely receiving the care they qualify for, though it does not mean that barriers do not exist for these groups as well.

Key findings from this analysis were used to inform decisions about reaching out to community organizations for further information about disparities in representation.



¹HCPF references Census data for disability prevalence and differences by race/ethnicity and age and not using as many of the services for which they are authorized in certain parts of the state.

Table 1: Children HCBS and Medicaid EnrollmentRates by Race/Ethnicity, 2021-2022

Ages 0-17	HCBS	Medicaid Overall
American Indian/Alaska Native	0.4%	0.8%
Black	3.3%	6.9%
Asian	2.7%	2.0%
Hispanic/Latino	12.3%	40.0%
Not Provided	0.6%	0.8%
Other People of Color	5.3%	6.8%
Other/Unknown	24.9%	13.0%
Native Hawaiian/Other Pacific Islander	0.0%	0.4%
White	50.5%	29.4%

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

Table 2: Adult HCBS and Medicaid Enrollment Rates by Race/Ethnicity, 2021-2022

Ages 18+	HCBS	Medicaid Overall
American Indian/Alaska Native	0.6%	1.1%
Black	6.3%	7.0%
Asian	4.5%	2.7%
Hispanic/Latino	15.3%	25.7%
Not Provided	0.5%	0.8%
Other People of Color	2.1%	3.5%
Other/Unknown	15.3%	12.4%
Native Hawaiian/Other Pacific Islander	0.1%	0.3%
White	55.2%	46.6%

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



Phase 2: External Stakeholder Input and Key Learnings

Phase 2 of the HCBS Equity Study focused on engaging external stakeholders to understand the dynamics behind the internal data analysis findings and to develop meaningful solutions for the Department to more equitably serve members and eligible Coloradans with disabilities. The following guiding questions guided this phase:

- How do people with long-term disabilities become aware of HCBS and get successfully enrolled?
 - What are the barriers to awareness, enrollment, and utilization?
 - How do people navigate those barriers?
- Why are members in communities of color not enrolling?
 - Are they aware of HCBS?
 - Are the barriers too insurmountable?
 - Are HCBS communications and programming culturally relevant?
 - What are ways HCPF could remove some of these barriers?

External engagement included four distinct touchpoints:

1. **Agency/Provider and Member/Caregiver Survey:** Engaged with active members of the OCL community through a survey sent out through OCL's listserv (approximately 500 respondents) to solicit input on barriers and solutions to address equity.

2. **Summit 1:** Engaged with active members of the OCL community through a virtual summit (approximately 130 attendees) to share survey results and gain additional input into the approach.

3. Learning Exchanges with Community-Driven Health and Resource Navigation Organizations: Led learning exchanges with nine trusted community-driven organizations and their staff specializing in working with underrepresented populations to achieve greater health and stability

4. **Summit 2:** Held a second virtual summit (approximately 90 attendees) where four learning exchange participants engaged in a facilitated discussion about their equity work for partnership with the HCBS community, and the project team reported on draft recommendations to get broader community input into the recommendations outlined later in this report.

Figure 1: Guiding Framework for HCBS Equity Analysis

Agecey/Provider & Member/Caregiver Survey	Summit 1	Learning Exchanges	Summit 2
 February 2023 Nearly 500 responses Gathered input on HSBS barriers and siolutions for awareness building, enrllemrnt and utiliaztion 	 April 4, 2023 Reported on Equity Study an Survey Hear from attendees to deepen understanding of solutions 	 April - May 2023 Learning exables with nine community-driven organizatins Interviews with additional community-driven organizations and state partners 	 June 6, 2023 Discussion with representatives from learning exchange participants Reach out on project findings, fndings, recommendations and next steps

Agency/Provider and Member/Caregiver Survey Findings & Summit 1 Discussion on Findings

Note: This is a brief summary of findings from the Survey and Summit 1. For the full report, please see HCBS Network Partners' Perceptions, Experiences and Solutions to Inequities within the Program on the <u>project report page</u>.

The purpose of the agency/provider and member/caregiver survey (the survey) was to identify what partners and participants perceive and experience as barriers to learning about, enrolling in, and utilizing HCBS along with potential solutions to remove these barriers. A fifteen question survey adapted to participant type was sent out through the Office of Community Living Stakeholder Newsletter in English and Spanish from January 25, 2023 through February 25, 2023. Four hundred and eighty five responses were gathered, 349 agency and provider respondents and 136 member and caregiver respondents.

In addition to being asked about barriers, respondents were asked about potential solutions. Respondents' ideas fell into four categories:

- Case Management Agency (CMA) Staff Education and Training
- Materials and Communication
- Accessibility & Outreach
- A Robust Awareness and Connection Support System

During a two-hour virtual Summit, approximately 130 attendees discussed the findings and generated priority solutions for removing barriers in accessing HCBS. These additional solutions fell into four categories as well:

- Family Engagement and Support
- Language Access and Communication
- Community Collaboration and Outreach
- System Understanding and Navigation

Additionally, participants discussed what community navigators need to know and be able to do to consistently give effective warm hand-offs of potential HCBS members to the appropriate case management agency. The following is a summary of the suggestions participants provided:

- Clear Communication and Role Clarity
- Education and Support for Navigators
- Streamlined Processes and Coordination

These findings and solutions informed the content and key discussion questions for the Learning Exchanges with community-driven organizations.

Learning Exchanges with Community-Driven Health and Resource Navigation Organizations

The survey data illuminated and Summit 1 confirmed that many members become aware of HCBS through their existing networks - family, friends, and community organizations. They also revealed that many members need extensive support to navigate the enrollment process successfully. Finally, the data suggested that the broader community, beyond the HCBS system and those working in the disability community, have little to no awareness about HCBS. These findings led to the core component of this study - Learning Exchanges with trusted, community-driven organizations that specialize in working with specific underserved populations.

The Rationale for Partnering with Community-Driven Organizations

Identifying with the disability community has a long history of marginalization, and people who identify with additional marginalized groups in terms of race, ethnicity, gender and sexual orientation, for example, often experience compounding barriers to accessing services and supports resulting in the disparities HCPF uncovered in the HCBS enrollment data (see Phase 1: Internal Data Analysis section above). As the survey data from Phase 1 showed (see Agency/Provider and Member/Caregiver Survey section above), many individuals and families who are connected to HCBS got there through relationships with people who were in the system already - friends, family, advocacy groups. But if a community isn't connected to these formal systems, then those individuals are likely to have an even lesser chance of knowing about the program, much less knowing how to navigate its complexity.

The survey data also acknowledged that many organizations that are not formally connected to the disability system are often unaware of HCBS. Thus, this phase of the Equity Study aimed to learn from trusted community organizations that specialize in supporting marginalized populations in connecting them with health services and other related programs. The logic being that the staff in these organizations are expert in their communities, cultures, histories, needs, and opportunities while also having expert language and understanding of how systems, like Medicaid, operate. They hold the social capital in their communities and act as the bridge or broker for their community and systems that have traditionally excluded them, either explicitly or implicitly. Without them to support their communities in navigating a complex system like HCBS, marginalized populations will likely continue to experience disparities in accessing these services.

The Learning Exchange Purpose and Process

The learning exchanges were set up as a two-way communication. HCPF talked about HCBS and how the system works, and the community-driven organizations sharing about how they currently help members and potential members navigate systems and how HCBS might fit within their work. The core questions for the learning exchanges were:

- What level of awareness, if any, do trusted community navigators working with marginalized populations have about HCBS?
- What barriers exist for their population in accessing health services and how do they navigate them?
- How does HCBS fit, or not, with the community's cultural needs and what would need to be in place to be a better fit?
- What would navigators need to know and be able to do to support their community in accessing HCBS and how can HCPF support them in building their capacity?

Initial meetings with leaders of the community organizations assessed how the organization currently works with people with disabilities, their desires to support them better, and their current knowledge of HCBS. This enabled each learning exchange to be tailored to the organization's and community's interests and needs. Learning Exchanges were scheduled for approximately two hours, either virtually or in-person based on what worked best for the organization. Organizations were encouraged to invite all staff who were interested in learning more about resources for people with long-term disabilities. The Civic Consulting Collaborative, CREA Results, and HCPF worked together to develop four segments with bite-sized information and provocative discussion questions:

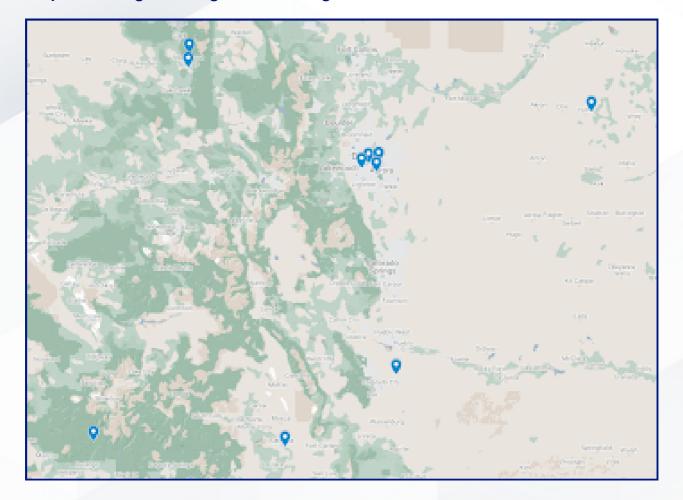
1. An Overview of Medicaid and Long-Term Services and Supports

- 2. Inequities with HCBS
- 3. An Overview of HCBS
- 4. The HCBS System and Navigating Enrollment

The Learning Exchanges took a strength-based approach, assuming all involved held learned and lived expertise in their community, the barriers they face in accessing resources, the strategies they employ to effectively connect them, and their ideas how systems like HCPF can help remove or simplify those barriers. After each section, partner organizations were encouraged to ask questions of the HCPF team to get further clarification, and partner organizations were asked questions that led to robust discussions after each section to understand their perspective on the research questions.

Learning Exchange Partners

Nine Learning Exchanges were conducted with ten organizations focused on health and stability within their communities. Additional one-on-one interviews were also conducted with an organization in southwestern Colorado, Compañeros, as well as with a larger non-profit human services organization, Jewish Family Services. The map below illustrates the geographic diversity of the partner organizations.



Map: Learning Exchange Partner Organizations

In addition to geographic representation, these ten organizations work with diverse populations that are highly marginalized and underserved by traditional systems. Despite having specific priority populations, all organizations are clear about "working with anyone who calls or walks in the door."

- **<u>Compañeros</u>** serves immigrants and families in southwest Colorado.
- <u>CREA Results</u> serves the immigrant community in Colorado through their Promotores de Salud model.
- <u>Denver Indian Center</u> serves the American Indian and Alaska Native population in the Denver metropolitan area and beyond.
- El Grupo Vida serves immigrants with disabilities and their families statewide.
- Integrated Community | Comunidad Integrada serves the immigrant population primarily in Routt and Moffat counties of northwest Colorado.
- <u>It Takes A Village</u> serves people of color, particularly African Americans, in the Denver metropolitan area.
- Jewish Family Services serves anyone in need with an emphasis on refugees, older adults, and those with disabilities in Colorado.
- La Puente Home, Inc. serves the unhoused, housing insecure, and community members in crisis in the San Luis Valley.
- <u>Project Worthmore</u> serves the refugee community in the Denver metropolitan area to foster self-sufficiency and increase quality of life.
- **<u>Rural Communities Resource Center</u>** serves the Northeast Colorado region promoting physical, emotional and economic health.
- Southern Colorado Harm Reduction An Overview of HCBS
- <u>The Center on Colfax</u> serves LGBTQIA+ community in Denver, Colorado, and the Rocky Mountain Region.

The Learning Exchanges engaged staff at all levels of these organizations, from board presidents and executive directors to data analysts to Americorps volunteers and front desk staff. The majority of participants held roles in health and resource navigation and described their positions in diverse ways, including family/community advocates/specialists, case managers, coordinators, directors, peer support specialists, wellness facilitators, peer navigators/coaches/outreach specialists, health promoter, and community health worker.

Two supplemental interviews were conducted with staff from two state programs - HCPF's Certified Application Assistance Site and the Colorado Department of Public Health & Environment's Health Navigator Workforce Development Initiative as these two programs were mentioned as opportunities to further connections and coordination.

How Community-Driven Organizations Champion Health Equity

The learning exchanges illustrated how community-driven organizations currently support people in their communities in navigating complex health care systems to get their needs met, driving health equity in their communities. Their health equity expertise illuminates the opportunities HCPF and its partners have to capitalize on their efforts through increased partnership and investment in these organizations and organizations like them across the state. Of significant note is that while the many participants were hopeful of achieving greater equity in HCBS, numerous community organizations expressed significant concerns regarding the potential ineffectiveness of their proposed solutions, particularly in rural areas, unless the underlying issue of provider availability is addressed. Consequently, it is imperative to tackle the pressing challenges related to provider shortages, turnover, and inadequate compensation simultaneously. Failing to do so risks exacerbating frustration during the enrollment process, which can further erode trust and lead to disengagement among underrepresented communities and their support systems.

Community resource navigation work is highly contextual and nuanced, responding to the unique cultural, regional, economic, linguistic, and logistical circumstances of individuals and communities. Organizations are constantly identifying and problem solving systemic challenges in addition to navigating the impact of generational and current traumatic experiences with systems that their communities face in order to help them access services and support to meet their basic needs, including complex healthcare. These organizations describe themselves as "the place where people show up with lots of questions" because "people feel comfortable coming to [them] to express needs and concerns." These organizations specialize in warm, even hot, handoffs to support their communities in (re)engaging in systems and services that they often mistrust. The following describes the key themes highlighted through the Learning Exchanges of how organizations navigate these complex barriers to champion health equity:

- Authentic, personal relationships grounded in dignity and respect
- Language and cultural justice
- Individualized navigation and support across the social determinants of health
- Strong personal, professional connections with other organizations

Authentic Personal Relationships Grounded in Dignity and Respect

Community resource navigators' work starts from a place of relationship and trust with their community, most often because they are part of that community. They understand that navigating an issue, accessing a resource or scheduling an important meeting is dependent on them establishing, and more often re-establishing, some inkling of trust in a system or agency after years, a lifetime, or generations of marginalization and discrimination. Thus, they are steadfast about their commitment to developing trusting, personal relationships with clients by promoting a culture of dignity, respect, and deep understanding. As one participant shared:

"We help families feel the pain and tell families to trust in me. For families and for us, it is exhausting because people do the same thing over and over again. Things disappear, and it makes it so difficult."

In particular, they ensure authenticity in their relationship building through their focus on staff, space and place, and person-driven interaction.

• Staff. These organizations are community-driven, not just communitybased, because most often, they were developed and continue to be led by people from that particular community or with shared experience. Thus, they recognize the inherent strengths in peer models and support others like them in having the opportunity to contribute to creating better outcomes with their community. This means "hiring staff who look and sound like them" and who have the personal, vested interest in the community and "the struggle."

- **Space and Place.** Community-driven organizations know that the environment matters in whether a person engages with them or not. They create spaces that are culturally validating, celebrating history, icons, and holidays. They offer formal and informal ways to connect with their services as well as offer community building and healing opportunities demonstrating their care and respect for their shared culture, backgrounds, and histories. However, if logistically or psychologically their physical space does not work for a client, they meet them where they are at their homes, on the streets, at work, at a library, on the phone, wherever makes the most sense for the individual. This is particularly true in rural communities as they recognize how significant of a barrier transportation can be.
- **Person-Driven Interaction.** Community-driven organizations provide connection, belonging, resources, referrals, emotional support, and, ultimately, hope through every interaction with clients and their community. They believe that working with people means meeting people where they are, both physically and emotionally. This means, as one participant described it:

"We listen to them about what's going on and let them express their frustration. We hear what they have tried or what they don't want to do through letting them vent. Then, we try to get them to brainstorm about what they are asking for more specifically."

Language and Cultural Justice

Community resource navigators go to great lengths to respond to the unique linguistic and cultural realities in their communities. As one participant shared,

"Language justice is the most important thing you can practice . . . Simultaneous interpretation as part of the culture of running a business and doing work is critical [in our community]."

- Engaging in Cultural Transcreation. For organizations that work with refugees or other newly arrived immigrants, health and healthcare in the U.S. doesn't always have literal translations. This requires a more complex process to help the community make meaning of the English language, terminology, and context. For example, a number of immigrants come from countries that lack certain neurological diagnoses, such as epilepsy, or the concept of mental illness as a treatable disease. Thus, community navigators go far beyond literal translation to develop a conceptual foundation for individuals to make sense of western medical terms and eligibility criteria for many resources, including HCBS
- Educating Agencies and Providers on Working with the Community. Organizations work with agencies and providers to help them understand the unique needs of people from different cultures and countries and more appropriate ways of interacting and engaging with specific medical or systems terms or processes. This includes working to dispel myths and stereotypes. As one participant shared,

"We help agencies support clients, and we dispel myths about Indians getting federal money."

Due to a lack of qualified medical interpreters or resources or out of convenience, several community-driven organizations reported that agencies and providers are inappropriately relying on minors and/or family members to interpret, sometimes breaking critical medical news. Some organizations are working diligently to counsel providers and agencies to not rely on family members, especially minors, to interpret.

• **Combating Stigma through Awareness and Education**. Communitydriven organizations understand that many individuals have cultural barriers of pride, fear of diagnosis, and mistrust of the healthcare system; so, they provide simple, affirming explanations of how services will support their lifestyle and the people they care about. As one participant shared,

"We need to explain the services in a way that is empowering and doesn't victimize."

They help people in marginalized situations, such as formerly incarcerated or experiencing homelessness, understand the opportunities to enroll in programs they are eligible for despite their fears of sharing their information or story or their disbelief that it will help.

Individualized Navigation and Support Across the Social Determinants of Health

Resource navigators engage in complex, multi-system, intersectional navigation processes, going far beyond informational referrals. Grounded in the client's needs and direction, they provide comprehensive hands-on, creative, and relevant support to ensure successful outcomes from their referrals, from initial awareness of a service or program to attending appointments as an advocate.

• **Comprehensive and Holistic Navigation.** Community-driven organizations work with people as whole individuals, recognizing the necessity of supporting them across the social determinants of health, even when it falls outside of their core mission or funding area. They recognize the holistic realities of individuals' lives and the complexities of engaging with care or services when social determinants are not a given. They are responsive and proactive in addressing individuals' and communities' needs, continually assessing what else they should be providing to increase access and equity. This is why they were eager to dedicate time to learn about HCBS - they know there are people with disabilities in their communities and that they could be doing more to support them better, even though people with disabilities are not their core audience. They are part of their larger community and, therefore, should be supported equitably. Similarly, they shared how they have to always stay up to date on immigration policies so as not to put their clients in jeopardy with public charge and other changing immigration regulations. As one participant shared,

"The more we know, the more we're able to help."

- Creative Problem-Solving. Community resource navigators shared that the work requires them to be "knowledgeable, strategic, and creative" because they are confronted with new barriers and new circumstances every day. One example shared was that agricultural workers are paid in cash; yet, they need pay stubs in order to apply for various programs. Navigators work with the employers to produce a suitable pay stub for the application. Another example is how they have computer labs or give people phones or tablets in order to connect to their PEAK accounts and stay on top of their appointments and treatment plans. Organizations provide transportation to appointments or provide services in their home, including purchasing box scanners so that they can bring them with them to scan documents for applications since many agencies do not accept photos. When people are unhoused, they allow them to use their address so that they can apply to services. Navigators go far beyond the extra mile to address any and all barriers to make sure their clients have access to services they need to help them thrive.
- Culturally Relevant Connections. Building relationships and connecting the community with culturally appropriate health providers and information is paramount; thus, these organizations bring culturally relevant speakers and providers to them to learn about various health topics and service providers that are geared towards their communities. For example, they host healing ceremonies. Another organization shared that through their monthly health series, they started a relationship with a health insurance broker to counsel clients on various options through the lens of their community's unique needs and interests. Again, recognizing that relationships are key, organizations are continuously finding ways to connect their community with culturally relevant health providers and information.

Strong Personal, Professional Connections With Other Organizations

Community-driven organizations prioritize cultivating personal and professional relationships, establishing inter-organizational connections, and ensuring trauma-informed referrals. They rely on strong relationships, both formal and informal, to provide effective navigation, support, and safe referrals for their clients, fostering a network of trust and collaboration with other organizations.

• Personal and Professional Relationships. Community-driven organizations cultivate and tend to relationships ongoingly, especially when there is turnover within organizations, to ensure both formal and informal ways of working are established and maintained. One participant described how they often only have an hour or two to successfully help their client get to the person/service they need before the client moves on; and if that person was unsure of the service to begin with, then that's it, they are lost. Thus, they rely on close working relationships to be able to call people directly to support their clients on-demand because that could be all the time they have to get them what they need. These connections enable navigators to help fast-track access, find answers to nuanced situations, follow up on an application, and troubleshoot issues as they arise. As one participant shared:

"We have tangible relationships with people, clients and other organizations, so that I can connect them and be a bridge through the trust I've established. Sometimes that also includes walking alongside people and supporting them, through going to appointments, making phone calls with them, following up with the organization."

- Interorganizational and Agency Connections. Community-driven
 organizations realize their success through their connections. They go to
 great lengths to establish strong relationships, collaboration with
 providers, and ways to work with other community organizations and
 agencies so that they can get to know their various processes for accessing
 services intimately. Sometimes they establish formal collaborative
 agreements to provide translation/interpretation, referrals, or other
 services; however, much of their collaboration is informal, the result of
 strong, trusting, professional relationships that enable warm handoffs.
 Finally, some organizations reported the benefits of hiring staff who
 previously worked at city and county agencies or provider organizations
 and bring with them a wealth of connections and knowledge. These
 navigators come with a ready-made network of personal and professional
 relationships as well as an understanding of the system to share with their
 new colleagues.
- Trauma-Informed Referrals. Recognizing that their clients may have experienced trauma, humiliation, or ridicule due to their social status or life circumstances, community-driven organizations go to great lengths to ensure safe and respectful referrals. They vet providers through research, word of mouth, and online reviews to gauge cultural competence and the quality of care reported by the community. Participants reported scanning an organization's website for look-fors of safety and inclusion, such as a Diversity, Equity and Inclusion statement, or looking at fields on forms and whether they have an option other than male and female or a space to include preferred name and pronouns. Since cultural responsiveness, dignity in the face of stigma, and respect are a driving orientation to their work, they need to know that when they make a referral, their clients will be in good hands, building on the trust they've built with the client and transferring some of that over to the new provider. As detailed in the section above, community-driven organizations provide incredibly nuanced resource navigation in communities throughout the state. Their ability to understand context, build off of trust and relationships, and problem solve, positions them as champions for health equity.

Summit 2

On June 6, 2023, a two-hour virtual Summit was hosted with the intent of engaging those active with HCPF and OCL and some knowledge of LTSS, as well as those who had previously participated during any of the Phase 2 External Stakeholder Engagement. The goal was to achieve the following outcomes:

- Report out on the key learnings of how community-driven organizations champion health equity;
- Illustrate these themes through a fishbowl conversation with Learning Exchange participants; and
- Share draft project recommendations for participant feedback.

Approximately 90 attendees joined, representing a range of roles, including provider, advocate, agency representative, community-driven organization, member, caregiver, and "other" (e.g., elected official, consultant, nonprofit member, state agency employee).

The majority of the time was spent hearing from four community navigators about their work and ideas for partnerships to enhance equity in HCBS. Community navigators from El Grupo Vida, La Puente Home Inc., It Takes A Village, and Denver Indian Center engaged in a robust facilitated discussion. Finally, the project team introduced the four draft recommendations (detailed in Phase 3 below) for participant feedback. Although minimal, overwhelmingly positive feedback was received. Phase 3: Community-Driven Recommendations for HCPF's Implementation Plan

Summary of Recommendations

The following recommendations are derived from the strategies, ideas, and solutions that stakeholders provided throughout Phase 2 of this project (see above), which included nearly 500 survey responses; participation from over 200 providers, agencies, members, advocates, and caregivers across 2 summits; 4 key informant interviews; and the perspectives of approximately 55 staff members from 9 community-driven health and resource navigations organizations during two-hour learning exchanges. These recommendations are addressed to HCPF's Office of Community Living as recommendations for increasing equity in HCBS awareness and enrollment.

A summary of recommendations to HCPF is provided here with detailed recommendations following in the next section.

- Continue to elevate trust and relationship building
 - Utilize HCPF's statewide reach to highlight community-driven organizations, develop a community-centered newsletter, and create a member-facing website to improve information dissemination and promote equitable access to HCBS.
 - Convene collaborative meetings to address specific access and enrollment challenges, facilitate problem-solving, and promote collaboration among RAEs, CMAs, community navigators, and advocates.

- Facilitate warm handoffs by providing community-driven organizations with up-to-date contact information and introductions for key stakeholders, improving collaboration and support for individuals navigating the system, and developing increased local/regional relationships.
- Prioritize capacity building through ongoing learning exchanges with navigators and trusted community-driven organizations with populations experiencing the greatest disparities in HCBS. These exchanges should be co-designed for a mutually beneficial exchange of knowledge. Community organizations identified this as a productive venue to invite RAEs, CMAs, and potentially other stakeholders.

Integrate HCBS throughout the system

- Explore opportunities to integrate HCBS more thoroughly within statewide training and certification programs, such as within the desk aid for Certified Application Assistance Sites. Develop HCBS content for training materials, such as recorded webinars on program benefits and enrollment basics for eligible Coloradans.
- Collaborate with RAEs and CMAs to identify additional opportunities and for effective integration across other training and certification programs.
- Prioritize increasing integration of HCBS within government agencies, for example, CDHS manages MINDSOURCE - Colorado's Brain Injury Network - and the Colorado Refugee Services Program, two statewide networks of providers and community organizations and advocates that would benefit from greater knowledge and access to HCBS.

- Partner with community-driven organizations to disseminate HCBS materials effectively, utilizing resource fairs, cultural events, and other platforms to raise awareness and increase enrollment. Offer incentives, training opportunities, and recognition to build strong relationships and lasting capacity in the dissemination process.
- Seize the opportunity presented by new community health worker legislation to capitalize on existing work by HCPF to integrate HCBS into the healthcare system's rulemaking and procedures, aligning with the training and hiring of community health workers. Collaborate with the Colorado Department of Public Health & Environment to incorporate HCBS into their partners' credentialing programs through the Health Navigator Workforce Development Initiative.

Develop accountability structures with continuous support

- Share local or regional data with demographic breakdowns, support communities in creating targeted outreach plans, and regularly analyze enrollment data to identify barriers and disparities in the enrollment process and ensure effective equity interventions are being implemented. Provide tailored support for Indian and tribal communities.
- Establish requirements for agencies to foster relationships with community-driven organizations, including locating on premises to support enrollment.
- Regularly audit the HCBS process to ensure it is as simple and straightforward as possible to minimize barriers and inequities.

- Ensure all critical documentation is in Spanish and commonly used languages, and that all forms also include a place for preferred name and pronouns and should consider removing sex, if the data isn't used, and move toward gender identity with multiple options, at least nonbinary and/or the option of "other".
- Implement a process for CMAs to prioritize calls and inquiries from community-driven organizations, ensuring timely resolution of complex situations and application status updates.
- Develop a standard agreement or pathway for community-driven organizations to check-in or receive relevant updates without violating HIPAA regulations.
- Ensure consistency in training and competence levels for CMA case managers to provide uniform quality care and support to individuals regardless of the organization or personnel involved.
- Mandate regular training and evaluation for case managers and agency representatives on culturally responsive, person-centered practices, as well as language and cultural justice, including assessments.

• Engage users in materials design

 Adopt a co-creation approach, involving the intended audience in developing communication materials with a designer and content expert from HCPF's team in all future efforts. Plan for ongoing engagement, compensation for community members, and that internal staff can lead co-creation processes.

- Adopt a transcreation approach by involving diverse users from the start to create materials that are relevant and accessible to Coloradoans with different languages and cultural backgrounds. Plan for ongoing engagement, compensation for community members, and that internal staff can lead co-creation and transcreation processes.
- Develop user-driven outreach materials for HCBS to increase awareness and support enrollment based on an ongoing set of community-driven design principles which include: being straightforward, emphasizing individual choice, using simple and plain language, and including descriptive visuals. Actionable details, such as points of contact and timelines, should be included to build trust. Design principles should continually guide the development and quality control processes of member-facing materials.
- User-designed materials should prioritize addressing various aspects related to financial eligibility, level of care eligibility, the enrollment process, services and utilization, participant-directed programs, the redetermination process, and the accountability process. Specific recommendations include using exact income thresholds, clarifying eligibility for undocumented individuals, providing clarity on asset limits, ensuring clarity on eligibility criteria for different waivers, and creating a person-centered enrollment process map. Additionally, guidance on services, such as transportation, alternative medicine, end-of-life planning, participant-directed programs, redetermination processes, and accountability rights and procedures, should be provided to participants.

Detailed Recommendations

Continue to Elevate Trust and Relationship Building.

Acknowledging the overwhelming mistrust of government agencies and systems, including skepticism of traditional engagement, that underrepresented communities hold, participants emphasized the imperative for authentic relationship building to cultivate an awareness and understanding of HCBS that ultimately leads to more equitable enrollment and service utilization. In many ways, the creation of OCL was a critical step in the direction of elevating relationship building and inclusion throughout LTSS.

Although many organizations can point to individual relationships with RAEs and CMAs, a sense of misalignment or being altogether sidelined when it comes to supporting an individual through navigation was the prevailing sentiment. This misalignment was often voiced in terms of mistrust, historical exclusion, or a general lack of awareness and connection. While structures are in place at the county and state levels to ensure basic levels of community engagement and relationship building (e.g., advisory boards, listening sessions and public hearings), navigators shared some skepticism about those being effective avenues for relationship building between system actors and the communities they serve or worthwhile uses of their time.

Thus, building off the Learning Exchanges, continuing to enhance and develop a system-wide culture that values partnership and leverages relationships to drive greater equity is strongly recommended. For this culture to take hold, HCPF will need to articulate and develop specific pathways for new and existing stakeholders to engage. If intentionally designed, HCPF can create a cascade of opportunities to foster trusting partnerships among community-driven organizations, RAEs, and CMAs through four critical avenues, each with a greater emphasis on relationships building leading to meaningful collaboration. With all of this in mind, the following is a list of distinct roles that HCPF can employ and model with other system actors (e.g., RAEs, CMAs) to elevate the importance and value of trust and relationship building:

 Information Provider. HCPF is a powerful information conduit statewide. The agency boasts a large and engaged audience of providers, professionals, members, advocates, and policy-makers, among others. HCPF has a powerful opportunity to highlight community-driven organizations through their email list-serves, social media, and other avenues to raise awareness about their work throughout the system. Through email listservs and its website, HCPF can highlight the importance of community-driven organizations and community resource navigators' work to encourage agencies to partner with them to capitalize on the incredible equity work they do in communities throughout the state.

In addition, HCPF has connections with over 250 organizations across Colorado through their status as a Certified Application Assistance Site (CAAS). This is an untapped resource to get information out about HCBS to support equitable access. Likely, other opportunities for easy communication and connection exist within HCPF to outreach to organizations outside of the HCBS network, including schools, hospitals, nursing homes, and community-driven organizations, with information on HCBS.

While OCL does offer a bi-weeky newsletter, its current format is not an appropriate communication channel for community audiences as much of the information is irrelevant to their work and in language that is inaccessible and meaningless to anyone outside of the system as the few learning exchange participants who had signed up shared. One could hypothesize that members, families, and possibly other advocates may benefit from a tailored outreach and information system. Thus, HCPF or OCL can create a community-centered newsletter that contains the relevant information about program updates and changes that are vital to community organizations. These communications could also focus on specific actions that community-centered audiences can take to support expanding equity within HCBS.

Finally, HCPF's website is unnavigable for members and the community. Many participants across all our engagement identified a navigable, member-facing website as imperative to addressing inequities in access. All audiences engaged in this project, including HCPF staff, consistently noted the difficulties with the existing website, including finding materials to answer questions, identifying a contact to reach out to, or determining what action to take when helping someone. In order to gain trust and begin building relationships with underserved communities, a member-facing website is needed so that people across the state with no- to low-levels of knowledge about Medicaid and the HCBS system can access relevant information and resources.

- Convener. HCPF regularly brings people together for statewide, public meetings to provide updates on new projects and rules to foster transparency. They often offer opportunities for the public to comment or even create public meetings specifically for feedback. To foster more collaboration and collaborative problem solving, HCPF could host convenings where CMA case managers, community navigators, and advocates can bring their current access and enrollment challenges for problem solving with peers and HCPF or to learn about important upcoming transitions.
- Facilitator of Warm Handoffs and Direct Contacts. With knowledge and relationships with county agencies, CMAs, RAEs and other key gatekeepers to Medicaid throughout the state, HCPF can be a go-to resource to ensure that community-driven organizations have the local and up-to-date contact information they need to serve their communities.

Because warm handoffs are so essential for their community members to engage with the system, community-driven organizations need direct contacts and support in building relationships with CMAs. However, the majority of community-driven organizations partners shared having little to no awareness of their regional CMAs and requested HCPF connect them with the appropriate people, so they can begin to do what they do build relationships for warm/hot hand-offs.

HCPF can begin to facilitate these relationships by staffing a phone line for members, potential members, and their support systems to be able to easily and quickly identify their correct, up to date, direct contact and support a warm hand-off themselves. This would be a significant value-add for community-driven organizations working on complex navigation and, likely, for individual members attempting to do it on their own.

• Capacity Builder through Learning Exchanges. Building relationships with navigators and trusted community-driven organizations across the state should be an ongoing commitment of HCPF, one that expands over time to include local CMAs, county agencies, and providers. Learning exchanges can go beyond delivering content or making introductions toward incorporating a sense of codesign and responsiveness to navigators and community-driven organizations. Topics and questions should be designed to foster a mutually beneficial experience. For example, community-driven organizations desired a deeper knowledge of the process so they can provide hot handoffs to CMAs to the extent where they could coach or model the process with clients proactively. These learning exchanges could be a place where agencies and organizations can role play the process, so community organizations can learn the process and agencies can be more prepared to work with new or previously harmed communities more effectively. Whatever the specific content is determined to be through a co-creation process, the long-term goal is fostering relationships and increased understanding and connection across organizations for partnership.

Community groups also called out the potential for more integration and learning exchanges about HCBS with resettlement agencies, Federally Qualified Health Centers, and healthcare providers.

Integrate HCBS throughout Systems

Driving toward greater equity in HCBS enrollment and utilization requires increased awareness, not just in more local communities throughout the state, but within and across government systems. Interactions with several critically positioned state employees and with community-driven organizations suggest a critical shortage of internal awareness about HCBS. As one of the state's largest agencies, HCPF can use its influence to infuse HCBS information and access opportunities more broadly throughout the parts of government that eligible residents are most often in touch with. HCPF can achieve greater awareness through the following pathways:

• Opportunities for More Integration in Statewide Training Programs. HCPF should more intentionally examine state and county run certification and training programs, not just narrowly relating to Medicaid or healthcare, but more broadly within the social determinants of health to identify opportunities to incorporate information about HCBS. For example, some community-driven organizations reported having currently or previously been a Certified Application Assistance Site (CAAS) run through HCPF; however, the certification process is minimal, and HCBS is not part of the brief desk aid training. A full accounting of training and certification programs run through HCPF, RAEs, and CMAs is needed, so resources can be identified to support building partnerships with the agencies and people who run these trainings to identify the materials, connections, and information they need to incorporate HCBS appropriately and effectively, such as a recorded webinar about HCBS and how the program benefits eligible Coloradans with enrollment basics.

- Increasing Integration of HCBS within and across Government Agencies. Equity within HCBS would benefit from HCPF ensuring that more government employees who work on social determinants of health and equity have a basic understanding of HCBS. This could start with a focus on other state agencies to identify opportunities to integrate HCBS information intentionally. For example, CDHS manages MINDSOURCE – Colorado's Brain Injury Network and the Colorado Refugee Services Program, two statewide networks of providers and community organizations and advocates that would benefit from greater knowledge and access to HCBS. Another example would be Colorado Crisis Services, which boasts a central phone number and statewide brick-and-mortar walk-in centers.
- Disseminating HCBS Materials. Partnering with community-driven organizations to promote materials and integrate them into their normal operations can be a significant way to increase awareness and enrollment in underserved communities. Groups shared they would be able to utilize materials at resource fairs and cultural events. Many may be willing to do so even without formal partnerships but would require the information be appropriate and ready for awareness activities. Best practice would ensure that when working with community organizations and partners, dissemination requests come with incentives and resources which could be training opportunities, recognition, and feedback loops that help build relationships and lasting capacity.
- Utilizing Colorado's New Community Health Worker Legislation to Embed HCBS into the System. With the recent passage of new legislation (SB23-002), it is anticipated that a new cadre of community health workers will be hired and trained across the healthcare system, providing a golden opportunity to infuse HCBS into the rulemaking and procedure process that Federally Qualified Health Centers and others must follow when staffing these positions.

HCPF can capitalize on its existing work with the Colorado Department of Public Health & Environment on the <u>Health Navigator Workforce</u> <u>Development Initiative</u> to embed HCBS in their partners' credentialing programs.

Develop Accountability Structures with Continuous Support

Accountability and support systems that help HCPF identify best practices, monitor pain points, and measure progress toward increased enrollment and utilization within HCBS through cultivating awareness and relationships, will help drive toward overall equity and sustainable systems change. Communitydriven organizations reported confronting a mindset from many agencies that there is little time for agencies to conduct engagement with community groups and that they do not have funding for it; thus, it is seen as unpaid work. Shifting this mindset will be critical to achieve greater equity. As detailed in the Specific Content to Highlight section below, community navigators had many questions about the accountability process and specific recommendations for communicating these rights with transparency. To be effective, HCPF would need to develop standards to evaluate partnerships for increased equity to apply internally and externally with RAEs, CMAs, and other partners. Strategies to accomplish this goal could include:

 Model Accountability with Internal Audit of Process. It is commonly acknowledged by all parties that HCBS enrollment is extremely complex. Particularly because of the population that HCBS serves, namely those with cognitive, intellectual, developmental, and behavioral health disabilities, the process should be regularly audited to ensure it is as simple as straightforward as possible to minimize barriers and inequities. Additionally, as culture changes, rules, guidelines, and forms should be updated to reflect the dynamic nature of Colorado's make-up. All critical documentation should be provided in Spanish and other common languages, such as Chinese, German, and Vietnamese.

- **Increased Data Disaggregation and Transparency.** Throughout this project, the HCBS equity data on access disparities surprised no one, including advocates, providers, agencies, community groups, and members; rather, they validated it through their own anecdotes. The hundreds of people who engaged in this project demonstrated a committed interest in addressing inequities as participation in each component was entirely voluntary. They were interested in seeing more specifics from the Internal Data Analysis report (found on the project website); and partners, including community groups, were particularly interested in learning more about the data as it pertains to their local area or specific community so they could prioritize outreach and partnerships. Thus, it would be beneficial for HCPF to share local, or at least regional, data analysis that includes demographics (at minimum ethnicity/race and language) for communities to establish a baseline for their equity work and then support them in developing targeted outreach and engagement plans. Then, HCPF could analyze enrollment and utilization data regularly to assess progress on equity outcomes and provide tailored support to address persistent equity issues. It would be helpful for HCPF to also provide tailored data and support for the Indian and tribal communities. Another area for inquiry would be to understand who is starting the enrollment process and then not completing to understand where people are getting stuck and if there are any disparities within specific points in the process.
- Developing Standards and Evaluation Protocols that Include Equity Outcomes and Community Collaboration. Recognizing that what gets measured is what gets done, HCPF can improve quality control standards, support, and accountability for how RAEs and CMAs support individuals navigating situations where people are being marginalized, such as identifying as transgender, being unhoused or undocumented, holding various immigration statuses, and working in the cash economy. These standards could help drive more equitable outcomes by requiring greater collaboration with

community-driven organizations working with underrepresented populations in their area. This could include:

- Defining requirements for agencies to develop relationships with community-driven organizations, including recommendations to locate on premises regularly to support enrollment.
- Requiring and developing a monitoring system to ensure CMAs have a process in place that prioritizes calls and inquiries from communitydriven organizations to help them solve complex situations or to follow-up on the status of applications quickly.
- Developing a standard agreement or pathway for community-driven organizations to receive basic updates and information when assisting with enrollment that doesn't conflict with HIPAA.
- Ensuring quality control and consistency in the level of training and competence required of CMA case managers so that each individual receives the same high level of care and support no matter the organization or person they engage with during intake or beyond.
- Requiring case managers and other agency representatives who work with community members to be regularly trained and evaluated on culturally responsive, person-centered practices, and on best practices for language and cultural justice, including for assessments.

Engage Users in HCBS Materials Design

HCPF's commitment to increasing awareness and enrollment in HCBS has been ongoing through a separately funded ARPA project, ARPA 3.04. This is in part to be responsive to requests from stakeholders to be included in the creation and review of materials. This final section is directed toward how HCPF should develop materials, and includes process recommendations, design principles, and specific content recommendations as highlighted by stakeholders through this Equity Study.

Process Recommendations: Ensuring Users Are at the Center of Materials Design

HCPF is committed to creating more member-facing and accessible informational materials to promote HCBS with many new materials currently in development. In addition to improving access and availability of materials for members and their families, community organizations and advocacy groups need information that they can use to provide a warm handoff to HCBS case managers. In order to ensure new materials are effective and relevant for diverse communities, people from these communities need to be engaged in the design process to inform the look, feel, content and utility of all materials, electronic and print. As a next step emanating from this Equity Study, a standing group, largely recruited from the Learning Exchanges, was recently launched to inform ongoing HCBS materials creation efforts led by HCPF under ARPA 3.04. The group is called HCBS Materials User Design Group. The purpose of this group is to:

- Refine and finalize design principles to evaluate existing materials and serve as a guide for developing new materials moving forward;
- Provide feedback on existing materials (e.g. LTSS pamphlets, waiver brochures, forms) and where and how they can best be distributed and utilized; and
- Identify gaps in information that needs to be co-created to effectively support members in enrolling in HCBS (e.g. process maps, timelines).

This process and all member or community-facing materials, training and communication development efforts moving forward will be most effective if they include the following best practices:

• **Co-creation.** Effective communication materials are reliant on engaging intended audiences in order to make sure the messages are clear, relevant, and received as intended. The process ensures that the intended audience has the opportunity to work directly with designers and content experts in mutually respectful and authentic ways to:

- Provide feedback on existing materials;
- Identify gaps in information that need to be developed to effectively support the audience in engaging the desired behavior change or action; and
- Develop effective dissemination strategies.

Thus, for ARPA 3.04, a designer and content expert from HCPF's materials design team will be part of the HCBS Materials User Design Group to ensure a seamless, iterative process between the group and the larger design team. HCPF representatives will report back to the User Design Group on how the group's recommendations were incorporated into the updated versions of all materials reviewed or created.

• Transcreation. A large and increasing number of Coloradoans speak and read primarily in languages other than English and come from counties where words, concepts and healthcare are understood differently. To increase equitable access and enrollment, the creation of materials must include diverse users from the start in order to infuse meaning and relevance into the materials creation process in everything from imagery to words to layout. Thus for ARPA 3.04, a subset of the HCBS Materials User Design Group members will be native Spanish speakers in order to ensure the translation of materials uses relevant language, messages, and context. As materials are translated into other languages, engaging native speakers in those languages will be necessary to ensure their relevance and accessibility. The Department will need to plan for this ongoingly, ensure the community is compensated for their expertise, and also that there are internal staff who can lead ,co-creation and transcreation processes.

The Beginnings of Design Principles

Most resource navigators had never heard of HCBS, and all reported being appreciative of learning about the program because of the utility for their community and their desire to better support those in their community with disabilities. They also all requested, throughout the two-hour discussions and in a follow-up survey, outreach materials that they could display or handout to their community. They desired more in-depth, yet still simple, materials that walk people through the process or allow them as navigators to support their community with confidence. Prior to that, survey respondents had identified accessible, standardized materials for HCBS as a solution to increasing awareness of HCBS with underrepresented populations.

The following outlines the beginnings of user driven design principles as well as content for outreach materials to build awareness and guidance materials to support enrollment. This is the starting point for the new HCBS Materials User Design Group taken primarily from Learning Exchange participants as suggestions for designing impactful outreach materials. These included:

- Straightforward" explain how they and those around them will benefit
- "Individual choice" emphasize that they can choose to have all services at their home
- "Simple" break down information into bite-sized pieces
- "Plain language" simplify language (no jargon or acronyms)
- "Descriptive visuals" employ useful pictures/icons instead of words whenever possible, particularly when describing services
- "Actionable" share important, action-oriented details, such as points of contact and a timeline, to build trust

Once the design principles are finalized, any HCPF effort to develop memberfacing materials can use them to guide their design and quality control processes.

Specific Content to Highlight in HCBS Outreach Materials

The Learning Exchanges illuminated a number of common questions that people learning about HCBS have. The following components would be helpful to include in general outreach materials and/or to develop supplemental materials that go into greater depth about each element of the program.

• Financial Eligibility

- Exact income thresholds as opposed to percentages of poverty levels
- Eligibility for people who are undocumented or in the immigration process with the myriad of statuses
- Buy-In programs and ABLE accounts
- Whether CHP+ children are eligible
- Clarity on how parental assets are not included in children's assets
- Whether primary homes and vehicles are included in the asset limits
- How social security eligibility and LTSS eligibility do and do not complement each other
- Group supported employment rules

• Level of Care Eligibility

- The specific criteria to qualify as a long-term disability inability to perform activities of daily living, length of time impaired, or others
- A list of diagnoses that qualify a person for each waiver, especially for mental health
- Documents needed to prove eligibility

• The Enrollment Process

 A person-centered process map - how to start the process, where to go, who to call, what documents are needed, how long each step should take, and how to follow-up when they haven't heard back.
 Emphasize that:

- People only apply once for all 10 waivers
- Financial and level of care eligibility processes happen concurrently
- Several different versions of the path that a "typical" HCBS user might take from their initial diagnosis, onset, or accident to finally getting into services
- Which waiver has a waitlist and what the alternatives are while waiting
- Emergency enrollment criteria and process
- Guidance on contacts to reach out to

Services and Utilization

- Use transportation to regular appointments or community events as an example of a easily utilized service that meets the 30 day requirement
- Approved alternative medicine approaches
- Whether end of life planning is a covered service

Participant-Directed Programs

- Benefits and process, including how people get the money and how the authorized representative supports managing it so as not to get taken advantage of
- Who delegates the authorized representative if the individual is unable
- Whether people who are undocumented can be a CDASS provider

The Redetermination Process

• The rationale, timeline and process, especially if the person has a chronic disability, to build trust and breakdown stigma

• The Accountability Process

- What are people's rights in this process?
- Where do people go when the process isn't working with their CMA?
- How do you identify if problems are a removable barrier, a systems issue, or an individual person?
- What if a person runs into barriers and gets stuck at intake before they get a case manager?
- What are the timelines for getting updated information and responses, including complaints?

HCPF Implementation Plan

As a next step, the Department of Health Care Policy & Financing will develop an implementation plan that details the Department's efforts in collaboration with other agencies, organizations, or stakeholders to utilize the key ARPA 3.01 project recommendations and learnings. The implementation plan will outline potential projects and further areas of inquiry to increase equity in HCBS based on the recommendations in this report. The plan will address strategies, potential funding sources (if needed), partners involved, and timelines for potential projects. HCPF will work with the broader community to present and vet project ideas.

People who are interested in following or contributing to this work can stay connected via the project website at <u>https://hcpf.colorado.gov/arpa/project-directory/improve-access-for-underserved-populations/equity-study</u>. The website contains all project materials, reports, and presentations.

Appendix: Community-Driven Policy Solutions

As mentioned above, numerous survey and learning exchange participants expressed significant concerns regarding the potential ineffectiveness of their proposed solutions, especially in rural areas, unless the underlying issue of provider availability is addressed. Consequently, it is imperative to tackle the pressing challenges related to provider shortages, turnover, and inadequate compensation simultaneously. Failing to do so risks exacerbating frustration during the enrollment process, which can further erode trust and lead to disengagement among underrepresented communities and their support systems. The following represents the suggested policy solutions participants would like to see to ensure equitable awareness and enrollment leads to equitable and quality utilization and outcomes.

- Increase home care provider pay to a liveable wage, and minimum of \$18/hour to create and maintain the workforce as well as enable caregivers to fill these roles.
- Increase income limits to \$2,200-2,500/month so that Social Security Insurance benefits do not affect eligibility.
- Increase income limits for working families.
- Support county offices in relocating near public transportation to improve physical access to locations.
- Develop and support the pipeline of CMA providers to minimize turnover.
- Develop and support the pipeline of Spanish speaking healthcare providers.
- Ensure RAEs and CMAs are supporting people transitioning from shelters to find stable housing.

- Include safe housing support and benefits as a HCBS service option so that unhoused people can utilize HCBS.
- Address barriers for people who are undocumented using Oregon and California as models.
- Pass funding from Medicaid to community-driven organizations to support eligible member HCBS access and support for enrollment and service utilization.

¹HCPF references Census data for disability prevalence and differences by race/ethnicity and age.