Civic Consulting Collaborative

June 2023

Home and Community-Based Services (HCBS)

Network Partners' Perceptions, Experiences and Solutions to Inequities within the Program

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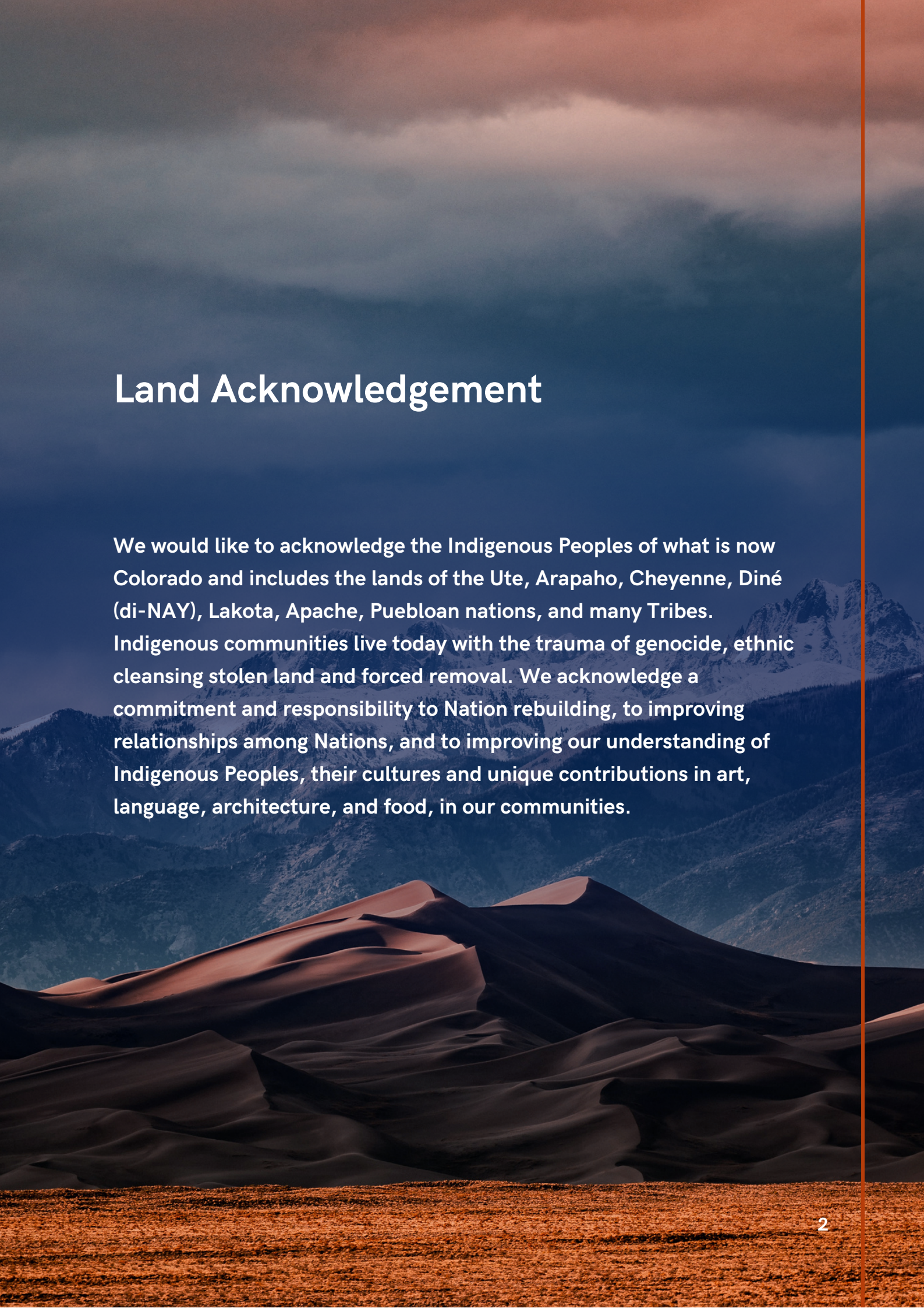


Land Acknowledgement

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 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.

Project Team

The Project team was overseen by The Colorado Department of Health Care Policy & Financing, Office of Community Living, implemented by the Civic Consulting Collaborative with partner CREA Results.

- **The Colorado Department of Health Care Policy & Financing (HCPF):** HCPF oversees and operates Health First Colorado (Colorado's Medicaid program), Child Health Plan Plus (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.

- **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 Citation:

Becker, J., Engelman, A., Bliss, R., Pineda-Reyes, F. (June 2023) Home and Community-Based Services Network Partners' Perceptions, Experiences and Solutions to Inequities within the Program. Civic Consulting Collaborative on behalf of Colorado Department of Health Care Policy and Financing and community-driven organizations."

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:

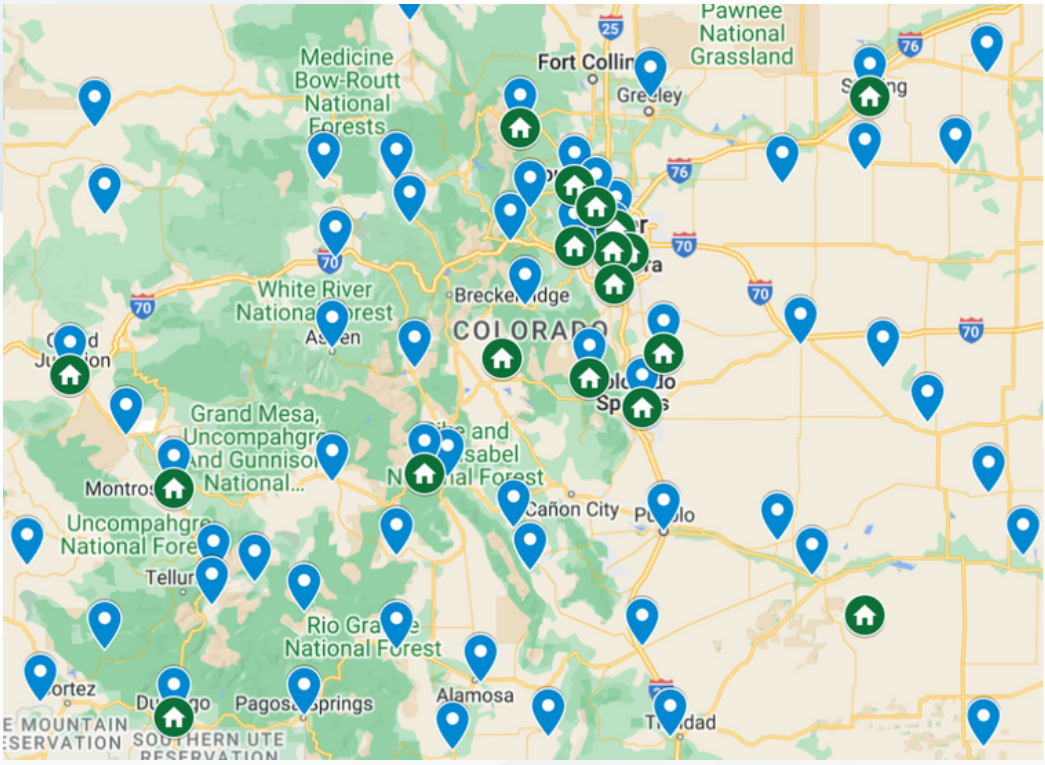
https://hcpf.colorado.gov/arpa/project-directory/improve-access-for-underserved-populations/equity-study

This report details the findings from engaging the HCBS network (defined as the Office of Community Living Stakeholder Newsletter listserv) in identifying barriers and solutions to equitable access, enrollment, and utilization of the program as one component of the larger equity study. HCBS network engagement included an agency/provider and member/caregiver survey (the survey) to identify what they perceive and experience as barriers to learning about, enrolling in, and utilizing HCBS along with potential solutions to remove these barriers. This fifteen question survey began with asking the participant's role and was adapted for either an agency/provider perspective or a member/caregiver perspective. It was distributed through Office of Community Living Stakeholder Newsletter in English and Spanish from January 25, 2023 through February 25, 2023 (see Appendix for the full survey content that was administered through SurveyMonkey and note only the member version was offered in Spanish). After the data was collected and analyzed, all survey participants and the broader HCBS network again through the Office of Community Living Stakeholder Newsletter were invited to a two hour virtual summit to discuss the findings and make additional recommendations.

Survey Respondents

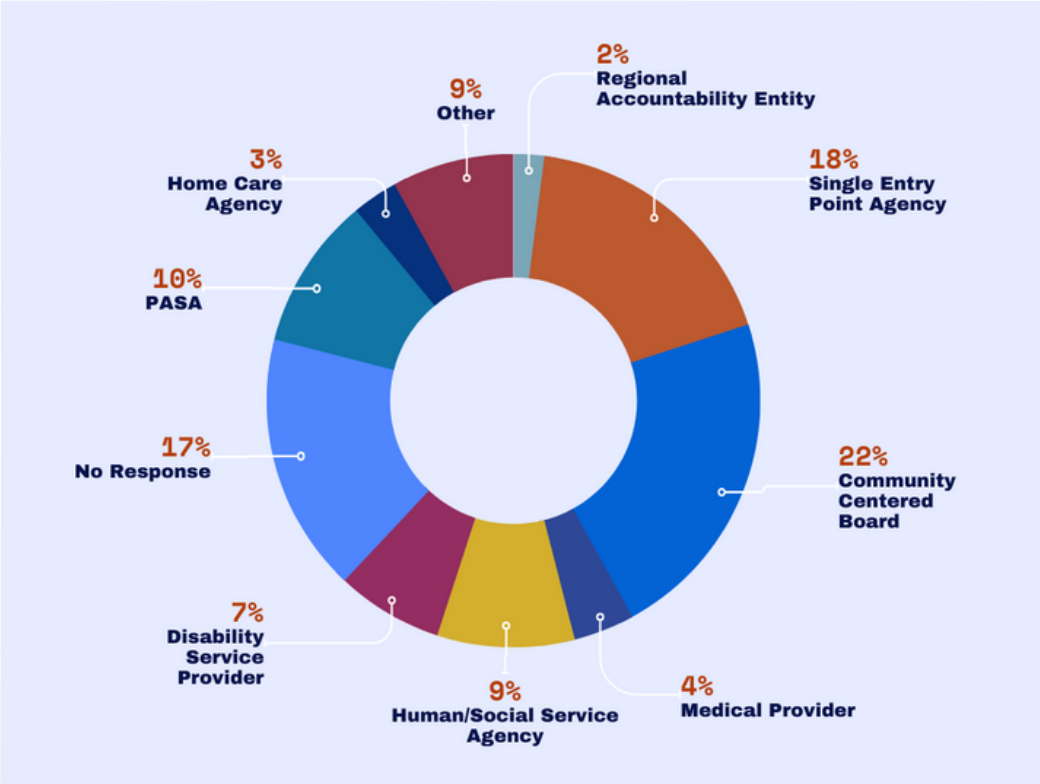
Four hundred and eighty five responses were gathered.
The Map below illustrates the counties that the 349 agency and provider respondents serve with the blue pins, and where the 136 member and caregiver respondents live with the green houses. Cheyenne county was the only Colorado county not specifically mentioned by agency/providers, although 30 agency/providers responded that they serve the entire state. Seventeen counties were represented by member/caregiver respondents, and an additional twenty member/caregiver respondents did not provide their location.

MAP: AGENCY/PROVIDER AND MEMBER/CAREGIVER SURVEY RESPONDENT LOCATIONS



Slightly over 40% of agency/provider respondents worked with a Case Management Agency (CMA), 17% did not share where they worked, and 10% worked with program approved service agencies (PASAs) (see Chart 1).

Chart 1: Survey Respondents' Agency and Provider Types



The vast majority (two-thirds) of member/caregiver respondents identified as White with an additional 19% not responding to the question. Fifteen percent identified as a person of color or multiracial. Additionally, only eleven respondents answered yes or unsure to identifying with the LGBTQIA+ community. Thus, the member/caregiver responses reflect the experience of those who dominate HCBS membership - white, heterosexual, cis individuals.

Survey Findings

The survey inquired about barriers to awareness, enrollment, and utilization of HCBS generally and then also specifically for consumer directed programs (i.e., Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS)). It also asked respondents to identify solutions to address these common barriers.

HCBS Awareness

Agency and provider respondents reflected on how they hear about members learning about HCBS with a family member or friend (17%), Community Centered Boards (16%), human/social service or Single Entry Point agencies (15% each), and medical providers (12%) being the most common (see Chart 2). Similarly, members and caregivers shared Agency and provider respondents reflected on how they hear about members learning about HCBS with a family member or friend (17%), Community Centered Boards (16%), human/social service or Single Entry Point agencies (15% each), and medical providers (12%) being the most common (see Chart 2). Similarly, members and caregivers shared that Community Centered Boards (28%), a family member or friend and disability/community organizations (14% each) as the most common (see Chart 3). However, human/social service and Single Entry Point agencies and medical providers were much less commonly reported as connectors by members/caregivers.

Chart 2: Most Common Ways Agency/ Providers Hear Members Learn about HCBS

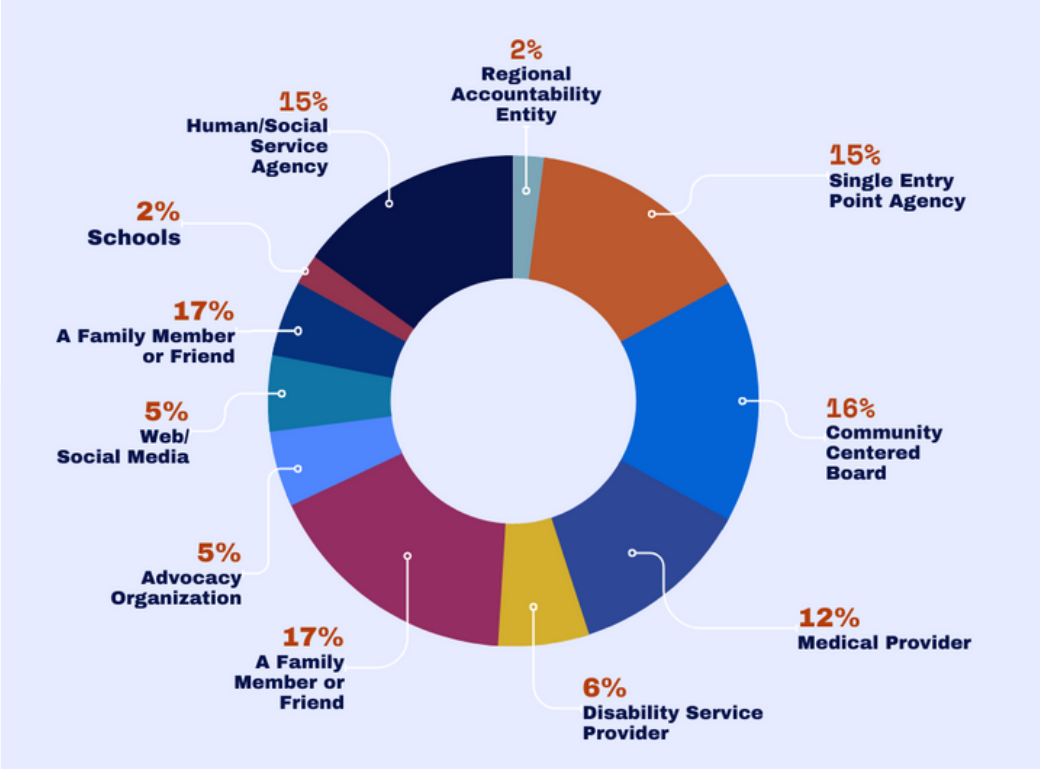
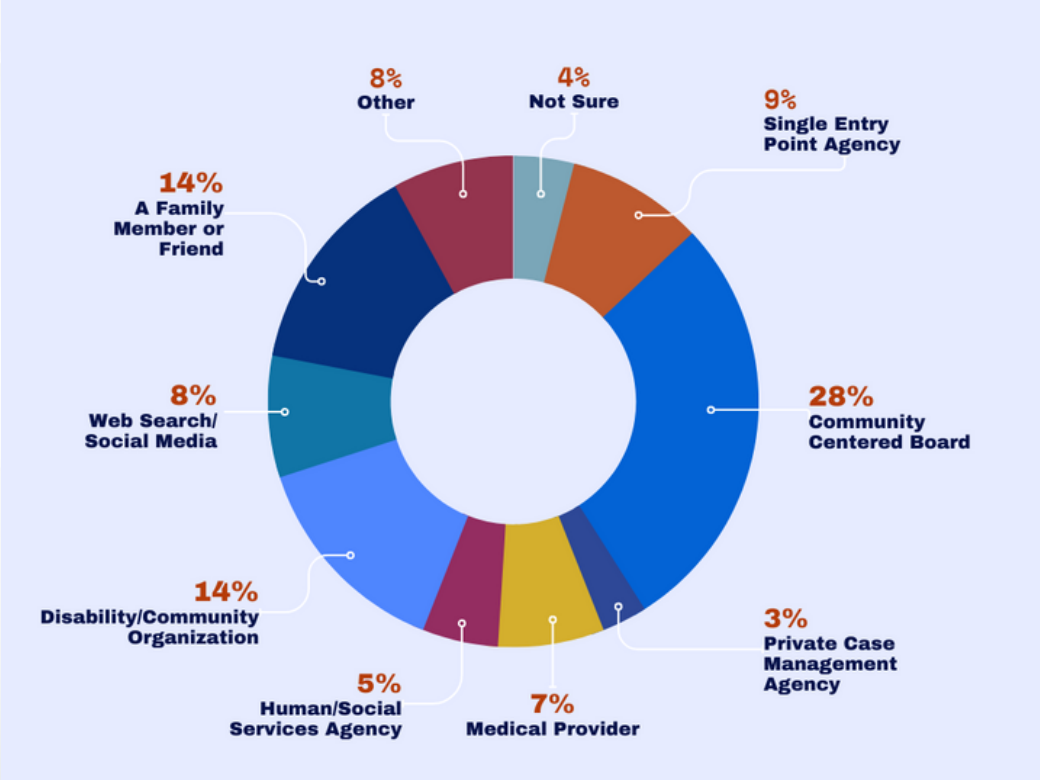


Chart 3: How Members/Caregivers Become Aware of HCBS



Agency/providers reflected on what they see as the biggest barriers for members learning about HCBS. These included not knowing where to find information about the program (21%), materials being confusing or hard to understand (20%), mistrust of the system/providers (12%), and not wanting outsiders in their home (10%, see Chart 4). Members and caregivers reported the biggest barriers to learning about HCBS as never hearing about it (20%), not knowing where to find information and materials being confusing or hard to understand (each 19%), and materials not providing enough or the right information (16%, see Chart 5).

Note that all of the member/caregiver barriers had to do with communications and outreach.

One member/caregiver described the missed opportunities:

"Not enough people who serve and support people with disabilities know that HCBS is available and how it can help children and adults with disabilities. There have been so many times schools had no idea, therapists had no idea, hospitals had no idea, etc. There are so many missed opportunities to educate the community about HCBS."

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Note that all of the member/caregiver barriers had to do with communications and outreach. One member/caregiver described the missed opportunities:

One agency/provider respondent described the challenge similarly adding the complications that not speaking English brings:

"There is very little outreach to families, families with language barriers need navigation, there is next to no community awareness of programs, even families that are involved with community centered boards through early intervention rarely continue with services."

Chart 4: Most Common Barriers Agency/ Providers See Member Encounter with HCBS Awareness

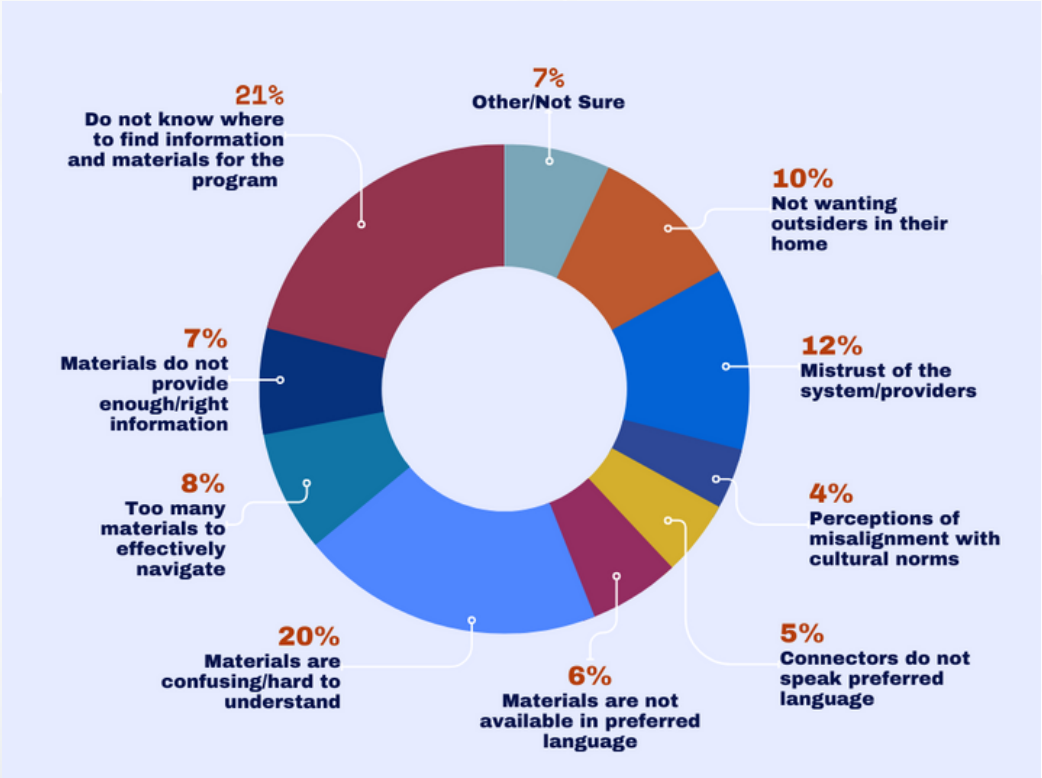
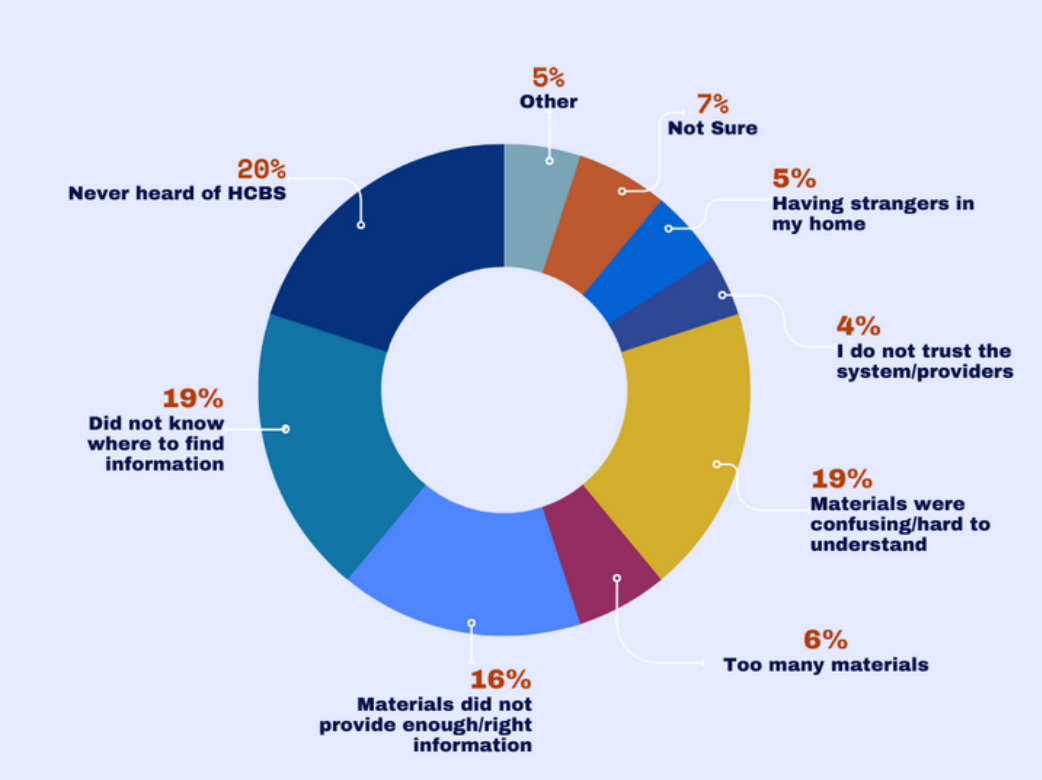


Chart 5: Barriers Members/ Caregivers Encounter when Learning about HCBS



HCBS ENROLLMENT

Agency/provider respondents were also asked to reflect on the most common barriers they see with the enrollment process. These included finding the right entity to start the process with (19%), document requirements (17%), and waiver waitlists (11%, see Chart 6). Member/caregiver respondents identified similar barriers, adding that it takes too much time to get enrolled as their most common (13%, see Chart 7).

Member/caregiver respondents shared their frustration with the process, and two are provided below:

"I have experienced lots of misinformation, confusion, from nearly everyone.The system is very complex and it's difficult for even providers or myself, someone who has been in the system for years."

"Case manager did not provide sufficient info…and there wasn't any transparency on how someone got a slot or where the individual was on the list, CCB did not provide much guidance and their "RFP" was extremely lacking so we had to do ALL the legwork ourselves. CCB and the system use too many terms that aren't easy to understand."

Providers outside the case management system also shared their frustrations with the process and how they are compensating to support their members:

"Case managers are not well trained and provide inaccurate information leading to service issues, provider issues, and distrust of the system. This has become so problematic that PASA'S now have to train their staff on what should be the case manager's job."

"...We have many members who, once they fill out the cumbersome paperwork and attend the appointment, they wait several months to hear back from a case manager, often following up multiple times without receiving a call back. They wait indefinitely to be connected to a provider often not knowing why. Sometimes, once we as an organization follow up, we find out they need to fill out a specific form that was missed, but were unaware."

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Chart 6: Most Common Barriers Providers See with HCBS Enrollment

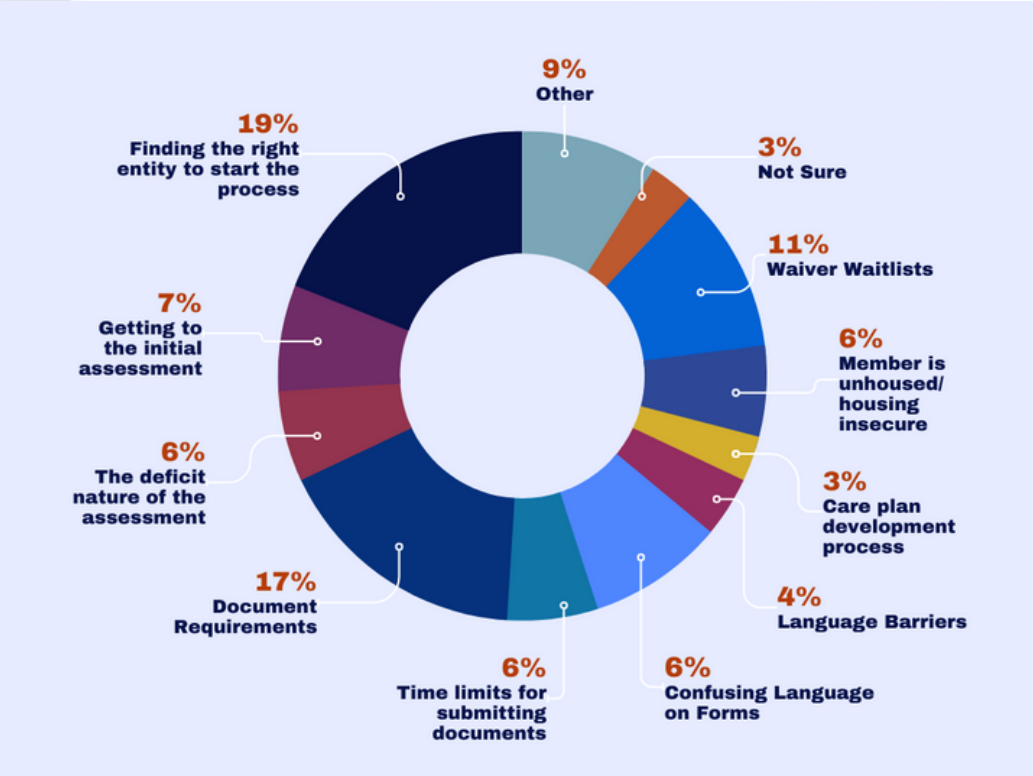

Chart 7: Most Common Barriers Member/ Caregivers Experience with HCBS Enrollment

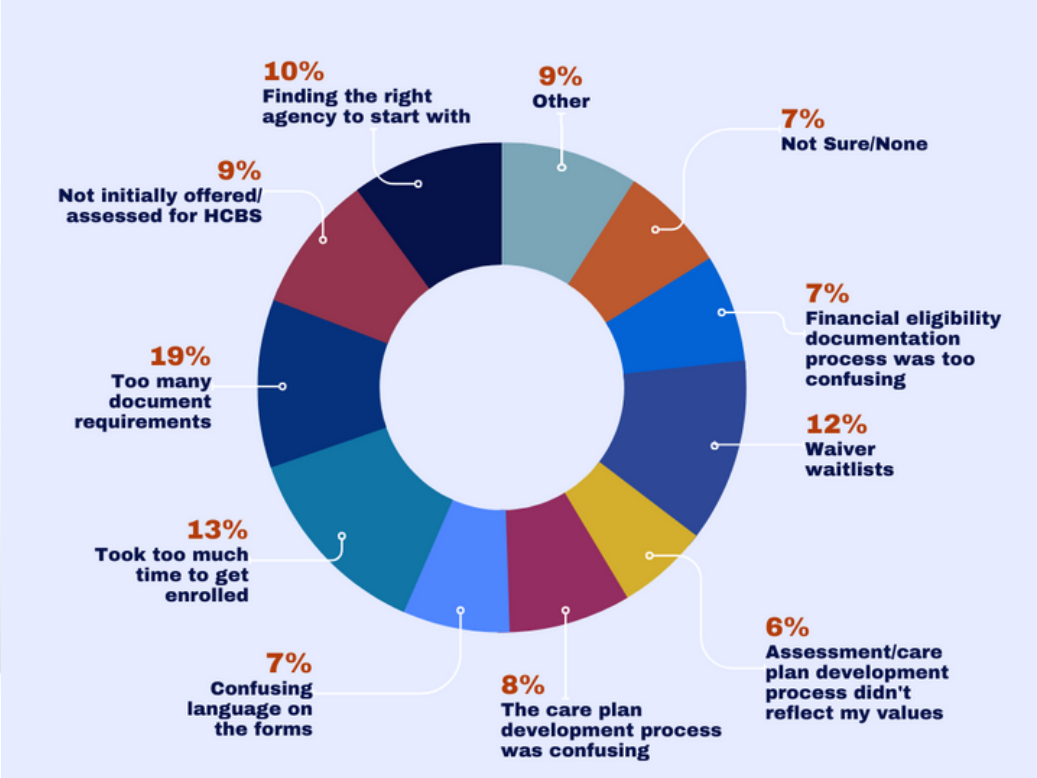

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Chart 8: What Enrollment Supports Agencies and Provider Would Like to Provide

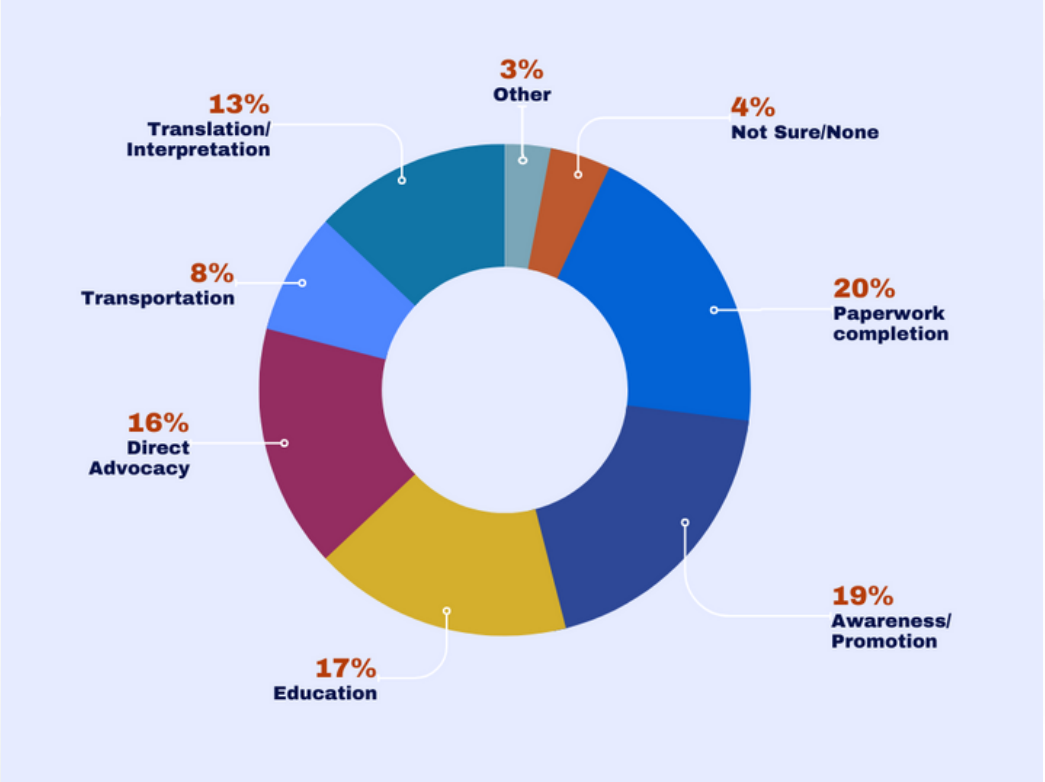
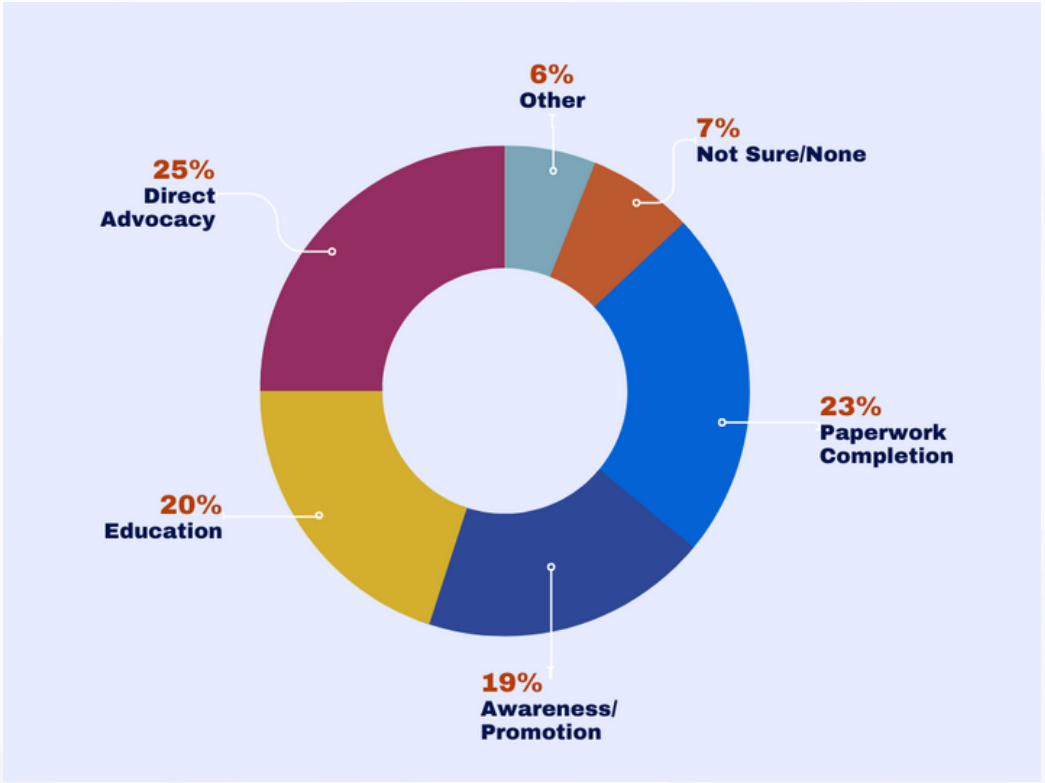


Chart 9: Enrollment Supports Members & Caregivers Would Like More of from Agencies



HCBS UTILIZATION

When agencies and providers were asked about their perceptions of the biggest barriers to members utilizing their HCBS authorized hours, they identified lack of HCBS providers in the area (21%), lack of direct care workers/clinicians in their area (19%), lack of trained providers for specific services, lack of knowledge about the disability system/services available, and lack of knowledge about accessing services (11% each, see Chart 10). Members and caregivers responded similarly with lack of providers in the area (27%), lack of trained providers for specific services (23%), and unaware of the disability system/services and how to access them (16%, see Chart 11). Overwhelmingly, the biggest barriers are around provider/service provider availability and lack of knowledge about how to access.

Chart 9: Most Common Barriers Agencies/ Providers See with Utilization

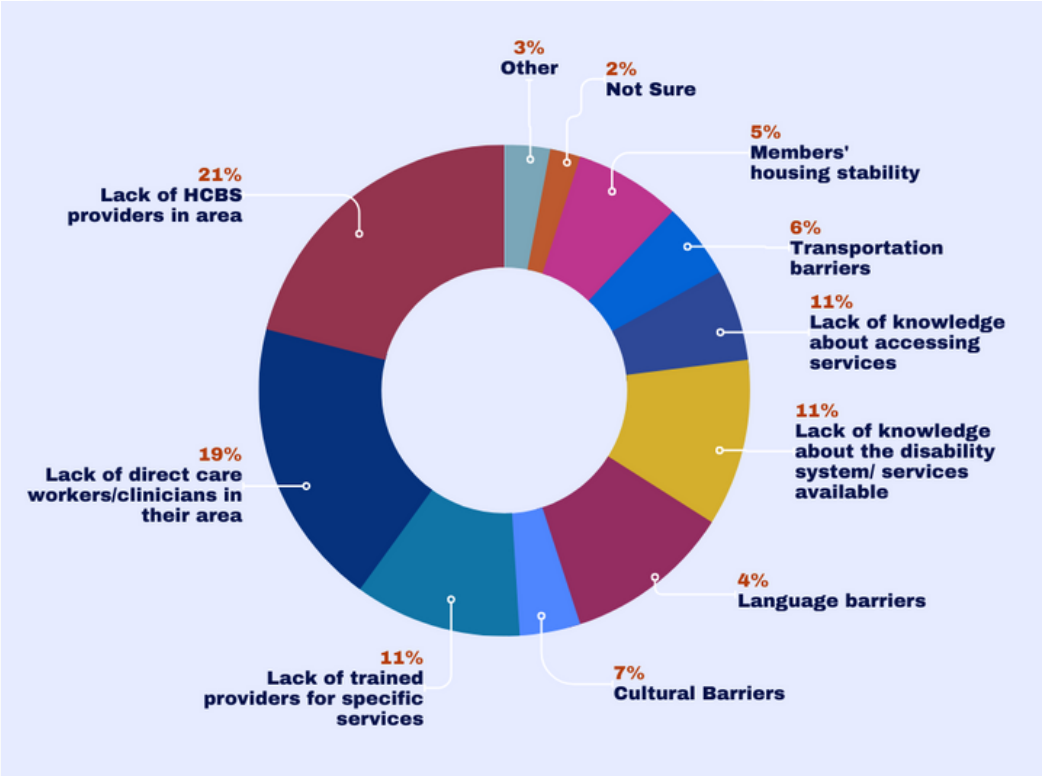
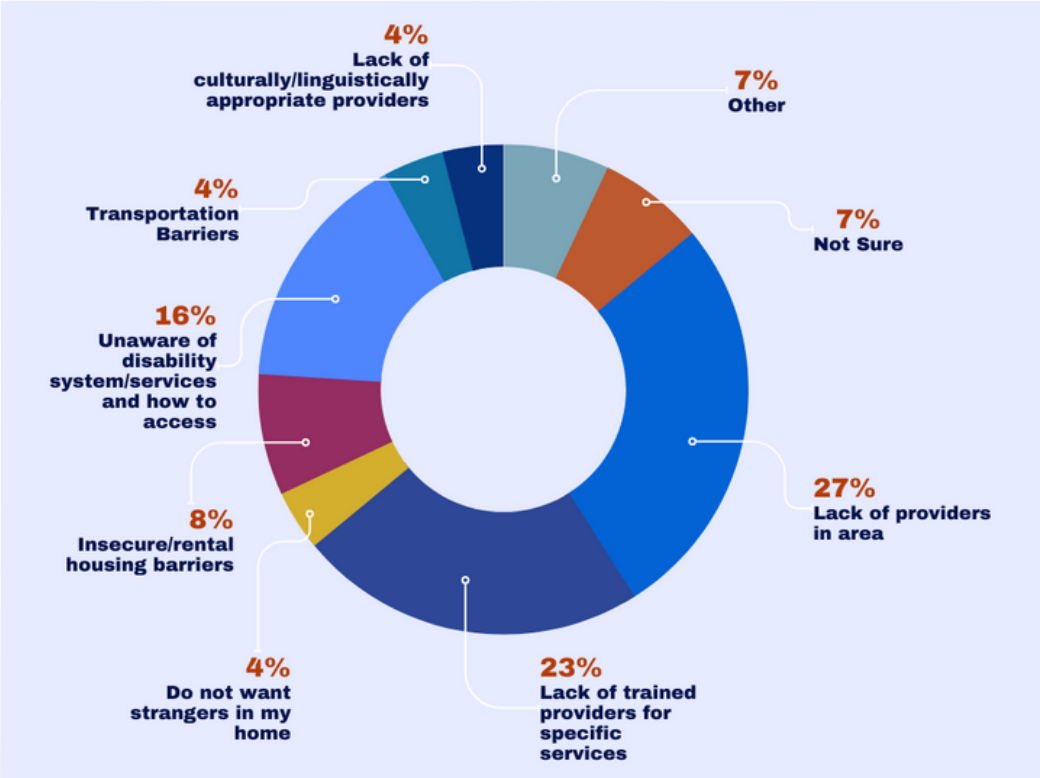


Chart 10: Members' and Caregivers' Biggest Barriers to Utilizing HCBS



MEMBER DIRECTED PROGRAMS

When asked about barriers specific to member-directed programs, Consumer Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS), agency/provider respondents identified members' inability to manage these services (22%), staff's lack of knowledge (20%), certification requirements (17%), and reimbursement limitations (11%) as the biggest barriers for members/caregivers in accessing these programs (see Chart 11). Nearly a quarter of member/caregiver respondents shared that the provider lacked (or withheld as expanded upon in the comments by a few participants) information about these programs. Eighteen percent reported choosing not to use them or not being eligible, and 16% reported not knowing about them. The combination of reimbursement, staffing, and management issues resulted in 12% of respondents identifying these as barriers; however, none in and of themselves rose to the top as they did for agency/provider respondents **(see Chart 12).**

Chart 11: Agencies' & Providers' Perceptions of Barriers to Member Directed Programs

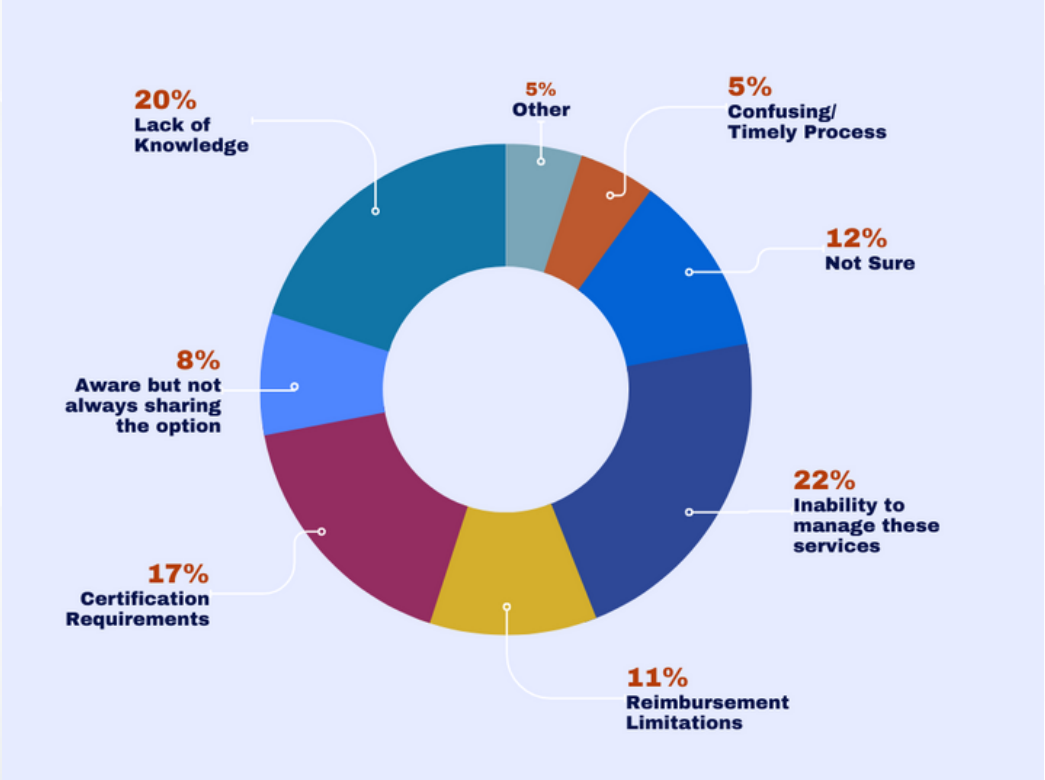
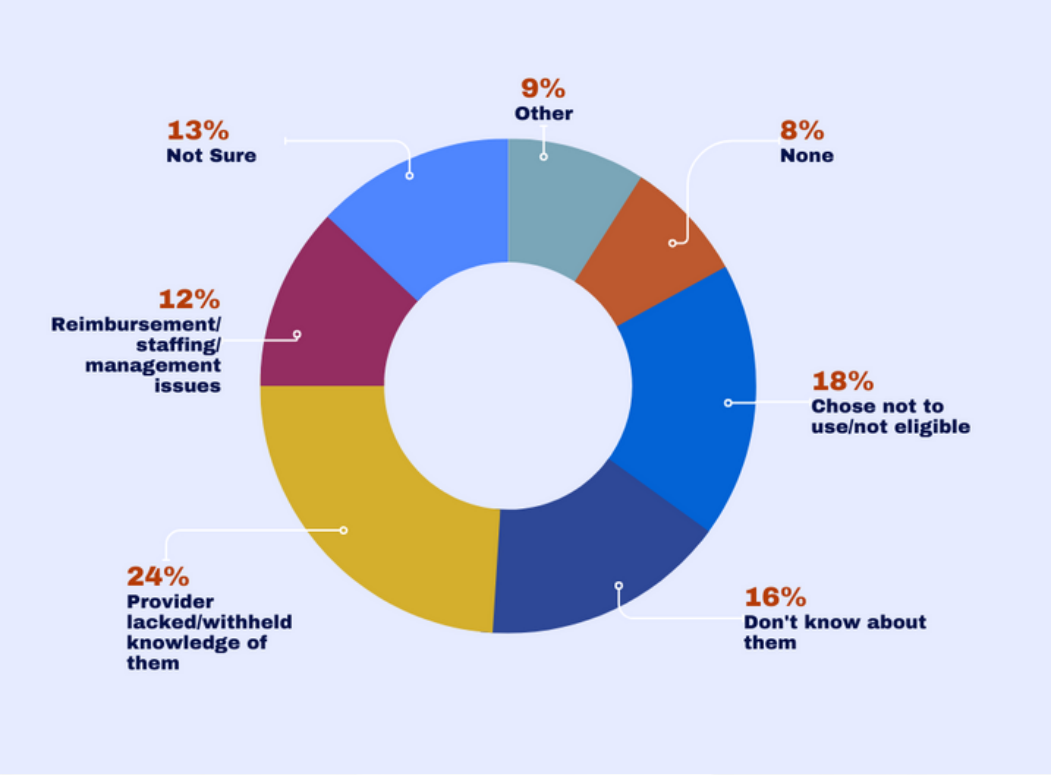


Chart 12: Members' & Caregivers' Barriers to Member Directed Programs



Solutions from Survey Respondents

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

- **Case Management Agency (CMA) Staff Education and Training**
    - Improve training of intake case management
    - Increase funding to CMAs for outreach and education
    - Train and develop highly qualified interpreters/translators with HCBS expertise
    - Offer live information sessions for providers to problem-solve real cases in real time
    - Decrease turnover of case managers
    - Offer on-call navigators that provide a spectrum of support, all the way to "hand-holding"

- **Materials and Communication**
    - Standardize informational materials across the state
    - Develop materials with more accessible language
    - Translate all materials, including forms, into Spanish and other languages
    - Develop educational videos, including a process map, with testimonials
    - Include more diverse representation in advertisements
    - Emphasizing that INS/ICE will not be involved in outreach/information
    - Include review of materials from those outside the system

- **Accessibility & Outreach**
    - Make the website and app more navigable
    - List HCBS as an option on the Public Assistance Application and Health First Colorado website
    - Provide immediate outreach upon intellectual or developmental disability (I/DD) diagnosis and those on Social Security Disability Insurance (SSDI) income
    - Use social media, print (for aging community), billboards, bus stop signs, TV, radio

- **A Robust Awareness and Connection Support System**
    - Educate and provide materials to primary care providers, clinics, hospitals, schools' special education coordinators, aging community organizations, libraries, booths at local events, human services and health departments, law enforcement, jails, community mental health, Department of Vocational Rehabilitation, immigrant organizations, religious/cultural organizations, and Certified Nursing Assistants

Summit 1

On April 4, 2023 a two-hour virtual Summit was hosted with the intent of engaging those active with HCPF and OCL and with some knowledge of LTSS. The goal was to achieve the following outcomes:

- To learn about and discuss the internal data analysis from Phase 1 (above)
- To learn about and discuss the agency/provider and member/caregiver survey findings (above)
- To generate priority suggestions and solutions for removing barriers to access HCBS

Approximately 130 attendees joined, representing a range of roles, including organizational provider, advocate, member, caregiver, and "other." After engaging attendees in a review of the findings from the internal analysis, participants were engaged in small group discussions around the question:

What have you seen work to break down the barriers to accessing HCBS and navigating the system?

The following is a summary of what participants identified as effective navigation elements and techniques:

- **Family Engagement and Support** included peer support and shared experiences among parents/people with disabilities, support from local parent organizations, and building awareness across different entities working with the disability population. As one group stated,

"Family led organizations can be critical in connecting diverse families to other families with experience with HCBS. Answering questions and sharing what has worked can be critical to supporting families to apply and access services for their children/youth."

- **Language Access and Communication** included addressing language barriers (e.g., ASL, Spanish), ethical and professional interpretation and translation services, face-to-face community outreach, and spreading information through social media and media blasts using plain language and accessible information.

As one breakout group shared,

"We feel it is helpful when we can speak the clients' language - literally! American Sign Language has been a big barrier and one client took a long time to help due to that. When we have Spanish speaking clients - we are able to help so fast!"

- **Community Collaboration and Outreach** included a focus on collaboration with trusted community organizations and utilizing existing community resources that are able to help provide information and connection to individuals who are eligible, such as schools, nursing homes, home health providers, and hospitals.

One breakout group shared,

> "As the CCB and SEP case management agencies, providing education and training to other community organizations about HCBS and how to start the process is critical. [We do that with] schools, DHS, criminal legal system, hospitals, etc."

- **System Understanding and Navigation** included having the awareness of available services and building an understanding with individuals on how to access them, essentially providing customer service support to access the various entry points.

After a brief large group report-back and a review of the survey findings (above), participants engaged in a second round of small group breakout sessions around:

What would 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** included developing a systematic communication process for navigators, families, clients, and agencies to establish trust through clarifying roles, reliable contact information, expectations, the process, and specific next steps and providing plain language educational materials that are widely available to referral sources in various media formats.

As one group shared,

"Develop a systematic way for navigator/family/client/agency to communicate voice to voice or person to person to develop trust and clarify next steps…determine a clear next contact person for the family/client."

- **Education and Support for Navigators** included a range of expertise necessary, though hopefully all were aiming for what one group shared, "instilling a team mentality among different communities and organizations." Some felt that "[Navigators] don't need to be an expert, just know enough that something could be helpful and who to contact" whereas others thought navigators should understand the HCBS process and be able to explain it to families, including how to complete the paperwork. Participants also suggested navigators attend community meetings and resource fairs and to enhance their knowledge of available resources.

- **Streamlined Processes and Coordination** included a myriad of system enhancements, including implementing a formal system to screen children with disabilities who are transitioning into adulthood for necessary service referrals; establishing a central location for easy navigation and understanding of programs; ensuring follow-up in 30-60-90 days to confirm connections and address issues; simplifying and standardizing the intake process, paperwork, and referrals; enhancing interviewer skills to gather accurate information from agencies and clients. One group also shared that navigation would benefit from an expanded focus "to include Social Determinants of Health (housing, food security, economic access, transportation, etc.)".

"As the CCB and SEP case management agencies, providing education and training to other community organizations about HCBS and how to start the process is critical. [We do that with] schools, DHS, criminal legal system, hospitals, etc."

Conclusions

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 the HCBS Equity Study – Learning Exchanges with trusted, community-driven organizations that specialize in working with specific underserved populations.

For more on that process, findings, and final recommendations, visit the following link:
https://hcpf.colorado.gov/arpa/project-directory/improve-access-for-underserved-populations/equity-study

"As the CCB and SEP case management agencies, providing education and training to other community organizations about HCBS and how to start the process is critical. [We do that with] schools, DHS, criminal legal system, hospitals, etc."

Appendix
Solutions from Survey Respondents

The Colorado Department of Health Care Policy & Financing (HCPF) administers Medicaid's Home and Community-Based Services (HCBS) waivers/benefits that help older adults and individuals with disabilities remain in their homes and community. HCPF has undertaken a project to identify and better understand disparities across HCBS. We are reaching out to members and their families, case managers, providers, connectors, and other advocates to ask for your expert input into understanding more about member and provider experiences pertaining to:

1) Awareness/Outreach
2) Enrollment
3) Use of HCBS.

The survey is organized around these three phases of accessing HCBS and concludes with some demographic information.

We appreciate you taking the time to share your insights with us. Your feedback will be used to guide our next phase of the project, which will include reviewing these findings with community members like yourself to determine key levers for change and potential solutions for reducing/removing barriers to enrolling and accessing HCBS, particularly with underrepresented populations.

Even if you find yourself responding "not sure" to many of the questions, please continue to complete the survey as awareness of HCBS programs and processes is important for us to understand. Additionally, please use the "Other" option to include reasons that we might not have heard yet.

The survey should take approximately 10 minutes to complete.

Responses to this survey are anonymous and cannot be traced back to the respondent.

No personally identifiable information is captured unless you voluntarily offer personal or contact information in any of the comment fields. Responses will only be available to a small number of project staff.

1. What is your primary perspective/role within Medicaid's HCBS system?

a. I provide services and support to members and potential members and their families.
b. I am a member or a person I care for is a member.

Organization Version
Awareness/Outreach

2. Please pick the top three (3) most common ways you hear that Medicaid members **become aware** of HCBS.

a. Single Entry Point agency (SEP, a case management agency)
b. Community Centered Board (CCB, a case management agency specifically for people with intellectual and developmental disabilities)
c. Private Case Management Agency
d. Regional Accountability Entity (RAE)
e. Medical provider
f. Human/social services agency
g. Disability advocacy organization (e.g., Colorado Cross-Disability Coalition, Disability Law Colorado)
i**h.** Disability specific service provider (e.g., Arc, BIAC, independent living centers)
i. Grassroots community agency (e.g., community-based group, Community Health Workers/Promotora de Salud, i.e. CREA Results)
j. A family member or friend
k. Searching websites or social media
l. Religious institution/place of worship
m. Other (please specify)
n. Not sure

3. Please pick the top three (3) most **common cultural and linguistic barriers** you see members encountering when educating them about HCBS options.

a. Do not know where to find information and materials for the program
b. Materials do not provide enough and/or the right information
c. There are too many materials to effectively navigate the program
d. Materials are confusing and hard to understand
e. Materials are not available in their preferred language
f. Connectors/educators do not speak their preferred language
g. Perceptions that HCBS do not align with cultural norms (for example, family providing the caregiving)
h. Mistrust of the system and/or providers
i. Experience of institutional racism and discrimination
j. Not wanting outsiders in their home
k. Other (please specify in detail)
l. Not sure

4. What solutions could be put in place in the next year to ensure members are aware of HCBS?

Enrollment

5. Please pick the top three (3) most common barriers to members **becoming enrolled** in HCBS.

a. Finding the right entity to start the process with
b. Getting to the initial assessment appointment
c. The deficit nature of the assessment when people want to talk about their strengths
d. Document requirements
e. Time limits for submitting documents after assessment
f. Confusing language on the forms
g. Language barriers
h. Getting to the meeting to develop the care plan
i. The care plan development process
j.The care plan doesn't reflect member's values and culture
k. Member is unhoused or housing insecure
l. Waiver waitlists
m. Other (Please describe in detail)
n. Not sure

6. What support **does** your organization provide to help people enroll in HCBS programs, if any:

a. Translation/interpretation
b. Transportation
c. Direct advocacy
d. Education
e. Awareness/promotion
f. Paperwork completion
g. Other (please specify in detail)
h. None/not sure

7. If you had the resources to offer them, what support would your organization provide or do you think are most needed to help people enroll in HCBS programs, if any:

a. Translation/interpretation
b. Transportation
c. Direct advocacy
d. Education
e. Awareness/promotion
f. Paperwork completion
g. Other (please specify in detail)
h. None/not sure

8. Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) are participant-directed programs that allow members to have more direct control over their services. What barriers do you see in **the enrollment process** for these specific service delivery options?

a. Organization/advocate/provider lacks knowledge about this service delivery option
b. Organization/advocate/provider is aware of this service delivery option but is not always sharing the option with members
c. The certification requirements
d. The reimbursement limitations
e. Members' (or their Authorized Representative's) real or perceived inability to manage these services
f. Other (please describe in detail)
g. Not sure

Utilization

9. Please pick the top three (3) most common barriers to members **utilizing** HCBS.

a. Lack of HCBS providers, like home health agencies or adult day providers, in their area
b. Lack of direct care workers or other clinicians in their area
c. Lack of trained providers for specific services
d. Lack of culturally appropriate providers
e. Misalignment between member's cultural preferences for care and available services or providers
f. Language barriers with providers
g. Inability to make home adaptations in rental properties
h. Lack of knowledge about the disability system and services available
i. Lack of knowledge about how to access services
j. Cultural norms around not challenging authority
k. Lack of advocacy/agency due to institutional racism/discrimination
l. Transportation barriers
m. Members' housing stability
n. Other (please specify in detail)
o. Not sure

10. Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) are participant-directed programs that allow members to have more direct control over their services. What barriers do you see for members in **utilizing** these service delivery options?

a. The certification requirements
b. The reimbursement limitations
c. The reimbursement process
e. Other processes are confusing or cumbersome
f. Services are unavailable due to waiver limits
g. Other (please describe in detail)
h. Not sure

Your Organization & Role

11. Your organization type:

a. Regional Accountability Entity (RAE)
b. Single Entry Point agency (SEP)
c. Community Centered Board (CCB)
d. Private Case Management Agency
e. Medical provider
f. Human/social service agency
g. Disability advocacy organization (e.g., Disability Law Colorado)
h. Disability specific service provider (e.g., Arc, BIAC, independent living centers)
i. Grassroots community organization (e.g., Center for African American Health, Asian Pacific Development Center)
j. Other (please specify)

12. Your general role (check all that apply):

a. Outreach/engagement
b. Enrollment
c. Assessment and plan development
d. Medical provider
e. Behavioral health provider
f. HCBS service provider
g. Specialized service provider
h. Advocacy
i. Agency administration
j. Other (please specify)

13. What counties do you work with?

Statewide

Next Steps

14. In the spring, we will convene partners, including yourself, to review these findings and begin to discuss opportunities for improvement. Please provide your email address if you would like to receive more information about this engagement. (Please note that this information will be communicated through the Office of Community Living Long Term Services and Supports Newsletter. You can sign up for those regular communications here.)

15. In the spring, we aim to work closely with community-based organizations who specifically work with populations who are less engaged in HCBS. If this is you, please provide your organization's name, primary population served, and your contact information.

Thank You

FOR SHARING YOUR TIME AND INSIGHTS WITH US TO MAKE HCBS MORE EQUITABLE AND HIGHER QUALITY FOR ALL MEMBERS!

Member Version
Awareness/Outreach

How did you become aware of HCBS? (Check all that apply)

- ☐ Regional Entity/regional organization (RAE)
- ☐ Single Entry Point agency (SEP, a case management agency)
- ☐ Community Center Board (CCB, a case management agency specifically for people with intellectual and developmental disabilities)
- ☐ Private Case Management Agency
- ☐ Medical provider
- ☐ Human/social services agency
- ☐ Disability advocacy organization (e.g., Disability Law Colorado)
- ☐ Disability specific service provider (e.g., Arc, BIAC, independent living centers)
- ☐ Websearch
- ☐ Grassroots community agency (e.g., community-based group,
- ☐ Community Health Workers/Promotora de Salud, i.e. CREA Results)
- ☐ A family member or friend
- ☐ Searching the internet or social media
- ☐ Other (please specify)
- ☐ Not sure

Please tell us about any problems you had learning about HCBS. (top 3)

- ☐ I had never heard of the program
- ☐ I did not know where to find information and materials for the program
- ☐ The materials did not provide enough and/or the right information
- ☐ There were too many materials to read about the program
- ☐ The materials were confusing and hard to understand
- ☐ The materials were not available in my preferred language
- ☐ Nobody was able to help me in my preferred language
- ☐ I wasn't sure if I wanted HCBS because I do not trust the system and providers
- ☐ I did not want, or was worried about, having strangers in my home
- ☐ Other (please specify in detail)
- ☐ Not sure

Enrollment

Please tell us about any problems you had enrolling in HCBS. (Check all that apply).

- ☐ Find the right agency to start the process with
- ☐ Not initially offered or assessed for HCBS
- ☐ Get transportation to the required appointments
- ☐ The assessment focused on what I can't do, not on my strengths
- ☐ Too many document requirements
- ☐ Took too much time to get enrolled
- ☐ Confusing language on the forms
- ☐ Forms were not in my preferred language
- ☐ The care plan development process was confusing
- ☐ The care plan development process didn't reflect my values and
- ☐ culture
- ☐ Being unhoused or housing insecure
- ☐ Waiver waitlists
- ☐ Financial eligibility documentation process was too confusing
- ☐ Other (Please describe in detail)
- ☐ Not sure

Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) allow members to have more direct control over their services. What barriers did you experience in the enrollment process for these service options?

- ☐ I chose not to use or am not eligible for these service delivery options
- ☐ I don't know about these specific services
- ☐ Organization/advocate/provider lacked knowledge about these services
- ☐ The certification requirements
- ☐ The reimbursement limitations
- ☐ I and/or my Authorized Representative was not able to manage these services
- ☐ Other (please describe in detail)
- ☐ Not sure

What support was helpful to you in getting enrolled in HCBS? (Check all that apply)

- ☐ Translation/interpretation
- ☐ Transportation
- ☐ Direct advocacy
- ☐ Education
- ☐ Awareness/promotion
- ☐ Paperwork completion
- ☐ Other (please specify in detail)
- ☐ None/not sure

What support would have been helpful to you in getting enrolled in HCBS? (Check all that apply)

- ☐ Translation/interpretation
- ☐ Transportation
- ☐ Direct advocacy
- ☐ Education
- ☐ Awareness/promotion
- ☐ Paperwork completion
- ☐ Other (please specify in detail)
- ☐ None/not sure

Utilization

Please rank the following barriers to using HCBS.

- ☐ Lack of providers in my area
- ☐ Lack of trained providers for specific services
- ☐ Lack of culturally appropriate providers
- ☐ Providers do not speak my preferred language
- ☐ I am unable to make home adaptations because I live in a rental property
- ☐ I am unaware of the disability system and services available
- ☐ I don't know how to get access to services
- ☐ I do not want strangers in my home
- ☐ Transportation barriers
- ☐ Housing instability
- ☐ Other (please specify in detail)
- ☐ Not sure

Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) allow members to have more direct control over their services.

What barriers have you experienced in using these service options?

- ☐ I am not enrolled in these service options
- ☐ I do not know what these services are
- ☐ The certification requirements
- ☐ The reimbursement limitations
- ☐ I and/or my Authorized Representative was not able to manage these services
- ☐ The reimbursement process
- ☐ Services are unavailable due to waiver limits
- ☐ I have a hard time finding caregivers
- ☐ I don't have enough money to cover rising costs as an employer
- ☐ I am having problems with Financial Management Services (FMS) vendors
- ☐ The training was not helpful enough
- ☐ Other (please describe)

A Little About You

Are you or a family member currently enrolled in HCBS?

- ☐ Yes
- ☐ No

If yes, How long have you or your family member been enrolled in HCBS?

- ☐ Under 4 years
- ☐ 4-10 years
- ☐ More than 10 years

What county do you live in?

What race/ethnicity do you identify with? (check all that apply, optional)

- ☐ African American/Black
- ☐ Asian American
- ☐ Hispanic/Latino/a
- ☐ Middle Eastern
- ☐ American Indian/Alaska Native
- ☐ Pacific Islander
- ☐ White
- ☐ Other (please specify)

Do you identify yourself as part of the LGBTQIA+ community? (optional)

- ☐ Yes
- ☐ No
- ☐ Unsure

Next Steps

14. Later this spring, we will meet with community members, including people like yourself, to review these findings and begin to discuss opportunities for improvement. Please provide your email address if you would like to receive more information about these opportunities. (Please note that this information will be communicated through the Office of Community Living Long Term Services and Supports Newsletter. You can sign up for those regular communications here.)

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Thank You

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