INVESTING IN CULTURALLY AND LINGUISTICALLY RESPONSIVE BEHAVIORAL HEALTH CARE IN OREGON

Oregon Health Authority

Coalition of Communities of Color

Acknowledgements

We do our work on the stolen land of the Kalapuya, Wasco, Cowlitz, Multnomah, Tualatin, Clackamas, Kathlamet, Molalla, Middle Band of Chinook, and many other tribes who made their homes along the Columbia River. We live in a nation of wealth created by the subjugation and exploitation of African people brought to Turtle Island through chattel slavery or the Maa'fa (which is Swahili for the great disaster). We uplift the original Native American stewards of the land and the forced contributions of generations of Africans. We ground our fight knowing that there is no Black liberation without Indigenous Sovereignty, and there is no Indigenous Sovereignty without Black liberation. We fight for Land Back and reparations and refute settler-colonialism, anti-Black racism, and imperialism.

This body of work could not have been completed without the guidance, commitment, and knowledge of members of the steering committee. Throughout multiple and ongoing crises, members offered support and crucial redirection of the process that was mindful and respectful of the conditions and limits of communities of color and the organizations that serve them. We were reminded that urgency and following dominant institution timelines does not often serve communities of color in ways that center their needs, strengths, and desires. We, as researchers trained in predominantly white institutions, unlearned many of our assumptions about doing "proper" research through our meetings with steering committee members. We learned the value of pausing and slowing down as a powerful way of doing community-led work.

so many community members who shared the survey throughout the state, and even helped folks complete the survey. This research would not have been possible without your support. We also thank CCC's leadership, Jenny Lee and Marcus Mundy, for their thoughtful edits and Eddie Sherman for supporting stylizing the report. As always, we are thankful for the consistent support and guidance of our colleagues, collaborators, and co-conspirators in all of the research and data justice work we do across the state, especially the BIPOC Decolonizing Data Council. Lastly, thank you to all the community members who took the time to share their experiences, knowledge, and wisdom with us. We recognize that mental and behavioral health can be difficult to talk about. We hope that in writing this report we have represented your experiences with care and respect, and that the changes advocated here will ensure that you are served in ways that affirm and support the fullest wellbeing for you, your families, and your communities.

- Research Justice Institute

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Executive Summary

The data and recommendations presented in this report are from a community-led statewide research process, guided by a 10-member steering committee of Black, Indigenous and People of Color (BIPOC) leaders. The aim of this research is to provide the Oregon Health Authority (OHA) and Coordinated Care Organizations (CCOs) with recommendations for culturally and linguistically responsive services for communities of color.

The goal is to improve the access, utilization, and outcomes for behavioral health care.

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Moreover, this report is a collection of stories, experiences, beliefs, and desires of BIPOC communities (not including federally recognized Tribal sovereign nations, even if some Tribal members may have participated as individuals in this research). What is captured here are years of requests and needs that multicultural and multilingual communities and their leaders have been sharing across various mediums, but continue to see little change. We acknowledge the fatigue and frustration experienced by many BIPOC leaders and community members when their calls for change are met with inaction. The authors hope this report will provide pathways for short – and long-term meaningful action.

The data presented in this report, including BIPOC people's accounts of interacting with health care systems in Oregon, must be situated within experiences and histories of trauma from the effects of racism, white supremacy, anti-Blackness, and exclusion and "othering." These conditions result in similar outcomes and shared experiences related to mental and behavioral health. Decades worth of research with Oregon's BIPOC communities continues to reveal the shortcomings of the state's culturally and linguistically responsive behavioral health care, despite significant health equity advances (see section 3 for more details).

Primary data for this study was collected by two online surveys in English and Spanish. Survey questions were co-constructed with members of the steering committee and other BIPOC community leaders. The surveys were disseminated across the state by a network of BIPOC colleagues. Survey questions asked about: sources of stress, anxiety, frustration and worry, including for children and elders; barriers to seeking care; experiences of discrimination; distrust of health care professionals; and local and culturally specific resources for behavioral health support.

Over 440 participants took the survey and represented diverse geographies including Eastern and Central Oregon, the Gorge, the Coast, the Portland metro area, Salem, Eugene, and Medford. Respondents who identify as Black/African-American and Latino, Latina, or Latinx/e were the majority of participants[1], but there was a community-led effort to ensure representation from Native/Indigenous, Asian, and Pacific Islander communities. The steering committee and other BIPOC community members reviewed and vetted survey findings and analysis. The recommendations presented below are paired with a key finding from this research process.

Majority of BIPOC people receive behavioral health care from religious figures, traditional healers, community-based organizations, and clinics

BIPOC communities seek behavioral health services from religious figures, traditional healers, and culturally specific and community-based organizations at higher rates than CCOs, urgent care facilities, and emergency rooms. These sources of care are often not recognized or resourced by dominant institutions and tend to be more family – and community-centered than dominant/individual-centered/Western forms of behavioral health care. We recommend that CCOs and health systems generally partner with, defer to, and invest in culturally specific leaders and organizations to support community-centered care networks as a strategy for improving culturally and linguistically specific access to behavioral health services.

> **Many survey participants shared that they hesitate to or do not visit behavioral health providers because of previous experiences of racism, discrimination, and cultural insensitivity.**

Awareness about behavioral health services is a major barrier and translation is insufficient for communicating culturally relevant information

We learned that lack of awareness about the availability of behavioral health services is a significant barrier to access. Translating information is needed but presently insufficient; cultural competency is critical for conveying information in culturally appropriate ways. We recommend investing in and hiring dedicated staff (from outreach to front-office to health care providers) embedded in their

cultural traditions to conduct outreach about services in their communities. Health systems need to rely on multiple communication formats (beyond written) and build awareness via community members who are culturally knowledgeable and trusted intermediaries. See section 5.3, Barriers to Accessing Behavioral Health Services, for more data.

Rates of behavioral health care utilization are low among BIPOC people largely due to a lack of multilingual and multicultural providers

There is a shortage of multilingual and multicultural behavioral health care workers across the state, especially in rural areas. Many survey participants shared that they hesitate to or do not visit behavioral health providers because of previous experiences of racism, discrimination, and cultural insensitivity. We recommend investing in a multilingual and multicultural behavioral health workforce that includes formal and consistent statewide processes for training, licensing, hiring, retaining, and compensating workers.

BIPOC people have low rates of enrollment in CCOs, especially outside of the Portland metro area

Communities of color use CCOs at low rates and the lack of awareness about behavioral health services is a top reason that prevents many from seeking care. CCOs must partner with culturally specific organizations in rural and urban areas to get the word out about what services BIPOC people can access and how. Again, culturally responsive communication—not only translation—is critical. See section 5.2, Utilization of Behavioral Health Services, for more information.

> **Again, culturally responsive communication — not only translation — is critical.**

BIPOC people experience high rates of racism, discrimination, and bias in medical settings

Responses showed that BIPOC patients experience high levels of discrimination in medical settings. In partnership with culturally specific organizations and community-based leaders, culturally informed training and practice based evaluation must be developed for providers. These areas should include empathy, bias/stereotyping, anti-racism, decolonizing and healing justice, bedside manner, trust-building, interpersonal communication, and supportive care practices. Providers should be educated about the cultural values, norms, and beliefs of the populations they serve and understand their social histories (e.g., immigration, resettlement, displacement by

gentrification, historical trauma). See section 5.5, Experiences of Discrimination from Providers, for narratives and more examples.

Needs and experiences of BIPOC communities cannot be understood without collecting disaggregated, community-informed, actionable data

Health systems must collect, protect, have the skills and capacity to make sense of, and make decisions based on disaggregated data on race, ethnicity, language, disability status, gender identity, and sexual orientation. Metrics, measures, and evaluation models must be developed with meaningful community engagement, informed by the needs and assets of local communities, and ideally should be community-led to avoid centering the needs, expectations, and outcomes of the dominant/white/U.S. born population.

> **Health systems must collect, protect, have the skills and capacity to make sense of, and make decisions based on disaggregated data on race, ethnicity, language, disability status, gender identity, and sexual orientation.**

Western and Anglo-centric assumptions about behavioral health alienate and harm BIPOC communities

Providing culturally and linguistically responsive care means avoiding reproducing dominant, Western, and Anglo-centric mental and behavioral assumptions that perpetuate the norms and expectations of whiteness.[2] Assumptions to avoid include: determining "good mental health" and "dysfunction" solely by methodologies of Western science; monitoring and measuring "good mental health" by dominant/Anglo-centric/Western models; assuming that mental and behavioral health issues can be isolated at the individual level; and only trusting and recommending biomedically-trained and secular licensed professionals as best suited to guide people through the health process.

1. Aim of this Study

With increasing demographic diversity and persistent health inequities due to historical and current oppression, a pressing question is: How can Oregon reimagine its behavioral health[33] care delivery system to better serve culturally and linguistically diverse community members across the state? To that end, the project's primary aim is to improve the access, utilization, and outcomes of behavioral health for all Oregonians through a co-constructed, community-led research process to provide the Oregon Health Authority (OHA) recommendations for culturally and linguistically responsive services at the level of Coordinated Care Organizations (CCOs).

To achieve this aim, the Research Justice Institute at the Coalition of Communities of Color (CCC) embarked on a community-based participatory action research (CBPAR) project that, at every stage of the research process, not only included but deferred to leaders and members of Black, Indigenous, and People of Color (BIPOC) communities (however, we did not explicitly engage with the 9 federally recognized Tribal sovereign nations, although some Tribal members may have participated as individuals in this research). We call this process and approach "Research Justice," which is discussed in more detail in section 4. While the COVID-19 pandemic drastically changed how we could engage communities of color, we maintained our primary commitment to deferring to community members throughout the process. This meant reviewing and adjusting our research strategies to respect the multiple challenges and ongoing crises that community-based organizations and community members are experiencing during the pandemic.

This work could not have been accomplished without the input and guidance of members of the steering committee. A more detailed discussion about how this research progressed in collaboration with members of the steering committee is discussed in section 4.2. We are truly grateful for their ongoing participation during these challenging times. Members of the steering committee included:

- Ebony Clarke, Interim Director, Multnomah County Health Department &
- Director of Mental Health and Addiction Services, Multnomah County
- Ibrahim Coulibaly, President, NAACP-Eugene-Springfield
- Joe Enlet, Consul General for the Federated States of Micronesia
- Roberto Gamboa, Operations Manager, Euvalcree
- Daniel Garcia, Equity and Inclusion Analyst, Oregon Health Authority
- Holden Leung, Executive Director, Asian Health and Services Center
- Olivia Quiroz, Executive Director, Oregon Latino Health Coalition
- Elizabeth Rentería-Holden, Clinical Program Manager, formerly at Deschutes County Behavioral Health
- Tawna Sanchez, State Representative, House District 43 & Director of Family

Services, Native American Youth and Family Center
- Lore Vences, Executive Director and Statewide Peer Mentor, Caminos Diferentes

With the guidance of members of the steering committee, we were able to continue our work despite many challenges and strains on individual capacity. Together, we accomplished the following:

- Meaningfully engaged diverse communities of color across Oregon to understand what barriers exist to accessing culturally and linguistically responsive behavioral health care.
- Gained an understanding of the communities' experiences and visions for a culturally and linguistically responsive behavioral health care delivery system.
- Identified community-informed promising best practices for culturally and linguistically responsive services that can be integrated into a continuum of care to reduce health inequities.

Before discussing the specifics and findings from this research, we provide readers with important context to consider when approaching behavioral health among communities of color. In the next section, we discuss how BIPOC encounters with health systems must be situated within experiences and histories of trauma from the effects of racism, white supremacy, anti-Blackness, and exclusion and "othering." These conditions result in similar outcomes and shared experiences related to mental and behavioral health. Following this section, we present the current state of culturally and linguistically responsive behavioral health care in Oregon based on a shortlist of recent studies.

2. Understanding the Conditions and Experiences Affecting Mental and Behavioral Health of Communities of Color

One of the significant challenges of this research project has been capturing and communicating the diversity of experiences of communities of color when seeking and accessing behavioral health care services. The wide variety of experiences within racial and ethnic groupings such as Black/African-American, Latinx, Asian, Pacific Islander, and Native American deserve to be visibilized and understood. Ideally, these experiences should inform culturally and linguistically responsive and affirming investments, programs, and interventions that meet the specific and contextually situated needs of different communities of color. However, no matter how community-led, one research study cannot provide such comprehensive details and community-specific recommendations. It is incumbent on health systems to ensure that providers learn about the cultures and social histories of the communities they serve and ensure that culturally

specific community-based organizations are resourced to lead or be involved in these efforts. Further, it is never sufficient to gather knowledge about diverse communities via quantitative measures only; instead, working with community partners to understand the needs, strengths, and desires of communities of color via stories and narrative is critical.[4]

There is a wealth of research and publications on how mental and behavioral health is understood, experienced, and dealt with from the perspective of different minoritized and racialized communities in the United States. Although culturally and linguistically diverse, communities of color share certain experiences, which must be understood and considered when developing any culturally and linguistically responsive services.[5]

Trauma from the effects of racism, white supremacy, anti-Blackness, and experiences of exclusion and "othering" result in similar outcomes and shared experiences related to mental and behavioral health. These include:

- Greater levels of chronic stress due to persistent experiences of racism.
- Social isolation and fear due to economic precarity, smaller networks of social support, and the looming threat of state-led violence and retaliation against community members with undocumented status, to name a few.
- Lack of access to affordable health care and insurance or being underinsured.
- Avoiding seeking treatment due to lack of culturally and linguistically affirming locations and providers.
- Lack of culturally and linguistically appropriate communication, and therefore awareness, about services.
- Mistrust of healthcare providers due to experiences of medical racism.

Dangerous assumptions by the mental and behavioral health profession is another overarching reason why highly diverse communities of color often experience similar barriers to accessing health care services. It is well-documented that mental and behavioral health diagnosis and intervention practices are rooted in colonial, white supremacist, and capitalist logics that marginalize and "other" different cultural worldviews about wellness.[6] Yet, within these logics, certain assumptions are received as objective singular truths, including:

- What counts as "good mental health" and "dysfunction" is determined and validated by methodologies of Western science.
- Within these ethnocentric definitions, "good mental health" is an end worth pursuing.
- The path to "good mental health" can be monitored and measured.
- Problems can be isolated at an individual level and interventions can be designed to treat the isolated/localized problem.

- Secular licensed professionals are best suited to guide people through the health process.

Far too often, these assumptions do not reflect or affirm the experiences and worldviews of communities of color. As a result, communities of color can experience further isolation, underutilization of services, mistrust, and perceived ineffectiveness of health systems and providers.

- Other shared experiences and barriers across communities of color related to mental and behavioral health include:
- Lack of providers and services that use family – and community-centered care and treatment methods.
- Social and cultural stigma associated with mental and behavioral health.
- Differing cultural understandings of "mental health," "behavioral health," and "emotional wellbeing" that do not necessarily correspond to Western biomedical understandings.

Finally, it is vital to recognize the unique and shared experiences of communities of color with recent histories of immigration to the United States or who arrived as refugees. First, second, and third-generation immigrants may have concerns about mental and behavioral health that are distinct from communities of color without recent immigration histories.[7] For instance, the social, political, and economic histories of communities that have been resettled to the United States often include multiple prior resettlements in other countries. These displacements can mean that refugee communities lose connections with family and kin and economic and spiritual support networks, experience trauma associated with war, violence, and displacement, and often face increased levels of poverty, stigma, and exclusion in their country of resettlement. In addition, there are often complex intergenerational tensions and dynamics that can affect the wellbeing of individuals, families, and communities. These particular experiences have significant implications for their physical, mental, behavioral, emotional, and spiritual health. It is imperative for health care providers and practitioners to recognize and understand that immigration—along with racism[8] and colonialism[9] —is a social determinant of health.[10] This requires the unit of analysis to shift away from individual behaviors towards understanding how individuals are embedded within and connected to cultural, social, and political formations and histories, including the inequitable systems that perpetuate exclusionary practices.

3. The Current State of Culturally and Linguistically Responsive Behavioral Health Care in Oregon

Oregon has made advances towards health equity and developing health delivery systems that are culturally and linguistically responsive. Many of these policy and programmatic efforts integrate national Culturally and Linguistically Appropriate Services (CLAS) Standards into developing goals, policies, and benchmarks. CLAS Standards provide overarching principles and strategies to address and eliminate health disparities.[11] In Oregon, CLAS Standards have been guiding principles for the following:

- The Oregon Health Authority's 2015–2018 Statewide Behavioral Health Strategic Plan
- The Oregon Health Authority's Cultural Competence Continuing Education Committee
- Senate Bill 21 Service Equity Subcommittee (2013)[12]
- House Bill 2011 (2019)[13]

Because of these efforts, Oregon is one of only ten states that requires mandatory cultural competency training for "any person authorized to practice a health profession regulated by any Oregon State Health Profession Board" (HB 2011).[14]

Oregon has also been a national leader in establishing a continuum of care model through its Coordinated Care Organizations (CCOs) network that serves people who receive health care coverage under the Oregon Health Plan (Medicaid). CCOs provide coordinated care across the spectrum of physical, mental and behavioral, and dental health care.

In addition to CCOs, in 2011, Oregon established the six Regional Health Equity Coalitions (RHEC) that support eleven counties and the Confederated Tribes of Warm Springs. The RHEC aims to support local, community-driven, culturally specific activities to reduce health inequities and address social determinants of health in Oregon. RHECs have the potential to impact 60% of the state's total population.[15]

In 2020, at the onset of the COVID-19 pandemic, the Oregon legislature passed a law that requires health care providers to (1) collect disaggregated data on race, ethnicity, language, and disability (REALD) during COVID-19 encounters and (2) share this information with the Oregon Health Authority.[16] The collection, analysis, and reporting of disaggregated data is necessary for advancing health equity. The pandemic also catalyzed the Oregon Health Authority (OHA) to require that CCOs ensure that all services, including telemedicine, are provided

according to national CLAS standards.[17]

Yet, despite these advances in health equity and innovations to health care systems, Oregon faces numerous challenges in providing culturally and linguistically responsive behavioral health care. While CLAS Standards provide a framework for principles and strategies that agencies and health systems can adopt, these recommendations for improving culturally and linguistically responsive services are not grounded in or driven by the everyday lives and insights of communities of color in Oregon. When it comes to CCOs, administrative rule-making stipulates that "CCOs shall assure that members have a choice of providers within the CCO's network, including providers of culturally and linguistically appropriate services and their providers participating in the CCO."[18] However, it is common that these services are by request only, and it is frequently unclear how to access them. Furthermore, CCOs face a chronic shortage of multilingual and multicultural providers, especially in rural counties.[19]

Previous studies and research about experiences of communities of color in Oregon related to mental and behavioral health and navigating the state's behavioral health care system point to many of the challenges and gaps in serving communities of color. Below is a short list of recent studies and critical takeaways that illustrate these challenges and gaps:

- *Crisis de Nuestro Bienestar: A Report on Latino Mental Health in Oregon* (2020) by the Oregon Commission on Hispanic Affairs is an important synthesis of research about Latinx mental health in Oregon. The report demonstrates, for instance, the lack of culturally specific mental health providers, especially in rural parts of the state, and the role of schools as essential sites for accessing mental health care, especially for rural Latinx youth. The report includes important actions to be taken, many of which align with the recommendations in this report. The report advocates for:
  - Gathering better data on why higher rates of Latinx people terminate their relationships with mental and behavioral health providers.
  - Resourcing and cultivating a multilingual and multicultural pipeline of practitioners and workforce.
  - More robust training for providers and health systems staff about the cultural complexity of Latinx communities.
  - Integrating the services and locations provided by culturally specific organizations into the continuum of care.

- *Leading with Race: Research Justice in Washington County* (2018) by the Coalition of Communities of Color was a multi-year community-led research project that revealed many of the mental and behavioral health issues experienced by community members and barriers to accessing culturally responsive health care services. Some key takeaways by community include:

- African: Large Muslim, immigrant, and refugee populations experience higher rates of stress and depression.
- African-American: Heightened sense of social isolation and higher levels of poor health outcomes due to stress.
- Asian and Asian American: Least likely to seek out mental health services, and when folks do, they report it doesn't work; also lack of good data on health status and outcomes due to no disaggregation by ethnicity, ancestry, and place of birth.
- Latinx: Exclusionary immigration policies, undocumented status, and stress contribute to barriers to access and poor health outcomes; also, many folks do not seek care out of fear of having to answer citizenship questions.
- Native American: There are no culturally specific resources to facilitate processes of healing.
- Native Hawaiian and Pacific Islander: Language barriers and mistrust are the most common barriers; similar to Asian populations, the lack of disaggregated data means a poor understanding of health disparities and outcomes.[20]
- Slavic: Many community members are immigrants and experience barriers around language and insurance accessibility. When culturally-specific health care services are offered, data shows increased visits to clinics. No data on health outcomes exists; therefore, better disaggregated data collection is needed.

- *Multnomah County Mental Health Analysis* (2018) found that many stakeholders do not experience the mental health system positively. This could be due to: the complexity of the system with its multiple pathways and touchpoints; the need for better peer support and long-term, tailored community outreach and engagement; the need to receive care in settings chosen by community members; the lack of racial, ethnic, and cultural diversity among mental health care workers.

- *Mental Health Disparities for Latino Oregonians: Exploratory Analysis Using Administrative Data* (2017) by Kimberly Voelker found that over half of Latinx folks receiving mental health care were under the age of 18 (compared to 29 years old for the total population), and a larger percentage of Latino patients terminate patient care without approval.

- *Mental Health Service Disparities of Latino Oregonians: A Qualitative Analysis* (2017) by Diane St. Amour found that Latinx populations in Oregon often do not seek mental health care except in times of crisis. The barriers Latinx people face in accessing care are both structural and individual. Structural barriers include the lack of multilingual/multicultural providers, with interpreters often creating more hardships and barriers for patients; lack of culturally relevant services such as more family-centric approaches

rather than individual-centric approaches to mental health care and more integration of traditional healers (i.e., curanderos); fear of seeking care especially in the context of hostile immigration policies; and Latinx patients often being referred to non-culturally specific clinics. Individual barriers include fear of seeking care due to residential status; lack of insurance; lack of education on mental health issues and care; stigma associated with mental health; and barriers such as childcare, transportation, and work hours.

- ***The Portland African American Leadership Forum's (PAALF) People's Plan*** (2017) reported that gentrification and displacement have adversely affected health outcomes for Black community members. Due to experiences of repeated displacement, which can result in a traumatic stress reaction known as Root Shock[21], many community members live with trauma. Lack of housing security and continuity can also have deep, lasting impacts on children's physical, emotional, and cognitive development, including poorer mental health and educational outcomes.

For health systems like Oregon's CCOs to advance health equity, it is critical to provide space for, defer to, and act on the insights shared by those facing the greatest barriers to accessing care—communities of color, LGBTQ+, disability, and low-income communities, and their multiple intersections. It is equally critical to recognize that, due to these barriers, many communities have built their networks of care that are often invisible to and lack support from dominant actors, including health systems and policymakers. Understanding both the barriers/gaps and community-based solutions is necessary for supporting and delivering culturally and linguistically responsive care.

4. A Research Justice Approach to Mental and Behavioral Health among Communities of Color in Oregon

4.1 WHAT IS A RESEARCH JUSTICE APPROACH?

Research justice is an approach that centers and defers to community members' knowledge, expertise, experience, and wisdom for guiding the entirety of the research process. This approach is a response to a long history of oppressive research practices that continue to cause harm towards historically marginalized populations. "Research Oppression" upholds entrenched hierarchies that value the training and contributions of credentialed research professionals over the knowledge of community members; quantitative data as objective over community-based narratives, stories, and other qualitative data; extracts knowledge from communities and yields little community control and ownership

over data and publications; and does not support the self-determination and agency of communities to lead, inform, and manage research and implement findings.

To overcome these entrenched hierarchies of value, research justice focuses on three broad possibilities for reimagining research so that the process is strategic, transformative, and revolutionary. The specifics of these three possibilities are summarized in Table 1.

Table 1: Principles of Research Justice

RESEARCH JUSTICE		
Strategic	**Transformative**	**Revolutionary**
Research should build capacity, call to action, and center community needs, challenges, and desires	Research should educate, be a collective process, validate experiences, and lay a foundation for critical reflection	Research should build sustainable social justice movements, community power, and self-determination

Research justice is fundamentally a process-based approach rather than a results-based approach. This means that the entire research process is co-constructed with the very community-based stakeholders who are most impacted by and knowledgeable about the area of research. The research questions, objectives, data collection, analysis strategies, and reporting are informed and led by the community. Regular check-ins, feedback loops, and time for data review and vetting are incorporated at many points during the process. Research justice is an inherently open-ended and co-constructed process, so the questions, objectives, and approaches decided upon and adopted by community members may shift the orientation and results of the research. The principles of research justice inform the methodology of community-based participatory action research (CBPAR), which for this project meant being grounded in "meeting community where they are at," training community members to collect and analyze data with their own communities, and meeting with and engaging community members across the state. With the COVID-19 pandemic, we could not do many in-person forms of research typical for CBPAR.

In the following two sections, we discuss how a community-led process was established and then sustained through the pandemic to best drive this research on how Black, Indigenous, and People of Color (BIPOC) communities across Oregon experience the state's behavioral health care system.

4.2 THE STEERING COMMITTEE

Community members, leaders, and activists were invited to join the steering committee because of their deep expertise and lived experience with Oregon's behavioral health care system. The steering committee, formed in March 2020, represented and worked with communities of color living in Eastern and Central Oregon, the Gorge, the Coast, and the Portland metro area. The steering committee met four times between April 2020 and April 2021 for two hours each meeting. We also had several one-on-one meetings with steering committee members to understand and adjust research timelines due to the pandemic and wildfires, and discuss strategies and feedback about the data collection process.

Steering committee members were tasked with:

- Guiding this research to ensure that the most appropriate and responsible methods and strategies were adopted to connect with different communities of color.
- Providing insight and access into the experiences and knowledge of diverse communities of color, living in different geographic parts of the state.
- Co-constructing and vetting the primary data collection tool, which was a statewide survey disseminated in English and Spanish, to make sure the questions were culturally and linguistically meaningful.
- Reviewing survey data collaboratively to make meaning of the results.
- Ensuring that data from this research represented, visibilized, and treated people's experiences in ways that inform CCOs about best practices for providing culturally and linguistically responsive behavioral health services.

One of the first engagements with steering committee members in early March 2020 was to gather their personal experiences with Oregon's behavioral health care system. Members shared their experiences of what they like about the current system and what they dislike and want changed. A summary of their responses is in Table 2.

Table 2: Steering Committee Members' Experiences of Oregon's Behavioral Health Care System

Like	Dislike/Want Changed
Establishing diversity committees at behavioral care workplaces	Delivery and engagement models leave out many culturally specific communities
Trauma-informed approach is, to some extent, working well Treating mental health more as a public health issue and allocating more resources	Too little attention to building capacity of racialized groups, including training and jobs [especially jobs] for Community Health Workers, Peer Support Specialists, counselors to serve their own communities
Awareness about the historical neglect of behavioral and mental health as essential to whole-person health	Lack of culturally specific services in rural communities
Integration of behavioral health care into a continuum of care, and being able to get all of one's care in one spot	Need better granular, disaggregated data that accounts for the unique experiences of unique cultures
Breaking down of professional silos due to continuum of care model (e.g., physicians working with social workers)	Need a health care system that looks like our communities and is willing to learn from them
A few well-established organizations that serve Latinx clients	Lack of credible substance use treatment at Oregon's behavioral health hospitals
	Racist stigmas about African-American patients suffering from drug-induced psychosis believed to be violent and neglected by staff
	Criminalization of behavioral health and inadequate treatment in jails
	Programs promoting health equity and clients' first are "all talk"
	No leadership of color at the local or state levels while clinging to dominant culture processes and programmatic structures
	Rigid administrative or compliance rules for entry into care that serve the needs of the bureaucracy and not the community
	Not enough behavioral health services for Latinx communities and lengthy waitlists
	The payment system for culturally specific programs around mental health is an extra barrier to access. Formulas and equations might work for the mainstream population, but not the rest

Shortly after this exercise, the COVID-19 pandemic dramatically changed the trajectory of this research but also served as a reminder of the adaptability and resiliency of the CBPAR research process. The next section discusses the various reorientations made in collaboration with steering committee members to ensure that this research was respectful and reflective of the multiple crises experienced by communities of color.

4.3 COVID-19, RESEARCH JUSTICE, AND BEHAVIORAL HEALTH

This research began when COVID-19 was revealed to disproportionately harm communities of color—especially Black, Latinx, Native American and Indigenous, and Pacific Islander communities in Oregon. The pandemic amplified the gaping health inequities in the state and the severe lack of culturally and linguistically responsive health services. Culturally specific community-based organizations, which many of the steering committee members led, worked over-capacity to provide immediate relief and services, including mental and behavioral health support, to their communities. The steering committee understood that it was inappropriate to conduct CBPAR in its entirety in the middle of multiple crises faced by communities of color. It was recognized that if our work together, even during the pandemic, could influence how the state provides culturally and linguistically responsive services via CCOs, then the project had to continue.

During our first two steering committee meetings, we discussed the immediate and ongoing mental and behavioral health care needs of communities of color (see Table 3) and how best we could move this project forward. We agreed that it was essential to collect statewide data about experiences often not captured in other large behavioral health surveys. The types of questions deemed necessary to ask communities of color included: what are the sources or areas of stress, anxiety, frustration, and worry for folks, including children and elders; what prevents people of color from seeking care; why are communities of color distrusting of health care professionals; what local and cultural resources do folks depend on when mainstream providers are not accessible. These discussions led to the collective decision that the best and least burdensome way to collect data—and at this point many communities of color were also dealing with the devastation of the wildfires in the fall of 2020—was to co-construct a survey with a balance of quantitative and qualitative questions.

Table 3: Behavioral Health Care Needs and Challenges During COVID-19 as Identified by Members of the Steering Committee

COVID-19 Needs & Challenges Identified by the Steering Committee		
Technology, education, and internet access are barriers to telehealth	Folks who are certified are not being hired into the system	Increase in numbers of under-insured and uninsured
Services are continuing via telephone calls, but this is creating more work for staff and disrupting substance abuse treatments	There are other providers in rural areas, but they are not covered by OHP and therefore inaccessible to many communities of color; CCOs have even less availability for mental health plans	Communication from the state/health systems about services is frustrating, with language access often being an afterthought
AA [Alcoholics Anonymous] & NA [Narcotics Anonymous] self-support groups have started, but none were for Spanish-speakers, so they started their own	Resources put into translation, BUT message is not culturally specific—people don't know what to do with this information	Need to modify the "treat first" model to meet culturally specific needs
Increase in substance abuse and domestic violence (often unreported)	CBOs are shifting to provide OHP enrollment services	Scarcity of providers, including tech education, and drug & alcohol counseling
Lack of continuous commitment from the state to provide culturally responsive services	Need regionally specific training for CCO staff on our culturally and linguistically specific needs	Too much paperwork/red tape to start a service is counterintuitive to how POCs reach out for assistance

The decision to move forward with a survey was not taken lightly. Members of the steering committee were clear that many communities of color are fed up with taking yet another survey and not seeing any tangible benefits from the research. With so much survey fatigue and apprehensions about participating in another study, we did weigh other options, such as partnering with community-based organizations (CBOs) to develop programming to support mental and behavioral health and collecting data through the delivery of programs and services. However, with the pandemic and the wildfires, this type of option was rightly deemed too burdensome for already over-capacity CBOs dealing with multiple crises. The group felt that, at this time, the most direct path to gathering data via an online survey was the best option, as long as we: asked relevant questions, compensated community members well for the time taken and knowledge shared when completing the survey, ensured that data was shared back to the community, and strong recommendations were clearly advocated to the state.

4.4 SURVEY CONSTRUCTION AND DISSEMINATION

Between September 2020 and November 2020, we co-constructed a survey asking communities of color about their experiences with mental and behavioral health, providers, and the health care system. Members of the steering committee provided extremely valuable feedback on multiple drafts of the survey. Members expressed the importance of ensuring that the wording of the questions in English and Spanish was accessible—meeting a 6th-grade standard—and that any Anglo-centric language was avoided. For instance, several steering committee members pointed out that terms like "mental health" and "behavioral health" may not be culturally appropriate or meaningful, or easily translated. Instead of using these biomedical and Western/Anglo-centric constructs, we included questions such as: "Thinking about your daily routine, what are some things that contribute to you experiencing stress, frustration, worry, and anger?"

Other feedback included adding questions like:

- Do you see yourself as needing some assistance with mental help? Have you ever been to a counseling session?
- How do patients feel about the treatment they receive from their providers? Do patients feel validated? Do patients feel heard and understood?
- Does your CCO provide the information necessary for you to access behavioral and mental health services in your area?
- What fears do you have when meeting with a provider?
- Do you think there are enough providers who look like you and speak your language available to you in your community?

These questions, or versions of them, were included in the survey with the steering committee's guidance and feedback. The survey was also vetted by members of two workgroups that were part of the Oregon Health Authority's survey modernization effort. The latter was a project that convened BIPOC community members about addressing the shortcomings of the Behavioral Risk Factor Surveillance System, an annual nation-wide telephone survey conducted in collaboration with the CDC. Both the Black/African-American workgroup and Latinx workgroup provided feedback on the survey questions and findings.

The dissemination of the survey was also a community-led effort. The survey was circulated by members of the steering committee and their statewide networks, both workgroups, and several members of the BIPOC Decolonizing Data Council. Intentional efforts were made to reach out to communities outside the Portland metro area and historically underrepresented communities including Native/Indigenous and Pacific Islander communities. It was also important for individuals to decide the most appropriate way, culturally or otherwise, for community members to take the survey. In one instance, a member of the Latinx workgroup was provided with additional community engagement funds

so that her organization's staff, who serve Latinx folks along the Gorge, could enter people's verbal responses to the questions into the online survey. Already having trusted relationships with community members and then recognizing and accommodating community – and relationship-centric data collection helped tremendously in reaching out to folks who may not have otherwise participated in this research.

The online English and Spanish surveys included 33 questions and was created in Qualtrics. Respondents were compensated with a $125 gift card after completing the survey.

4.5 DATA ANALYSIS

In total, 444 participants completed or partially completed the English and Spanish language surveys. The English language survey was completed or partially completed by 260 people, and the Spanish language survey was completed or partially completed by 184 people. The responses of people who partially completed the survey are also included in the findings, so the sample size number (n) varies depending on the question being analyzed.

Closed-ended or quantitative questions were analyzed using Excel and Statistical Package for the Social Sciences (SPSS) software to present descriptive statistics for each question. Pivot tables and crosstabs were used to gain insight into relationships between two or more variables. Open-ended or qualitative questions were analyzed by first doing open coding and then synthesizing these codes into more meaningful and encompassing categories that could convey emerging patterns from the responses to each open-ended question. Demographic information was collected using the REALD format in both surveys.[22]

We analyzed all of the quantitative questions in both the English and Spanish language surveys and disaggregated a selection of English language questions by race. The majority of the participants identified as Black/African-American (BAA) (53%) and Latinx (32%). Other racial and ethnic groups from the English language survey are represented in Table 4. In the English language analysis, participant experience was disaggregated by race. The Spanish language survey participants all identified from across the range of REALD Latinx categories (See Appendix 1 for details). Due to time and capacity constraints, we were only able to analyze a selection of the English language qualitative questions and no Spanish language qualitative questions—a complete analysis will be done in the future. Yet, the qualitative questions we did analyze provide a tremendous amount of context for gaining insight into the needs and barriers relating to mental and behavioral health care that communities of color experience.

The data analyzed in this report have also been presented to members of the steering committee and the survey modernization workgroups (Black/African-American and Latinx). We set aside ample time with each group in March and April 2021 to review the data and engage in "meaning-making" exercises. Each group reflected on the findings from several of the survey questions by responding to the following prompts:What does this finding mean to you?

- What about this finding does or does not resonate with you?
- What recommendations might come out of a finding like this?
- Any other thoughts on this finding?

These meaning-making sessions allow folks to see the survey results that they had co-constructed and create a space for us to collaboratively interpret the data and draw conclusions and recommendations vetted by those who have the expertise and lived experience of Oregon's behavioral health systems.

Table 4. English and Spanish Speaking Participant Race and Age Demographics

Race/Ethnicity	English Speaking %(N)	
Black/African-American	53%(121)	
Latinx	32%(72)	
Native American/ Indigenous	6%(13)	
Asian	4%(8)	
White	1%(2)	
Middle Eastern	1%(3)	
Pacific Islander	4%(8)	
Age	**English Speaking %(N)**	**Spanish Speaking %(N)**
>18	0.8%(2)	0.5%(1)
20-25	17.3%(45)	8.5%(17)
25-30	19.6%(51)	10.6%(21)
30-35	9.2%(24)	9.0%(18)
35-40	9.2%(24)	10.1%(20)
40-45	9.6%(25)	9.5%(19)
45-50	8.1%(21)	6.0%(12)
50-55	5.0%(25)	4.0%(8)
60 +	16.9%(44)	0.5%(1)
Missing	13.8%(36)	37.7%(75)

5. Findings

The survey findings presented in this section are organized according to the following themes:

- Types of support needed (qualitative analysis and findings)
- Utilization of behavioral health services (quantitative analysis and findings)
- Barriers to accessing behavioral health services (quantitative analysis and findings)
- Sources of behavioral health support (quantitative and qualitative analysis and findings)
- Experiences of providers (quantitative and qualitative analysis and findings)

The English and Spanish language survey findings are presented separately. Even though both surveys were identical in terms of the questions asked, we felt it was important to separately present the two surveys' findings so that any disparities in the data attributed to a person's preferred language could be visible.

5.1 TYPES OF SUPPORT NEEDED

In response to the steering committee's request to use accessible language around mental and behavioral health, we framed open-ended questions about experiencing stress, frustration, worry, and anger as mental health and addiction to alcohol, drug, gambling, domestic violence, and child abuse as behavioral health. In addition, participants were asked what types of support they need personally and for their children, elders, and community. Respondents overwhelmingly agreed that everybody needs more counseling and mental and emotional support. They explain that this could also include motivational support and encouragement, should be low-cost or no-cost, and culturally and linguistically specific. In addition to this most common response, the top six categories from participant responses are detailed in Table 5.

Table 5. Qualitative Mental and Behavioral Health Support Needs (N = 259)

Needs Identified for Self	Needs Identified for Children, Elders, and Community
Cultural group/community connection	Basic needs, financial support, food
Basic needs, financial support, food	Cultural group/community connection
Peer support groups and group therapy (e.g., Black mothers and teens affinity groups)	More access to low cost or no cost behavioral health programs, social services, health, and dental providers
Physical human contact and in-person social interaction	Referrals to more advocates and guides for navigating health systems, and more information/materials in various languages
Fun, creative, and stimulating activities, including art-based activities and access to nature	Affordable and culturally specific and community-centered rehabilitation options
Education, tutoring, and student support including culturally and linguistically specific reading resources	Physical human contact and in-person social interaction

The three overlapping support needs self-identified by participants and those of their children, elders, and community include cultural group/community connection; basic needs, financial support, food; and physical human contact. Most interesting in these comments were that many of the solutions to mental and behavioral health issues lie in connecting the community along cultural lines (i.e, those who share their experiences), getting basic human needs met, and having more social interaction and in-person connections.

Other self-support needs included peer support groups and group therapy centered on affinity groups like Black mothers or teens. Even though the question was about self, many of the respondents focused on their kids' needs, such as fun and stimulating activities (e.g., art and being in nature) and culturally and linguistically specific educational resources, tutoring, and overall student support.

More access to behavioral health programs and services like dental and health care at low or no cost, and affordable and culturally specific rehabilitation services for children, elders, and the community were typical responses. Many also mentioned the need for information and referral beyond the traditional 211 model. They do not want phone numbers to call an organization to help them. Instead, they prefer a community advocate, someone who can walk them through the services available and aid them in finding the help they need.

Overall, many of the responses were overlapping and demonstrated that many BIPOC people are not oriented toward self alone but see their needs in relation to their family and community. Other essential examples in this section include the need for sports, physical outlets and free exercise opportunities; mentors, leaders, and forms of training that provide motivation and encouragement; training to care for children and the elderly; and wraparound services for those experiencing domestic violence or child abuse.

5.2 UTILIZATION OF BEHAVIORAL HEALTH SERVICES

Participants were asked to share their proximity to behavioral health services—in other words, whether they have accessed services themselves or know someone who has (e.g., family, friends, community members). Of those who did use behavioral health services, participants were asked whether they seek services at a CCO, and if so, which one. Lastly, participants were asked how often they use the services of health care interpreters and traditional health workers.
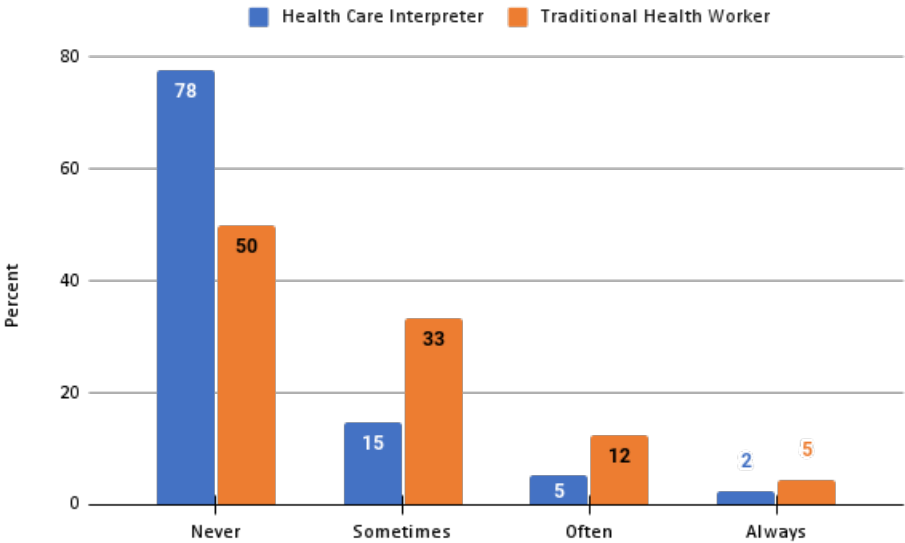
English Language Findings
Among English-speaking participants, the majority (53.8%) knew someone in their family (16.6%), friends (18.8%), or community (18.4%) who have received behavioral health services. Only 23.1% used behavioral health services themselves, and 23.1% did not know anyone. Among Black/African-Americans (BAA) and Latinx groups, 48% BAA personally used behavioral health services, while amongst Latinx participants, 22% used behavioral health services. Among those who did use behavioral health services, only 20.6% used Coordinated Care Organizations (CCO), and the majority indicated that they are enrolled with Health Share of Oregon (Multnomah, Washington, & Clackamas) (see Table 6). Among those receiving behavioral health services, most participants indicated there were limited health care options that understood their cultural background (62%) or had providers that spoke their language (47%).

Table 6. Utilization of CCOs by Participants (N = 259)

CCOs	Count
Columbia Pacific Coordinated Care Organization (Clatsop, Columbia, & Tillamook)	3
Eastern Oregon Coordinated Care Organization	1
Health Share of Oregon (Multnomah, Washington, & Clackamas)	17
InterCommunity Health Network Coordinated Care Organization (Benton, Lincoln, and Linn)	2
PacificSource Community Solutions – Columbia Gorge (Hood River & Wasco)	2
Trillium Community Health Plan (Lane & NW Douglas)	1

When it comes to using (sometimes, often, or always) health care interpreters (HCI) and traditional health workers (THW), 22% of participants use HCIs and 50% of participants use THWs (see Figure 1). It is interesting to note that (1) THWs are utilized at twice the rate as HCIs, and (2) when asked to elaborate on why participants use HCIs and THWs, many interchanged peer support specialists with THWs in the context of having positive experiences.

Figure 1. Utilization of Health Care Interpreters (HCI) and Traditional Health Workers (THW) (N = 259)

Spanish Language Findings
Among Spanish-speaking participants, the majority (61.1%) did utilize behavioral health services or knew someone who did. Among those who did use behavioral health services, 31.2% used Coordinated Care Organizations (CCO), but none of the participants indicated which CCO they primarily used. Only 18% Spanish speaking participants receive behavioral health services from CCOs, while the vast majority receive assistance from other sources. Among those receiving behavioral health services, most participants indicated there were limited health care options that aligned with their cultural background or had providers that spoke their language. Subsequently, only 18% of participants indicated that they always used a health care interpreter, which could be due to the limited options of providers who spoke their language. Among those who knew someone who used behavioral health services, more participants knew friends (13.5%) than family members (9.3%).

5.3 BARRIERS TO ACCESSING BEHAVIORAL HEALTH SERVICES

It was important to capture, in as much detail as possible, the factors that prevent BIPOC people from accessing behavioral health services. Table 7 presents the options available to participants. There was also an "other" option for any qualitative responses. These same options were provided in the Spanish language survey.

Table 7. List of Barriers on the English Language Survey (N = 259)

Distance	• CCO/health provider is too far away Don't have access to transportation Don't have access to childcare The service(s) I/we need is not available near me
Cultural and Linguistic	Provider cannot communicate in a language that I'm comfortable using Provider doesn't have the same cultural background as me Information about services is not provided in a language that I'm comfortable using Don't trust that my CCO/health provider will be respectful of my cultural values
Process	Process for making an appointment with a provider is difficult
Communication	Don't have consistent access to internet for virtual appointments Not aware of what services are available near me
Safety	Don't feel safe visiting my provider
Insurance	Don't have health insurance The service(s) I/we need is not covered by my insurance

We also asked participants about the level of ease or difficulty they experience in accessing specific types of behavioral health services, such as counseling/therapy, suicide prevention, tobacco cessesation, substance abuse treatment, etc.

English Language Findings

Participants selected what barriers prevent them from using behavioral health services (see Figure 2). The majority of participants (29.3%) indicated cultural and linguistic differences or lack of cultural understanding as the top barrier to participating in CCOs. The next pressing barrier for participants was a lack of communication (28.4%), followed by insurance concerns, and distance-related concerns. The top three barrier types by race and ethnic groups are represented in Table 8.

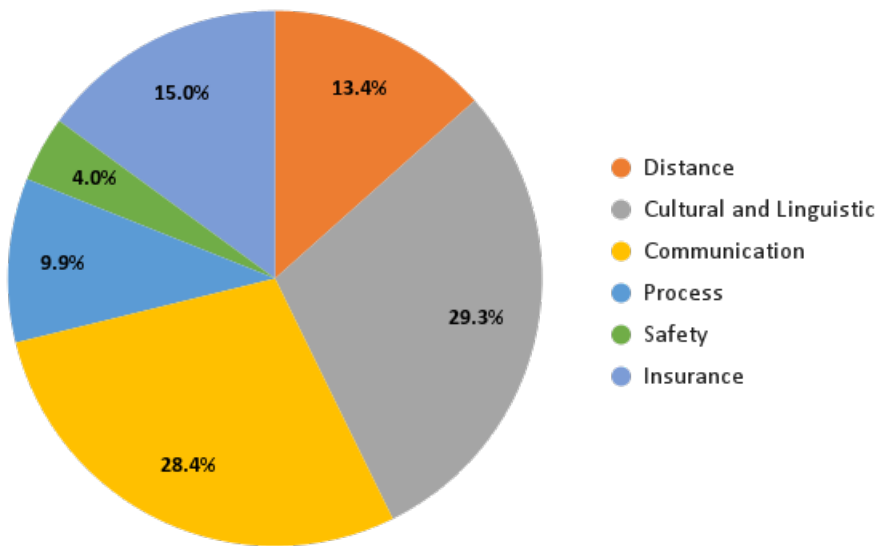**Figure 2. Barriers to Accessing Providers (N = 259)**

Table 8. Top 3 Most Frequently Chosen Barrier Type by Race/Ethnic Group (N = 259)

Communication	Culture/Language	Insurance	Process

		Top 3 Most Frequently Chosen Options			
BAA	**Latinx**	**Native/Indigenous**	**Asian**	**Pacific Islander**	**Middle Eastern**
Not aware of what services are available near me	Not aware of what services are available near me	Don't have consistent access to internet for virtual appointments	Not aware of what services are available near me	Provider doesn't have the same cultural background as me	Provider cannot communicate in a language that I'm comfortable using
Provider doesn't have the same cultural background as me	The service(s) I/we need is not covered by my insurance	The service(s) I/we need is not covered by my insurance	Process for making an appointment with a provider is difficult	The service(s) I/we need is not covered by my insurance	Provider doesn't have the same cultural background as me
Don't trust that my CCO/health provider will be respectful of my cultural values	Process for making an appointment with a provider is difficult	Process for making an appointment with a provider is difficult	The service(s) I/we need is not covered by my insurance	Not aware of what services are available near me	Not aware of what services are available near me

In terms of accessibility of services, all of the participants had some level of awareness about services. English-speaking participants indicated that tobacco cessation was the easiest program to access, while counseling and therapy were the most challenging services to access (see Figure 3).

Figure 3. Accessibility of Behavioral Health Services for English Speaking Participants (N = 259)
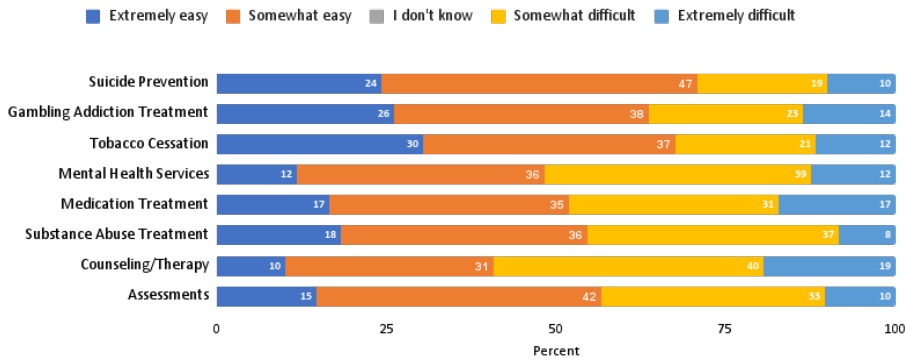
Spanish Language Findings

Participants selected what barriers prevent them from using behavioral health services. In terms of barriers to participating in CCOs, the majority of participants (36%) indicated that not having health insurance or not having services covered by health insurance was a barrier (see Figure 4). The next pressing barriers for participants were a lack of communication (27%), awareness about CCOs, or the lack of access to the internet. All of these barriers may coincide with low enrollment in CCOs among Spanish-speaking participants. In terms of accessibility of services, all participants had some level of awareness of the listed services. Spanish-speaking participants indicated that substance abuse treatment was the most accessible program, while mental health services were the most challenging service to access.

Figure 4. Accessibility of Behavioral Health Services for Spanish Speaking Participants (N = 184)
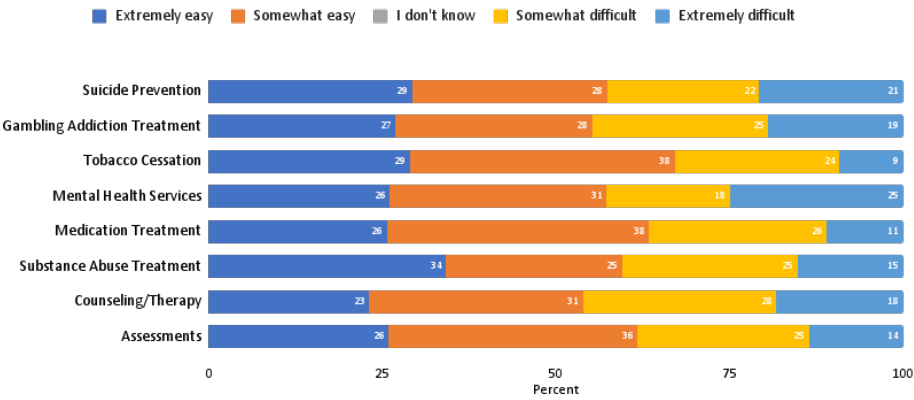
5.4 SOURCES OF BEHAVIORAL HEALTH SUPPORT

Participants were asked where they, or their family members, seek out mental and behavioral health care services and support. In analyzing the data, we grouped the options into dominant sources (CCO, urgent care, ER), culturally-specific sources (traditional healer, religious figure, culturally-specific organization), and community-based sources (community clinic and community organization).

English Language Findings
42% of respondents find behavioral health care at culturally-specific sources, with religious figures being the most visited source for care among all categories (20%). Among dominant behavioral health sources, the majority received services from CCOs (17%), followed by urgent care (12%) and emergency rooms (9%). Among community-based sources, participants primarily sought support from community clinics (14%), followed by community centers (6%). See Table 9 for the breakdown of responses.

Table 9. Where English Language Speakers Received Behavioral Health Care Services (N = 259)

Culturally Specific		Dominant		Community-based	
Religious Figure	20%	CCO	17%	Community Clinic	14%
Cultural Organization	14%	Urgent Care	12%	Community Center	6%
Traditional Healer	8%	ER	9%		
Total Utilization		Total Utilization		Total Utilization	20%

Spanish Language Findings

Respondents mostly (40%) found behavioral health care at community-based sources, with community clinics being the most visited source for care among all categories (27%). Among dominant behavioral health sources, the majority received services from CCOs (18%), emergency rooms (10%), and urgent care (5%). Among culturally specific sources, participants primarily gained support from religious leaders (13%), culturally specific organizations (10%), and religious figures (3%) for their behavioral health needs. See Table 10 for the breakdown of responses.

Table 10. Where Spanish Language Speakers Received Behavioral Health Care Services (N = 184)

Community-based		Dominant		Culturally Specific	
Community Clinic	27%	CCO	18%	Religious Figure	13%
Community Center	13%	ER	10%	Cultural Organization	10%
		Urgent Care	5%	Traditional Healer	3%
Total Utilization		Total Utilization		Total Utilization	

Participants were asked if they or their family members had experience with Traditional Health Workers and why they utilized them for issues regarding stress, frustration, worry, and anger. Many participants were unsure of the distinction between traditional health workers and medical professionals; thus, it was difficult to distinguish which they were referring to in some responses. Further, many participants indicated that they and their family did not need outside support for mental or behavioral care. See Table 11 for the breakdown of responses.

Table 11. English Language Speakers Experiences with Traditional Health Provider* (N = 259)

English Language Speakers Experiences with Traditional Health Provider	
Traditional Health Provider*	• Religious leaders and ideologies • Friends and families • Massage therapists • Community-based organizations and community members
Reasons for Utilizing Traditional Health Provider*	• Meeting mental health needs and supporting during times of crisis • Cultural understanding • Shared values and life experiences • Financial burden (high cost) of institutional/dominant options • Substance abuse programs, include Alcoholics and Narcotics Anonymous and interactions with sponsors • Distrust or animosity toward medical professionals • Experiences of cultural shock
Benefits	• Cultural and linguistic relevance to participants • Helpful one-on-one health training and support
Challenges	• High quality health care is dependent on the individual health care provider • Pushing beliefs or agendas

"Provider" is used here in place of "Worker" to distinguish many participants' conflation of Traditional Health Workers, as established by the Oregon Health Authority, with traditional, often non-dominant support providers such as religious leaders, friends and family, and community organizations, etc. We define dominant providers as hospitals, doctors, social workers, etc.

Among those participants who had used this type of support or knew some who did, many sought care and counsel from religious or spiritual figures. Spiritual wellness was also an essential aspect of health care among participants. This highlights how vital it is to collaborate with and support religious or spiritual figures in addressing mental and behavioral health needs among communities of color. Participants also gained support from religious ideologies through prayer or faith and their religious community members. Collective community support either from members or community-based organizations (CBO) was mentioned a few times by participants as a source of mental and behavioral support. The second most significant source of support came from friends and family members, especially during challenging life events. Many participants used peer support specialists and doulas for health needs from personal connections and religious leaders. Below we provide some of the responses that speak to these sources of care. Some responses have been edited for clarity.

"My family and I have all sought out our own shamans, if you will, over time. We believe there is more than medicine and science and that the spiritual world is of much value, too."

"My mother would often speak to her attorney for counseling purposes during her depression and divorce because they were a family friend, and they were advising on the divorce privately."

"Honestly sometimes it is better to receive care from other community members and provide care for them because we get each other, we validate each other, and we don't feel as isolated."

Participants said that they used traditional or non-medical sources of behavioral health support for a variety of reasons. Many participants indicated that they used traditional care options because of previous negative experiences as well as time and financial burdens associated with medical professionals. Participants also noted that those offering more traditional forms of care had similar cultures and values, which was an important aspect of support. Some participants sought help from sponsors and religious-affiliated programs for substance use. Many participants received language interpretation from traditional health care workers, but language barriers were still a significant factor concerning care quality. Participants were more satisfied when traditional health care exhibited high levels of helpfulness, mutual trust, and active listening. For both medical and traditional providers, those who pushed an agenda on participants were deemed poor quality. The quality of traditional sources of care was very dependent on the individual health care worker, which highlights the need for more resources in this field to encourage a consistent level of care.

"We have gone to chiropractors, acupuncturists, and other alternative-medicine professionals. The reason is simply it's cheaper than going to a real doctor."

"I chose to have a home birth due to my distrust with the medical field, specifically with my local delivery unit. If you don't meet their specific birthing timelines, they intervene. I did not want those interventions, so I chose to seek out a midwife that came recommended by fellow Hispanic community members."

"I work with some [traditional health workers]. Some are better trained than others. Many have good intentions but often lack some professional expertise."

5.5 EXPERIENCES OF DISCRIMINATION FROM PROVIDERS

Participants were asked to share experiences of discrimination during encounters with medical providers. We used a modified version of the "Everyday Discrimination Scale"[23] and followed up with open-ended questions about why participants may fear seeking support and why providers are perceived and experienced as untrustworthy.

English Language Findings
The frequency of discrimination was primarily dependent on the type of discrimination experienced by English-speaking participants. Of those who did experience discrimination sometimes, 44% experienced poorer service from their providers, and 43% experienced less courtesy due to their race or ethnicity (see Figure 5). Of those who did experience discrimination most of the time, 19% said that their provider did not listen to them, 16% experienced less courtesy, and 16% said their provider presumed they were less competent due to their race or ethnicity. In addition, the majority of participants (52%) indicated that their mental and behavioral health providers were only somewhat considerate of cultural background.

Figure 5. Types of Discrimination Experienced by English Speaking Participants
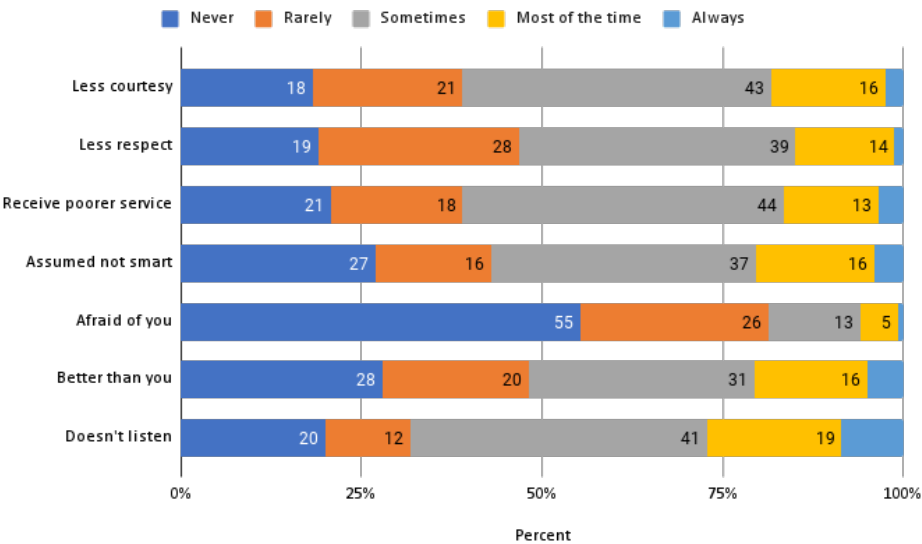
Participants were asked to share some of their fears when meeting a provider. A total of 245 participants responded to this question, and after analyzing responses, several themes emerged related to fears. The most common responses around fear included:

- Being judged and stereotyped by providers because of their identities and beliefs
- Not being taken seriously by providers
- Experiences of cultural insensitivity from providers
- Experiences of not being listened to and understood by providers

Many of these fears are implicitly or explicitly connected to experiences of racism by medical providers. Below we provide some of the responses that speak to each of these areas of fear. Some responses have been edited for clarity.

Fear of being judged

"I fear being shamed for things I fundamentally believe to be positive. I fear not being heard or dismissed and underestimated. I fear judgement and being misgendered. I fear that they will not take me seriously or refuse to let me decline treatment plans that do not align with my values and boundaries."

"Fear of being judged, and treated according to their preconceived racist and oppressive service delivery. Then weighing options for care between traditional cultural approaches and western medicine views. It is public knowledge that the health care industry has historically misdiagnosed, mistreated, and mis-cared for people of color. And not believing patients of color in pain management needs, or other mental and physical needs. Whyyyy on earth are we to believe this has just randomly stopped across the board?"

Fear of not being taken seriously

"I worry about asking for help because I worry they don't take me seriously or have started judging me the minute I start talking."

"Because of my language barrier they may not take what I would say seriously or have the patience to understand what I was trying to say."

Fear of cultural insensitivity

"I didn't see a doctor for a few years until I was able to find a Black Woman OB/GYN who went to an HBCU (Historically Black College or University) and has knowledge regarding my culture. I was tired of my physician not understanding and not caring or showing any empathy."

"That they don't listen, or will make grand assumptions and not understand some of the concerns I have based on cultural norms."

Fear of not being listened to and understood

"They don't listen and have preconceived biases, and it's known that they treat black people poorly so I have that feeling going in."

"That they won't actually listen to me. That they will assume I don't really know my own body. That they will assume I am only trying to score medications rather than help."

Participants were also asked to describe why they might experience providers as untrustworthy. A total of 220 participants responded to this question, and after analyzing responses, three top themes were identified for why patients experience providers as untrustworthy: providers lack empathy, patients have experienced harmful care practices, and patients have been stereotyped by providers. Table 12 provides specific examples for each of these themes.

Table 12: Reasons for Experiencing Providers as Untrustworthy (N = 259)

Top 3 Themes	Examples
Providers lack empathy	• Dismissive • Patient feels unheard • Disrespectful • Rushed appointments
Experiences of harmful care practices	• Denied care • Misdiagnosis • Unnecessary treatment • Need to self-advocate
Stereotyping by providers	• Presumed incompetent • Assumed drug addiction

Spanish Language Findings

The majority of Spanish-speaking participants did not experience the types of discrimination listed in the question. Among those who did experience discrimination sometimes, 32% experienced less respect from their providers, and 31% experienced less contact or received poor service due to their race or ethnicity (see Figure 6). In addition, the majority of participants (52%) indicated that their mental and behavioral health providers were only somewhat considerate of cultural background.

Figure 6. Types of Discrimination Experienced by Spanish Speaking Participants (N = 184)
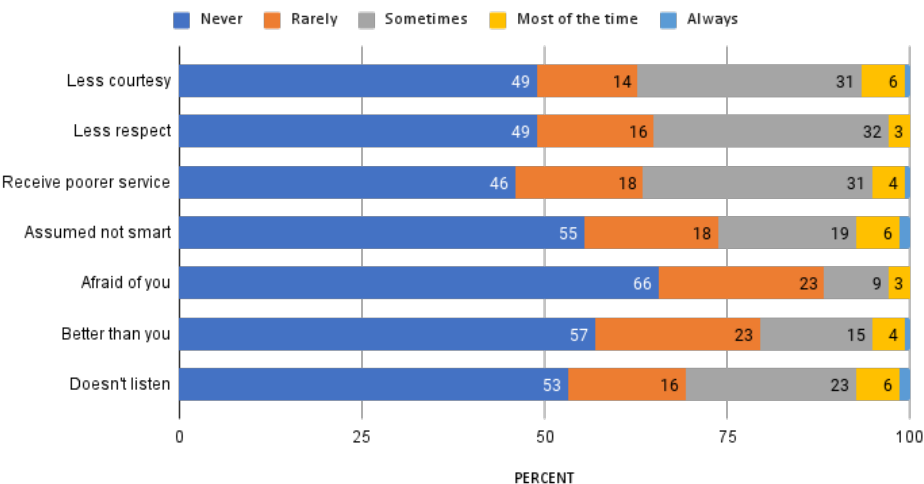
5.6 Providers' Consideration of Cultural and Linguistic Needs

Participants were asked to share how they experienced providers' consideration of their cultural backgrounds and language needs, especially in terms of how providers communicate about services and how participants experience encounters with providers. Participants also shared how health systems and providers can do a better job of understanding their community's needs when communicating about services and what they wished providers knew about their communities.

English Language Findings
More English-speaking participants indicated that providers did not consider their cultural background (31%) compared to their language (17%) when communicating about services. However, most participants indicated that both their cultural background (58%) and language (53%) were somewhat considered by providers. English speakers indicated that their language (30%) was very much considered by providers, while only 12% indicated that their culture was very much considered. Very few English-speaking participants indicated that providers were never considerate of their concerns; most participants indicated that practitioners were either sometimes considerate or often considerate of their concerns. Figure 7 depicts the overall provider consideration of English speaking participants' health concerns. Figure 8 represents the count of those

who indicated they are always listened to, understood, affirmed, and provided with enough information by providers, disaggregated by race and ethnicity.

Figure 7. Health System Consideration of Culture and Language when Communicating about Services (English Speaking) (N = 259)
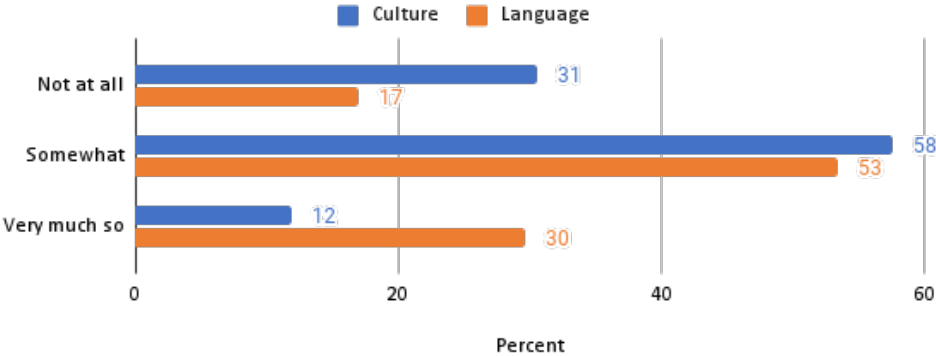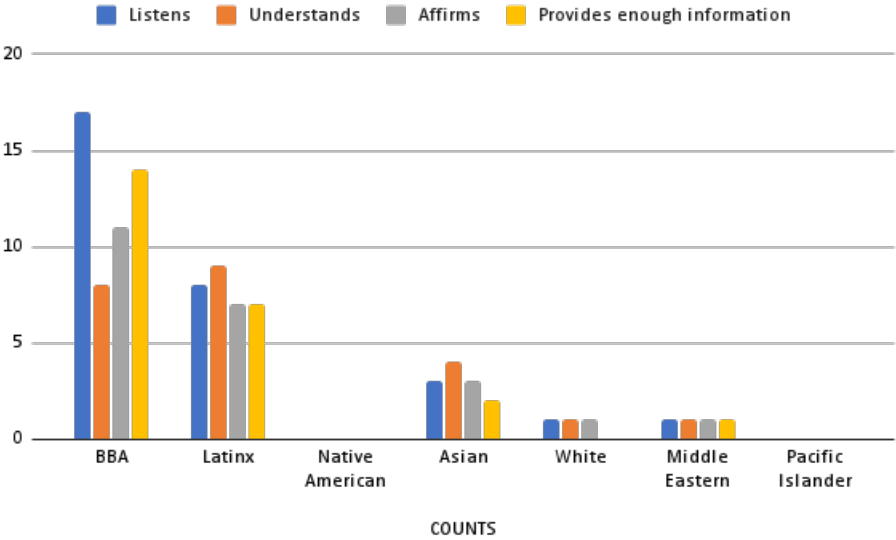

Figure 8. Provider "Always" Considers Health Concerns by Race and Ethnicity (English Speaking) (N = 259)

Note: Figure 8 depicts providers that always consider participants' concerns. None of the Pacific Islander or Native American participants indicated that their concerns are always considered.

Two qualitative questions were asked about their providers' consideration of cultural and linguistic needs: (1) How can health care systems do a better job of understanding your community's culture and language when communicating information about stress, frustration, worry, anger, addiction, violence, and/or abuse to your community and (2) what do you wish you provider knew about you and your community? Overall, most participants shared that health care systems generally fail at providing a good experience for BIPOC communities. Below are the most common areas that, according to respondents, need to change for better mental and behavioral health encounters paired with quotes that detail their experience and desires.

Health care systems and providers need to:

Be More Open Minded and Curious: The most common response was a desire for systems and providers to be more open and curious about their patients' lives and needs by asking more and better questions. Participants also desire for providers to listen carefully, demonstrate understanding and empathy, and not make assumptions about folks based on the information that systems collect and physical appearance.

> *"Be curious. Ask questions to gain understanding of why someone might be hesitant to take a prescribed remedy. Spend time learning about the individual in front of them and how their culture has informed who they are on that day that they are seeing the care professional."*

> *"By asking questions and by creating the environment for us to talk freely, to be patient, to listen and understand."*

Educate & Train: The next most common response was that systems and providers need provide more culturally-informed, anti-racist, and decolonizing training.

> *"Taking time to familiarize themselves with tribal values, most tribes have cultural centers that would be happy to offer training and information on these matters."*

> *"I speak English, but there are certain dynamics with how BIPOC folks and women of color express and/or articulate our experiences with racism, sexism, etc. If health care providers were better trained, they would know what kinds of questions to ask."*

Accommodate & Acknowledge Cultural Realities: In addition to education and training, participants clarified that this knowledge must be practiced through skills that help providers accommodate and acknowledge cultural realities. No formal education or training will give all of the tools to provide culturally specific and trauma-informed care (including race/ethnicity, gender, sexuality, religion,

etc.). The best way to begin learning and practicing culturally specific and trauma-informed care is to accommodate folks, meet them where they are, and acknowledge cultural and trauma-specific realities that patients share during their visits.

"That no one enters a clinic room or hospital for fun. Thus, take concerns seriously the first time and approach us with the full range of options and facts. To understand that what you learned in school isn't the only/right approach to "health" and that every community looks at it differently. To work with us where we are at in our journey instead of forcing us to jump to a standard that is nonsensical and unachievable."

"I wish they knew more about the family structure. A lot of the time, the oldest daughter or son will become sort of an interpreter of the family and a leader. I wish they wouldn't look down on that."

"I wish they were more knowledgeable about my community's cuisine and make recommendations that healthily support the good and bad of it for overall improved wellness. Same goes for recognizing cultural norms and factoring what can/cannot easily be changed."

Hire Diverse Staff & Decision Makers: Another typical response explained the need for more diverse staff and decision-makers with shared experiences as BIPOC people and who are culturally competent in their areas of expertise. Respondents did mention the importance of having good allies in the healthcare system, too. However, the sentiment was clear: the best way to provide better culturally and linguistically appropriate care is to hire folks with firsthand experience.

"At this point, hiring and training more queer POC folks as well as diversifying the ways one can get care outside of the health care system i.e. birthing folks using doulas and being able to get those paid for by insurance. I think we've repeatedly had this conversation and there's a point where the current people and systems have to step back and let the folks who have the knowledge of the community and other ways of health lead."

Improve Interpretation & Cultural Competency: Participants often mentioned the lack of written and spoken [or American Sign Language] translation available to them about mental and behavioral health care. Most importantly, they discussed considerable gaps in cultural competency when materials are translated. It was clear that translation from English to another language is insufficient to provide good culturally and linguistically specific care. Interpreters also need cultural competency. One solution for this is to invest in more peer support specialists, so that community members have both interpretation and cultural competency

when receiving care.

"Knowing about our culture and family dynamic. If using an interpreter, it'd be nice if they found someone that not only spoke the language but also has had training in cultural competency. It's hard not all Latino families are going to be the same and in that not all families of any ethnicity will be the same. We all have our own way of dealing and coping. Latinos for the most part don't do counseling. You don't share what happens behind closed doors with strangers. Your family's issues are yours and we are used to taking care of each other which tends to sometimes be more enabling. Getting straight answers and asking very personal questions directly is very uncomfortable for many people in my ethnic group. So, it's tricky when you're discussing medical and emotional issues. It's easier and less invasive to try and take care of yourself and your family since sometimes people are scared of what could cause them to get in trouble."

"They should understand that Hispanic people not all of them believe like in mental health they don't really believe that that is an issue or an illness so I think that providers would be nice if they knew that somehow"

"Having interpreters with skills of medical terminology. This is very important especially for any chronic illness. It is very important to understand very well in their own language."

Take Time with Patients: The final most common response was that all of these culturally and linguistically specific approaches require more time with patients. Participants feel rushed in their interactions with a medical professional, which results in a lack of understanding on both sides.

Spanish Language Findings

More Spanish-speaking participants indicated that providers did not consider their cultural background (30%) compared to their language (22%) when communicating about services (see Figure 9). However, the majority of participants indicated that providers somewhat considered both their cultural background and language (66%). Spanish speakers indicated that providers very much considered their language (38%), and 30% said that their culture was very much considered. Very few Spanish-speaking participants indicated that providers were never considerate of their concerns; most participants indicated that practitioners were sometimes considerate or always considerate of their concerns. Figure 10 represents the extent to which participants' health concerns are listened to, understood, affirmed, and whether they are provided with enough information by providers.

Figure 9. Health System Consideration of Culture and Language when Communicating about Services (Spanish Speaking) (N = 184)
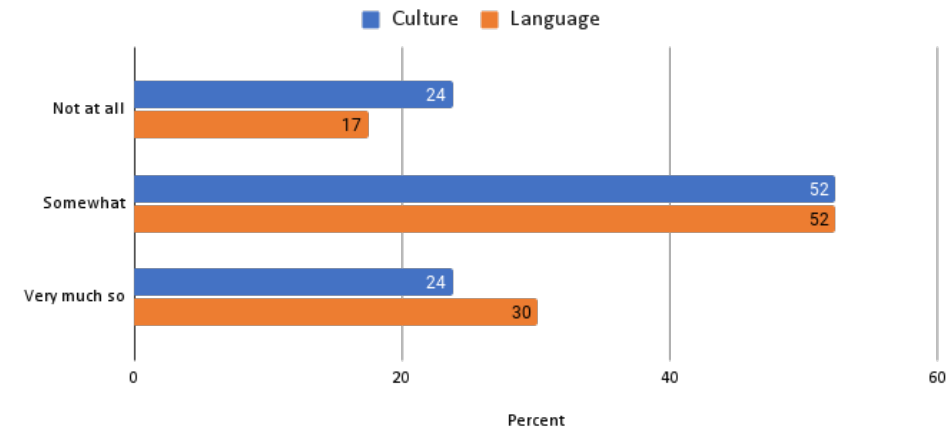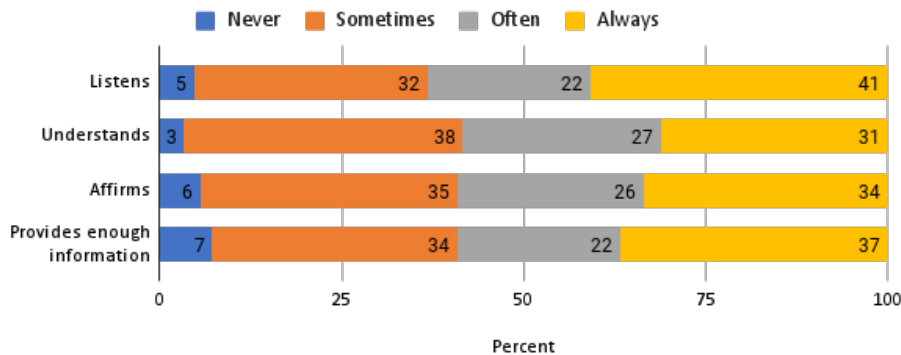

Figure 10. Provider Considers Health Concerns (Spanish Speaking) (N = 184)

6. Recommendations

Reality: Majority of BIPOC people receive behavioral health care from religious figures, traditional healers, community-based organizations and clinics

Action: Partner with, defer to, and compensate trusted culturally specific leaders and BIPOC-serving organizations

In the aggregate, respondents utilize more culturally specific and community-based behavioral health care—religious figures, traditional healers, culturally specific and community-based organizations, and community clinics—compared to dominant providers such as CCOs, urgent care facilities, and emergency rooms. This finding indicates that CCOs, and health care systems in general, must invest in outreach and communication about services in partnership with culturally specific leaders and organizations (e.g., churches, mosques, temples, community centers, faith leaders, coalitions), as these are the trusted stakeholders in the community. In addition, resourcing culturally specific outreach methods can also more effectively broach cultural forms of the stigma associated with mental and behavioral health.

BIPOC communities have culturally and linguistically specific and affirming spaces and services —in other words, networks of care that emerge in the absence or ineffectiveness of mainstream/dominant forms of care—that are unrecognized and underutilized by health care providers. For instance, specific to Black/African-American communities, one steering committee member recommends "meeting community members where they are at." Black community members have culturally specific spaces/locations, like barbershops, where they visit for services and connect with other community members. These are healing spaces. How can folks in these spaces be included in the behavioral health care system? How can culturally specific service providers, like barbers, who are embedded in communities be trained and licensed to provide behavioral health services? These folks must be included in outreach efforts and training programs for peer support specialists, community health workers, and traditional health workers.

CCOs must also resource and collaborate with community-based organizations to provide culturally specific community – and family-centered modes of physical interaction to mitigate social isolation and its mental and behavioral health consequences. These include:

- Art-based activities
- Opportunities for outdoor/nature-based activities
- Peer-support groups and affinity groups that foster meaningful human connection
- Wraparound services that include meeting basic needs such as childcare,

food, financial support (e.g., rent and utility assistance, stipends, financial literacy training)

Reality: Awareness about behavioral health services is a major barrier and translation is insufficient for communicating information that is also culturally relevant

Action: Invest in culturally and linguistically specific communication and awareness-building that yields resources and power to community-based leaders and organizations

"When we create flyers and announcements we always start with English and then translate, instead of creating them in their language first." – Steering Committee member

Participants cited communication—especially lack of awareness about services—as a major barrier for accessing behavioral health services. Translating information about CCO services, and hosting this information online, is insufficient. A lot is lost in translation, especially when conveying any technical information that has no comparable meaning in a different language or culture (e.g., there is no word for behavioral health in many languages). Messaging about behavioral health care services, options and providers, CCO enrollment, and insurance and investments in health literacy programs must be co-constructed with community members.

Relying on health care interpreters is essential but insufficient. Communication must be culturally legible and meaningful, especially for mental and behavioral health issues that may carry a stigma and are considered taboo subjects.

- Hire culturally embedded and knowledgeable folks to translate information and communicate with their community members in interpersonal, culturally informed, and sensitive ways. Health systems need to adopt multiple communications formats that do not only rely on written text or online platforms such as flyers, websites, and social media.
- Partner with and compensate culturally specific organizations, local media outlets, etc., to raise awareness about services and access them.
- Collaborate with, train, hire culturally and linguistically specific guides and peer support specialists who can help people navigate health care systems.
- Culturally and linguistically specific webinars (see Oregon Latino Health Coalition model) and in-person community-situated informational sessions effectively communicate information about services.
- Do not burden multilingual staff with interpretation, especially without compensation.

Reality: BIPOC people do not utilize behavioral health services because there are not enough multilingual and multicultural providers

Action: Invest in building a workforce of BIPOC health care workers and providers, and ensure that clear career paths are available, secure, and sustainable

The most cited barrier to accessing behavioral health care is that providers, and the services they offer, are not culturally and linguistically responsive, which leads to less utilization, awareness, and trust in the health care system. Therefore, investing in a multilingual and multicultural behavioral health workforce is necessary. And BIPOC people must be trained and provided with a clear career path. Achieving this will entail:

- Building a coordinated continuum of training, mentoring, hiring, and retaining a range of health care professionals, including traditional and community health workers, health care interpreters, and peer support specialists.
- Providing incentives and paid internships and apprenticeship-type training for BIPOC community members to specialize in behavioral health care (counselors, clinicians, peer support specialists, community and traditional health workers, etc.)
- Introducing formal and consistent statewide standards and processes for training, licensing, hiring, and compensating workers. For instance, steering committee members mentioned that the services of peer support specialists do not currently have insurance codes.
- Training among all health care workers, traditional and medical, should be community-led, meaning community members should be involved in training development and implementation. This will ensure community members are receiving the care they need.

Reality: BIPOC people have low rates of enrollment in CCOs, especially outside of the Portland metro area

Action: Invest in culturally and linguistically responsive outreach to BIPOC communities, especially those living outside metro areas

Only 21% of English-speaking respondents and 18% of Spanish-speaking respondents are enrolled in Coordinated Care Organizations. The majority of English-speaking respondents are enrolled in CCOs that serve the Portland metro area. This indicates a need for CCOs to improve outreach and communication about services, especially to BIPOC communities living outside of urban areas. Furthermore, respondents in both language groups shared limited options for services tailored to their cultural and linguistic needs.

Reality: BIPOC people experience high rates of racism, discrimination, and bias in medical settings

Action: Invest in culturally responsive training and practices for accommodating cultural realities for health care providers

"Institutional trauma keeps BIPOC folks from going to dominant organizations." – Steering Committee member

BIPOC clients and patients experience high levels of discrimination and medical racism. This only serves to sow distrust of healthcare providers. While adherence to CLAS Standards should be tracked and evaluated, it is equally, if not more important, to co-construct culturally responsive curriculum with the communities most served by different CCOs. Culturally informed training is needed around empathy, bias/stereotyping, anti-racism, decolonizing and healing justice, bedside manner, trust-building, interpersonal communication, and supportive care practices. Further, providers should be educated about the cultural values, norms, and beliefs of the populations they serve and understand their social histories (e.g., immigration, resettlement, displacement via gentrification, historical trauma). The development and delivery of educational curricula should be community-led and substantially resourced by health care systems. While providers must undergo training, it is equally crucial for providers to adapt their everyday professional practices to accommodate the cultural realities of BIPOC clients and patients.

Reality: BIPOC needs and experiences cannot be understood without collecting disaggregated, community-informed, actionable data

Action: Implement data equity and data justice practices

Health systems must collect and have the skills and capacity to make sense of, protect, and make decisions based on disaggregated data on race, ethnicity, language, disability status, gender identity, and sexual orientation. Therefore, CCOs must collect REALD and SOGI (sexual orientation and gender identity) data on the service population's diversity to meet their needs.

Assessment of system metrics and evaluation must be community-centered and – led. Dominant systems develop data metrics around needed information to ensure funding and to demonstrate outcomes. However, these metrics tend to center the experiences and realities of dominant populations, primarily white/U.S. born folks, which will always drive systems to incrementally and inconsistently expand services for non-dominant populations. Equity work requires that this logic is flipped by centering the most marginalized; this will lead to the inclusion of everybody.

Reality: Western/Anglo-centric assumptions about behavioral health alienate and harm BIPOC communities

Action: Avoid using a one-size-fits-all approach to mental and behavioral health care

Providing culturally and linguistically responsive care means avoiding reproducing dominant, Western, and Anglo-centric mental and behavioral assumptions that perpetuate the norms and expectations of whiteness. These include: determining "good mental health" and "dysfunction" solely by methodologies of Western science; monitoring and measuring "good mental health" by dominant/Western models; assuming that mental and behavioral health issues can be isolated at the individual level, and only trusting and recommending biomedically-trained and secular licensed professionals as best suited to guide people through the health process.

Endnotes

1. The term "Black/African-American" includes people with different ethnicities, regional connections, and social histories, including Afro-Caribbean, Afro-Latinx, African, and immigrants and refugees. The term "Latinx" is similarly plural and includes people with connections to South and Central Americas, the Caribbean, and immigrants and refugees. We recognize that not all people in this category are Spanish-speaking and therefore avoid using "Hispanic." Further, "Latinx" is a term that may not resonate with all, and thus we recognize Latina, Latino, and Latine as other markers of identity and positionality. Throughout this report we have adopted a standardized use of "Black/African-American" and "Latinx," while fully understanding their limitations.

2. "Whiteness, as a set of normative cultural practices, is visible most clearly to those it definitely excludes and those to whom it does violence" (Frankenberg 1993:229-229). Some examples of whiteness include: focusing on individuals over groups; creating the standard for judging values (e.g., what is good health); centering white bodies and marginalizing others. See Frankenberg, Ruth. 1993. White Women, Race Matters: The Social Construction of Whiteness. Minneapolis: University of Minneapolis Press.

3. The authors recognize that many of our research partners and collaborators do not subscribe to the term "behavioral health." This is largely due to the focus on individual behavioral changes as opposed to institutional and structural changes, which has been especially harmful to BIPOC communities. Also, "behavioral health" can be a confusing catch-all term that blends multiple service areas including mental health, substance abuse treatment, and domestic violence support. Terms like these often leave community members unsure about where and how to seek out the appropriate services. More meaningful language should be considered to describe the breadth of services classified as behavioral health. Although we chose to use "behavioral health" because it is a term adopted by state agencies, this report and the recommendations presented here are firmly situated in addressing and transforming systems to deliver community-centered and community-led care.

4. For a good discussion on how to conduct community-based qualitative research, see Sangaramoorthy, Thurka, and Karen A. Kroeger. 2020. Rapid Ethnographic Assessments: A Practical Approach and Toolkit for Collaborative Community Research. 1st ed. London, England: Routledge.

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