

# AMPLIFYING UNHEARD VOICES OF THE MEDICAID COMMUNITY: PEOPLE OF COLOR, WITH DISABILITIES, AND LGBTQ+

# 1. Research Briefing

Health inequity significantly impacts people eligible for and enrolled in Medicaid within marginalized communities of color, LGBTQ+, and those with disabilities. To create informed policy that works to achieve health equity, it is essential to understand the unique challenges Medicaid eligibles and enrollees (MEE) face, and the opportunities for improvement, inclusion, and empowerment.

The goal of the research outlined in this report is twofold. First, to generate insights about the Medicaid consumer journey that will drive improvements in health equity, policy, and advocacy. Second, to examine the relationship between three key social needs – food insecurity, housing, and social isolation - and Medicaid delivery, effectiveness, and outcomes.

The Robert Wood Johnson Foundation supported a qualitative and quantitative research study of MEEs representing communities of color, those with disabilities, and LGBTQ+ to better understand the Medicaid experience. The study included focus groups, in-depth interviews, and an online survey (see Methodology in Appendix).

# Research Highlights

Our research participants shared their Medicaid experiences, including enrollment, quality of care within the health system, and whether Medicaid can play a part in addressing three social needs; specifically, food insecurity, housing insecurity, and social isolation.

Our research gathered the diverse opinions and experiences of 3,080 Medicaid eligible and enrolled (MEE) people of color, individuals with disabilities, and LGBTQ + across age and gender groups. Our research consisted of MEEs, who we've defined as either Medicaid eligibles - individuals eligible for, but not currently enrolled in the Medicaid program, or Medicad enrolled - individuals eligible for and currently enrolled in Medicaid. Participants in this research communicate the hope that policymakers continue to collaborate with program administrators and community organizations to improve the collective health of all Americans regardless of their circumstance or station in life. Findings from our qualitative indepth interviews and focus groups and quantitative questionnaire survey uncovered the following key insights:

#### **Searching for Information**

 Medicaid eligibles and enrollees (MEEs) learn about Medicaid from a variety of sources because of the lack of a central, comprehensive source for information.

Acculturation refers to a person's level of cultural and linguistic immersion into the dominant culture. In our study, acculturated refers to high immersion in U.S. cultural customs and English-language abilities, whereas unacculturated refers to minimal or no Englishspeaking abilities in addition to low immersion in dominant U.S customs with preference for one's native culture and traditions.

"I feel that I was definitely treated differently and also like certain medicines you can't get on Medicaid. So, you have to go back and get a different prescription and stuff like that. It's ridiculous. You're just treated differently, very, very differently. The look of, oh, you have Medicaid, oh never mind. And I've had both Medicaid and private insurance with the same doctor and definitely treated differently."

-NV, Focus Group

- When searching for initial information about the Medicaid program, 70% of MEEs have not visited the official Medicaid website and 27% of respondents find searching for Medicaid applications, resources, or information on the internet difficult.
- Medicaid eligibles and enrollees find value in offline support. Over a quarter of these individuals search for information by either visiting a Medicaid or other social service office (27%). 24% ask a family member.

#### **Understanding Enrollment and Renewal**

- 39% of Medicaid eligibles and 26% of Medicaid enrollees find the overall process of applying to Medicaid to be difficult.
- Acculturated Hispanic MEEs prefer to enroll online (50%), compared to 38% of unacculturated Hispanic MEEs.
- Native Hawaiian/Pacific Islanders and unacculturated Hispanic respondents report low renewal rates. 53% of unacculturated Hispanics and 40% of Native Hawaiian/Pacific Islanders surveys renewed Medicaid coverage. Additionally, 42% of unacculturated Hispanic MEEs and 47% of acculturated Hispanic MEEs have submitted a Medicaid application online.

#### **Examining Delivery of Care**

- Nearly a quarter of respondents report a negative experience finding a provider who accepts Medicaid (24%). Medicaid enrollees say their options are limited because many doctor's offices do not accept Medicaid, and the clinics that do accept Medicaid insurance are not in locations accessible to their communities.
- There is a high level of interest in telehealth among MEE audiences. 71% have an interest in using telehealth services, with nearly half of the respondents having used it during the COVID-19 pandemic (45%).
- Although Asian Medicaid enrollees report positive experience navigating the Medicaid system once they started to use its services, they also report experiences of classism (43%) and racism (42%) from clinical staff while receiving care in our survey.
- Native Hawaiian/Pacific Islander (NHPI) MEEs do not have high self-reported usage of telehealth (18%) but share high levels of interest in exploring telehealth (94%). NHPI MEEs in our qualitative research suggest introductory telehealth consultations as a helpful option for familiarizing this audience to the telemedicine and e-appointment system.
- MEEs who identify as LGBTQ+ have an interest in Telehealth and those enrolled in Medicaid are likely to renew program coverage, but 30% of LGBTQ+ enrollees report negative experiences during the delivery of care

#### **Rethinking Social Needs**

 Medicaid eligibles and enrollees desire Medicaid program assistance accessing affordable, nutritious foods. Over half (54%) of MEEs surveyed have "I liked [telehealth]. I liked it better than going to the office. I didn't have to wait too long. I didn't have to drive and find parking and all of that stuff. He [the doctor] couldn't bounce from room to room. He had to talk to me."

—American Indian/Alaska Native, ND, Focus Group

- interested" in the Medicaid program helping them get nutritious food.

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  - Social isolation and loneliness are the most commonly experienced social need among MEEs. 62% surveyed say they, or their families, have been concerned about being lonely and away from friends at some point.

cash payments to help with utility bills and rent payments.

experienced concerns about having enough food, with 78% being "somewhat"

- MEEs with disabilities have a strong desire for housing support, with 51% interested in the Medicaid program to help with direct placement in affordable housing.
- Among Black or African American MEEs, there is an interest in the Medicaid program helping with social isolation and mental health issues. 56% of Black or African American MEEs surveyed report concerns about being lonely or away from family/friends, with 40% of Black or African American MEEs recommending home visits and wellness checks as the best way for the Medicaid program to offer aid with loneliness.

#### Recommendations

As the federal-state program providing access to essential health care to over 77 million people, Medicaid has a unique opportunity to address inequities that impact people of color, people with disabilities and the LGBTQ+ community. This research uncovered ways in which individuals who receive Medicaid services may be better served by the program.

#### <u>Access</u>

Close the Medicaid coverage gap. The American Rescue Plan offers to raise the Federal Medical Assistance Percentage (FMAP) by 5 percentage points for two years in an attempt to induce recalcitrant states to expand Medicaid. If the remaining twelve states expand Medicaid eligibility it could cover more than two million people currently in the coverage gap. If non-expanding states do not take advantage of increased FMAP, Congress should consider using either the Marketplace or other federal approaches, including but not limited to a public option to close the coverage gap.<sup>1</sup>

## **Enrollment and Renewal Experience**

Robust State and Federal Funding for Consumer Assistance. Medicaid beneficiaries struggle to renew and keep coverage and consumer assistance can play a role in preserving coverage. Consumer assistance should be adequately

I feel like just providing information to people in the community. Some people probably just don't know what their options are."

"I would honestly say maybe some type of

seminars, even how we're doing right now,

these Zoom type calls.

—Native Hawaiian/Pacific Islander, CA, Focus Group

<sup>&</sup>lt;sup>1</sup> https://www.rwjf.org/content/dam/farm/reports/issue briefs/2021/rwjf464539

funded to both assist new enrollees and to support renewals, as many beneficiaries return to the same sources of assistance provided in the past.

**Modernize renewal/enrollment systems.** Current application and renewal systems create confusion, with multiple notices and letters sent throughout the enrollment period.

Enrollment and renewal through multiple channels. Enrollment and renewal should be available through multiple avenues (telephone, online, paper, in-person) and require no or extremely minimal paperwork and documentation.<sup>2</sup> Slowdowns in mail delivery and closure of offices needed for identification and documentation<sup>3</sup> suggest that states should preserve some of the documentation submission deadline extensions<sup>4</sup> that were created early on in the pandemic.

# Expand peer-to-peer services that connect MEEs to trusted in-community care representatives.

Care advocates, community health workers and trusted community groups with roots in the communities they serve can offer MEEs from communities of color the comfort and familiar means of communication needed to confidently apply for or renew Medicaid benefits. Explore opportunities to increase access to community care advocates and community health workers.

# Increase investment in language support services to bridge the gap between some communities and Medicaid health services.

Our research uncovered a need for language support within some Hispanic and Asian communities. Expanded language assistance services, particularly peer-to-peer translation, may offer improved access to care for individuals who continue to experience difficulty navigating Medicaid due to language barriers. In addition, recruitment of qualified bi- and multi-lingual interpreters with personal experience utilizing Medicaid services would be valuable, as these individuals have the linguistic, cultural, and experiential capital necessary to build trust and support populations unfamiliar with the healthcare system.

# Accessing Doctors/Interactions with the Health Care System and Culture of Care

Make access to care and delivery of care easy for both Medicaid enrollees and the providers who serve them. During the pandemic, some states waived prior authorization rules for Medicaid providers, but reinstated those regulations by mid-2020. There may be an opportunity for state and federal government to

"I thought that they were just very laborious with the paperwork, with the requirements and so forth, and even with providing documentation."

—Englishg-speaking Hispanic, NY

"I know for a fact that it's kinda looked down upon, even by providers. When I used to call the doctors, they would just totally disregard you and say, 'Oh, sorry, we don't accept that, no. No Medicare, no Medicaid."

—Individual with Disabilities, TX

<sup>&</sup>lt;sup>2</sup> https://www.kff.org/medicaid/issue-brief/outreach-and-enrollment-strategies-for-reaching-the-medicaid-eligible-but-uninsured-population/

<sup>&</sup>lt;sup>3</sup> https://www.clasp.org/blog/cutting-medicaid-and-snap-red-tape-during-pandemic

<sup>4</sup> https://www.floridapolicy.org/posts/covid-19-response-safety-net-policy-tracker

examine the effect of temporarily rescinding prior authorization rules and how to minimize prior-authorization requirements post-pandemic. Reducing the paperwork and time burdens for Medicaid providers is important to ensuring their continued participation in the Medicaid program and ensuring a robust network of providers for MEEs.

Shift the burden for finding a provider from the MEE to the Medicaid managed care plans. The survey found respondents had a hard time finding a provider. States should do more to ensure that MCOs are meeting their obligations and offer consumer assistance to connect enrollees to care.

Fund Enrollment Assisters to provide connections to care. Organizations helping people enroll are also the first groups asked to help the MEE find care. This post-enrollment work is provided across the board but is often uncompensated. To improve access to care, use of care, and placement with culturally competent providers, state and federal government can consider how to fund and support post-enrollment services provided by assisters to ensure coverage leads to care.

There is room to improve the relationship between those receiving care and those delivering care. Health care and long-term services and supports must be high quality, including being patient-centered, responsive to cultural, social, behavioral, and linguistic needs, and allow individuals to receive the right care, at the right time, and in the setting best suited for their needs.

The health care workforce serving Medicaid beneficiaries, must be robust, diverse, culturally competent and stable. Medicaid beneficiaries should have access to robust provider networks and be able to access the providers that best fits their needs. States should also invest in providers who are committed to serving the Medicaid population, building trust with patients, and who support critical needs like availability of data, expanded hours of service, and resources to address whole person needs.<sup>5</sup>

Ensure rates appropriately compensate and encourage providers to serve the Medicaid population.<sup>6</sup> Providers that predominantly serve Medicaid enrollees and/or deliver services primarily financed by Medicaid may face disproportionate risks to their continued financial viability as their pre-pandemic operating margins were already modest due to low Medicaid reimbursement levels. To address fiscal challenges faced by providers, states and the federal government can implement various options to support providers directly or by directing plans to do so.<sup>7</sup>

https://www.publicagenda.org/reports/a-two-way-street-building-trust-between-people-withmedicaid-and-primary-care-doctors/

<sup>&</sup>lt;sup>6</sup> https://www.chcs.org/media/Medicaid-Primary-Care-Rate-Increase-Brief.pdf

<sup>&</sup>lt;sup>7</sup> https://www.shvs.org/wp-content/uploads/2020/09/Revisiting-Medicaid-Provider-Payment-Strategies-During-COVID.pdf

#### Social Needs of Medicaid Beneficiaries

Medicaid should address social needs by providing flexibility and resources to connect individuals and families with a full array of services to meet socioeconomic challenges as well as medical needs.

Connect program participants to organizations and resources specializing in healthy food solutions. There is widespread support for Medicaid to promote innovative food solutions, such as food stamp use at local farmers markets and healthy grocers, and physician allocated prescriptions for food. Additional solutions tailored for multicultural and hard-to reach populations are needed.

Combine the SNAP food assistance and Medicaid applications into one process. Throughout the course of our focus group and survey research, MEEs consistently shared the desire to see Supplemental Nutrition Assistance Program (SNAP) and Medicaid benefits combined into a single application. Merging these programs into a single application not only provides efficiency for application processing, but also ensures families are able to access healthcare services and food without delay.

Social isolation and loneliness can have serious health consequences that may be exacerbated during the coronavirus outbreak. Digital tools can help address social isolation and help us feel connected during the COVID-19 pandemic.<sup>9</sup>

Medicaid and supportive housing programs can be effective partners.<sup>10</sup> Medicaid provides more comprehensive benefits than private insurance, such as offering targeted case management based on enrollees' needs. Medicaid can also link individuals to community-based organizations that meet social needs, such as housing. States and managed care organizations can use this flexibility to build partnerships across sectors, such as partnering with housing agencies and other service providers.<sup>11</sup>

## **Quality Measures and Data Collection**

Medicaid must collect and report comprehensive data to help reduce disparities in Medicaid access, including who among applicants gets enrolled/renewed and who is getting services.

<sup>8</sup> i.e., https://doubleupfoodbucks.org/

https://www.chcs.org/dual-eligible-special-needs-plans-addressing-enrollees-social-determinant-of-health-needs-related-to-the-covid-19-pandemic/

<sup>10</sup> https://www.shvs.org/wp-content/uploads/2020/01/Supportive-Housing-Chart Final.pdf

<sup>&</sup>lt;sup>11</sup> https://www.cbpp.org/research/health/medicaid-can-partner-with-housing-providers-and-others-to-address-enrollees-social

Medicaid quality measurement initiatives have largely ignored the issue of health equity, missing a key opportunity to drive reductions in health disparities and risking inadvertent widening of disparities. State and federal policymakers should take advantage of system transformation efforts and their oversight of Medicaid health plans to ensure that quality measures are stratified by gender identity, orientation, disability status and race and ethnicity and that reducing disparities in these measures is directly incentivized.<sup>12</sup>

Work with social justice organizations to share the experiences and the unique user journeys of Medicaid eligibles and enrollees of color, persons with disabilities, and LGBTQ+. There is an opportunity to learn more about the Medicaid journey as experienced by marginalized and hard to reach audiences, and to better detect variation within states about the geographies, Medicaid plans, local government office, or enrollment channel where barriers may be most pronounced. Specifically, qualitative and quantitative research would be conducted to create case studies across a sample set of states to examine the enrollment, care and renewal experiences of communities of color, those with disabilities, and LGBTQ+. These detailed case studies would reflect experiences among states that have expanded Medicaid and those that have not.

Conduct further research on the impact of language and identity in recruiting of unacculturated and LGBTQ+ communities. Given the significant challenges presented in the language and definitions of the unacculturated audiences, LGBTQ+ individuals, and the disabled population, we recommend conducting an extended qualitative and quantitative study to better understand their identification preferences.

For more details and information about different policy options in this report, go to <a href="https://www.statenetwork.org/">https://www.statenetwork.org/</a>

<sup>12</sup> https://www.shvs.org/wp-content/uploads/2019/06/Equity-Measures-Brief-FINAL.pdf

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# 2. Background

Our research traced the experiences of Medicaid enrolled and eligible (MEE) participants from all 50 states, with a special emphasis on people from communities of color, LGBTQ+ and individuals with disabilities. We conducted research in two phases, focus groups followed by an online survey, asking respondents about their experiences learning about enrollment and renewal in Medicaid, the quality of care they receive in the health system, and how social needs – food, housing, and social life – affect the overall well-being of self and family.

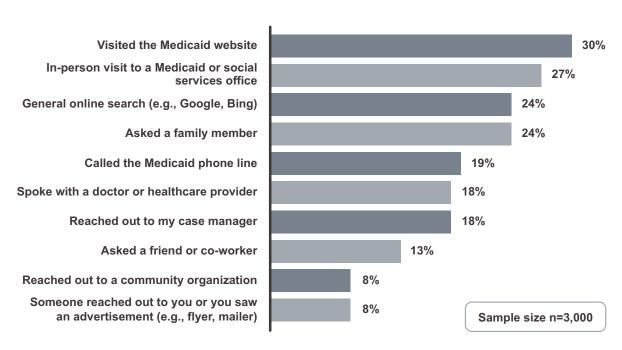
# 3. Key Research Findings

# Searching for Information

The care journey begins by searching for information about eligibility requirements and the benefits of the program. The ways and methods of learning about eligibility requirements are unique to the circumstances of the applicant. In this section, we explore key issues MEEs encounter when searching for critical program and application resources.

Medicaid eligibles and enrollees learn about Medicaid from a variety of sources because of the lack of a central, comprehensive source for information. When searching for initial information about the Medicaid program, 70% of these individuals have not visited the official Medicaid website and 27% of respondents find searching for Medicaid applications, resources, or information on the internet difficult.

Table 1. Which steps or actions did you take to learn more about the Medicaid program? (Multiple choices permitted)



Participants in our focus groups describe the dependence on a variety of sources for program information and application details as potentially valuable for individuals in need of quick answers. However, they also share the belief that reliance on too many unvetted sources can also produce conflicting or inaccurate information, which may negatively impact an individual's application. 27% of Unacculturated Hispanic, 22% of acculturated Hispanic, and 21% of American Indian/Alaska Native MEEs report difficulty finding Medicaid applications, resources, and information on the internet.

Medicaid Overview: Medicaid provides health coverage to eligible lowincome adults, children, pregnant women, elderly adults, and people with disabilities. Medicaid is jointly funded by federal and state governments and administered by the states Because each state administers the program differently, this study focused on the experience of people as they navigated the system generally. The study did not seek to analyze any statespecific administration of benefits.

Medicaid eligibles and enrollees find value in offline support. Over a quarter of MEEs surveyed search for information by either visiting a Medicaid or other social service office (27%) or asking a family member (24%). MEE focus group participants report other ways they learn about Medicaid, such as the occurrence of a medical event, such as injury, surgery, or pregnancy, which often results in on-the-spot enrollment. MEEs find peer-to-peer communication to be one of the most effective means for receiving accurate answers to critical inquiries about the program.

#### **Additional Findings of Interest**

College-educated respondents surveyed prefer using online resources to learn about Medicaid. Medicaid eligibles and enrollees with college experience are more likely to use online resources compared to those with a high school degree or less. 34% use Google compared to 20% of people with a high school education or less. College-educated MEEs at also more likely to visit the Medicaid website (39%), compared to 25% of people with a high school education or less.

Medicaid eligibles and enrollees with disabilities prefer visiting Medicaid offices in person when searching for information. When looking for information in-person at a Medicaid office, 31% of MEEs with disabilities surveyed report a peference of visiting a Medicaid office, compared to 24% of MEEs without disabilities. Conversely, 27% of disabled MEEs visit the Medicaid website, in contrast to 34% of MEEs without disabilities. Our focus group research finds MEEs with disabilities are more likely to prefer in-person and in-office visits than online searches in comparison to those without disabilities.

Younger adults and gender non-conforming respondents turn to family for support when looking for information on Medicaid. When turning to family for support and guidance, younger populations are more likely to turn to their families. Although the sample size of gender non-conforming individuals (transgender, non-binary, non-descriptive) is not large enough to provide statistically significant findings, it is worth noting that those who identified as such are also more likely to turn to family for help. Compared to all other age groups, 18–26-year-old MEEs (44%) have the highest percentage of people who turned to family for support in finding Medicaid information.

"Basically, word of mouth, people who already enrolled in the program. People who got some kind of expertise in being in the program, telling the basics of it, eligibility, what the program's about, how it can help you, assist you, those kind of things there. Mostly word of mouth because you can learn a lot from a person to a person."

- Native Hawaiian/Pacific Islander, GA
- "I wish sometimes they would call in and check in every now and then. My case managers don't do that. Once you get approved, their job is done unless there's like a serious problem, which nothing occurred."
- English-speaking Asian, NY
- "I would honestly say maybe some type of seminars, even how we're doing right now, these Zoom-type calls. I feel like just providing information to people in the community. Some people probably just don't know what their options are."
- Native Hawaiian/Pacific Islander, CA

- When examining survey respondents by age bracket, 18–26-year-old MEEs (44%) have the highest percentage of people who turned to family for support in finding Medicaid information.
- 40% of MEEs who identify as transgender and 54% of non-binary MEEs turn to family for support in finding Medicaid information.

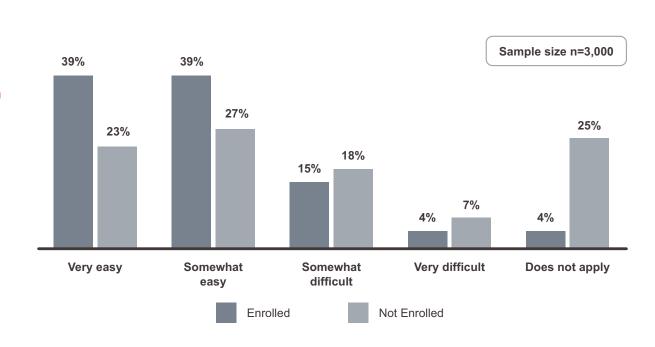
# Understanding Enrollment and Renewal

After researching the program's requirements, MEEs continue the journey toward accessing Medicaid healthcare benefits by submitting an application during enrollment and/or renewal. Many aspects of the process can be difficult for communities of color, LGBTQ+, and disabled individuals, such as compiling the necessary documentation, completing complex forms, and finding sustained support during the preparation process. In this section, we uncover the key issues MEEs experience during the submission process.

39% of Medicaid eligibles and 26% of Medicaid enrollees surveyed find the overall process of applying to Medicaid to be difficult.

Medicaid eligibles are more likely to report experiencing difficulty finding Medicaid applications, resources, or information online (24%) compared to Medicaid-enrollees (19%). Without a central, comprehensive resource for support, principally during the enrollment stage, multiple sources of information must be combined in order to gain a full grasp of the program, its benefits, and the eligibility process.

Table 2. Understanding the words or language used in the Medicaid program application: In your experience how easy or difficult were each of the following activites?



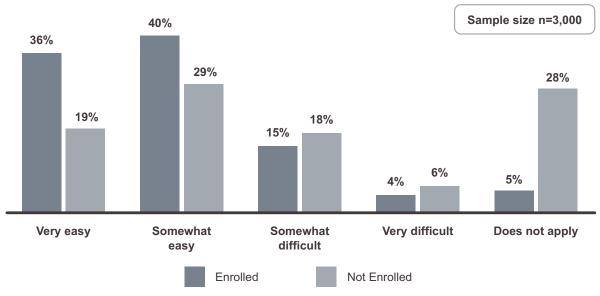
"I think the main reason [Chinese people do not apply for Medicaid online] is that their data are in English and need translations, which are not always accurate."

Unacculturated Chinese, CA

"It's their certification period that can be very, very frustrating and overwhelming...they give you a short window of time to submit whatever the requirements are. And a lot of times in my experiences, I lose coverage for, let's say, just a small amount of time because things haven't been submitted correctly, or it's just like the waiting game."

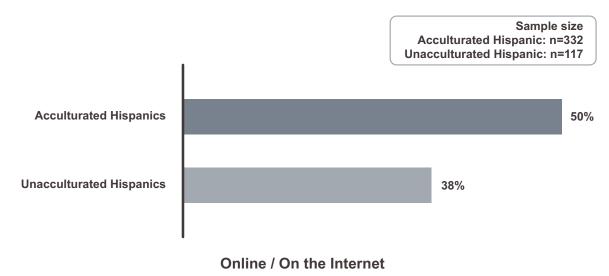
Black/African American, CT





An individual's preferred method of enrollment is influenced by the level of acculturation. Of the Hispanic MEEs surveyed, 50% of those acculturated and 38% of the unacculturated prefer to enroll online. Our focus group research uncovered struggles struggles with online enrollment in Medicaid among unacculturated Hispanic and Asians. MEEs from these groups cite struggles commonly due to the lack of non-English language Medicaid program materials available online, compared to phone and in-office resources which tend to offer greater access to translators and in-language support.

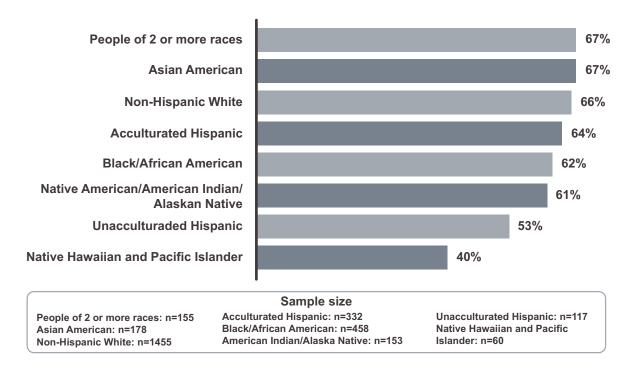
Table 4. Regardless of how you applied, what is your preferred method of applying for the Medicaid program (online, in-person, phone, etc.)?



#### **Additional Findings of Interest**

Native Hawaiian/Pacific Islanders and unacculturated Hispanic respondents report low renewal rates. 53% of unacculturated Hispanics and 40% of Hawaiian/Pacific Islanders surveyed renewed Mediciad coverage.

Table 5. Have you been through the Medicaid renewal process? (Yes)



Women, younger adults, and non-college educated respondents report higher rated of Medicaid renewal during the Covid-19 pandemic. Of the MEEs surveyed, 58% of female respondents and 37% of males renewed for the program during the Covid-19 pandemic. Non-college educated respondents (56%) also renewed at high rates during the pandemic while 35% of survey respondents with college degrees reported renewal. Of the MEEs surveys across all age groups, 62% of respondents in the 18-26 age bracket renewed during the pandemic.

## **Examining Delivery of Care**

Access to doctors, medicine and wellness resources make delivery of care one the most critical aspects of the Medicaid experience. This section examines the Medicaid experience and quality of healthcare services to better understand pain points and opportunities.

Nearly a quarter of respondents report a negative experience finding a provider who accepts Medicaid (24%). Medicaid enrollees say their options are limited because many doctor's offices do not accept Medicaid, and the clinics that do accept Medicaid insurance are not in locations accessible to their communities. When examining enrollees by gender, women are more likely to report a negative experience (24%) compared to men (18%). Medicaid enrollees 65 or older also have a negative experience (31%) in finding a provider. Difficulty finding providers who accept Medicaid is a significant barrier to receiving care.

Focus group respondents have experiences of provider unresponsive to patients with Medicaid insurance, suggesting limited options for Medicaid health assistance. Transportation issues and remote locality also contribute to this difficulty as well.

Table 6.1 Experience Finding a Medicaid Health Care Provider Among Medicaid Eligible and Enrolled Individuals (By Age)

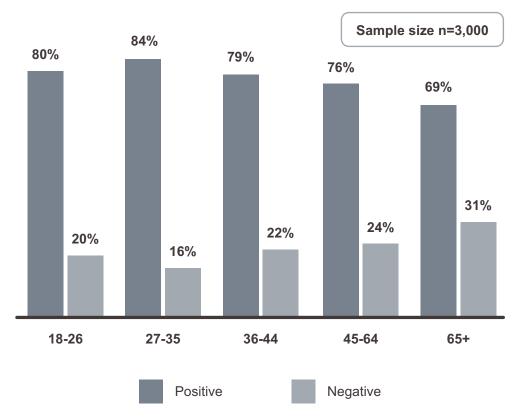
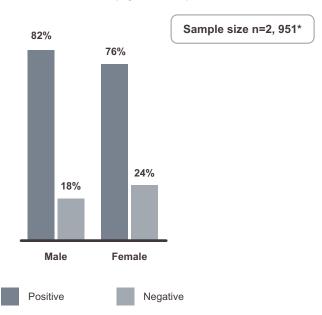


Table 6.2 Experience Finding a Medicaid Health Care Provider Among Medicaid Eligible and Enrolled Individuals (By Gender)



<sup>\*</sup> Note sample sizes of other selections such as non-binary did not provide enough data to be considered statistically significant.

There is a high level of interest in telehealth among MEEs. 75% have an interest in using telehealth services, with nearly half of the respondents having used it during the COVID-19 pandemic (45%).

**Non-Hispanic White** 49% **Asian American** 46% Black/African American 42% People of 2 or more races 41% 40% **Acculturated Hispanic** 40% **Unacculturated Hispanic** Native American/American Indian/ 38% **Alaskan Native** Native Hawaiian and Pacific Islander 22% Sample size People of 2 or more races: n=155 American Indian/Alaska Native: n=153 Non-Hispanic White: n=1455 Asian American: n=178 Acculturated Hispanic: n=332 Native Hawaiian and Pacific Islander: Unacculturated Hispanic: n=117 Black/African American: n=458

Table 7. Medicaid Eligible and Enrolled Individuals using telehealth during COVID-19

#### **Additional Findings of Interest**

At least a quarter of all Medicaid enrollees from communities of color indicated they have experienced discrimination from administrative or clinical staff, including forms of racism, sexism, and classism. Of the respondents' questions in our survey, 28% reporting classism from both Administrative staff and clinical staff.

Table 8. Medicaid Enrollee Experiences of Racism in Care (Yes)

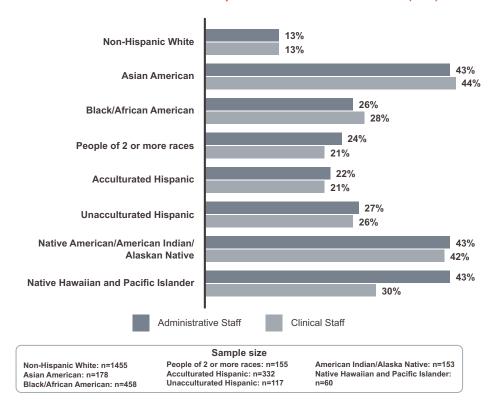
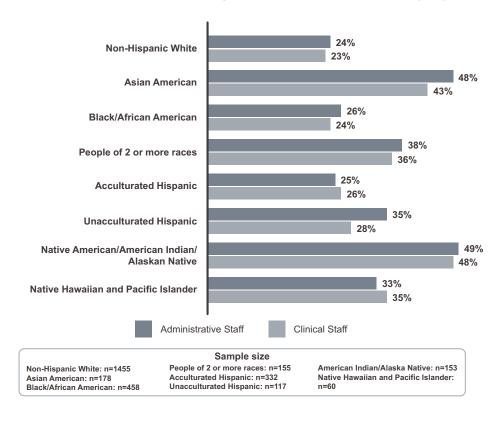


Table 9. Medicaid Enrollee Experiences of Classism in Care (Yes)



LGBTQ+ persons have more negative treatment by healthcare staff (21%) than respondents as a whole (14%). LGBTQ+ persons also report a higher level of sexism from administrative and clinical staff, compared to overall survey, 27% vs 19%.

Social Needs and Medicaid: A person's environment can play a dramatic role in their wellbeing and the health of their family, mitigating or exacerbating underlying medical conditions. This study also looked at whether Medicaid could or should play a role in helping diverse communities address social needs. such as food insecurity, housing instability, and social isolation.

Enrollees who identify as multiracial (i.e., two or more races), as well as LGBTQ+ enrollees, report difficulty finding care and negative experiences with the quality of care they receive in addition to their treatment by healthcare staff. Of the respondents surveyed, 33% of Medicaid enrollees identifying as multiracial and 27% of LGBTQ+ enrollees report difficulty finding a healthcare provider that accepts Medicaid.

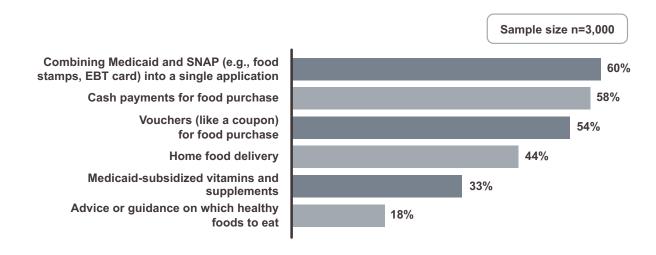
American Indians, Native Hawaiians or Pacific Islanders, and Asians enrolled in the Medicaid program report high rates of college attainment. 8% of Native Hawaiian or Pacific Islanders, 47% of Asian, and 25% of American Indian/Native Americans surveyed who are enrolled in the program had a college education. Among other Medicaid enrolled key audiences surveyed, 14% of non-Hispanic Whites and 13 % of Black/African Americans report having a college education.

## **Rethinking Social Needs**

Medicaid eligible and enrolled individuals have a holistic concept of health. This community understands good health is not confined to medical care access; it also entails access to nutritious food, stable housing, healthy socializing, and mental well-being, with a lack of access to any one component potentially compromising their overall health.

Medicaid eligble and enrolled individuals desire Medicaid assistance accessing affordable, nutritious foods. Over half (54%) of MEEs surveyed have experienced concerns about having enough food and 78% report being "somewhat interested" in the Medicaid program helping them get nutritious food. 60% of MEEs say 'combining Medicaid and SNAP into a single application would be helpful if they did not have enough food – making it the most preferred intervention for alleviating food insecurity.

Table 10. If you and your family did not have enough food, what would be helpful to you and your family? (Multiple choices permitted)



"I feel like if people have that option where they could be taught healthier ways of eating, and then even learning how to cook but with healthy foods. That type of information is like — honestly, the second you said imagine, I was like "Man, that's just-" That would have changed my childhood."

-Native Hawaiian/Pacific Islander, CA

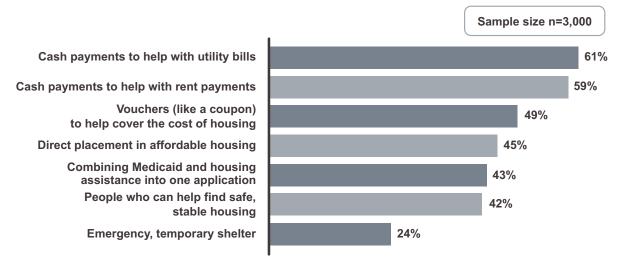
"I mean it goes on to priorities and rents are just rising and rising so when you're looking at your budget and how much money you have coming in and how much you have to go coming out, that gap gets smaller and smaller and then you have to make it up somewhere so sometimes that happens and food and healthyou're not going to prioritize a small health thing if you have to pay for rent and even just gas to go to the doctor or the hospital if the clinic that you need to go or the hospital you need to go to is an hour away."

-Native Hawaiian/Pacific Islander, HI

Focus group MEE participants report the cost of healthy foods and a lack of knowledge on how to prepare healthy foods as two significant barriers to eating well. Our research found MEEs draw strong links between efforts to alleviate food insecurity and improving overall health.

Our research uncovered MEEs struggle with costs associated with housing rather than finding housing. 61% of MEEs say it would be helpful for the program to offer assistance in the form of cash payments to help with utility bills and rent payments (59%). 4% report lack of housing or a safe place to stay as a concern. MEEs struggle to maintain the costs associated with safe, stable housing, specifically with the rising price of rent as their greatest challenge. The cost of housing can become such a burden, MEEs are commonly forced to reprioritize other essential needs, such as food, medicine, or healthcare.

Table 11. If you and your family needed housing or a safe place to stay, what would be helpful to you and your family? (Multiple choices permitted)



Social isolation and loneliness are the most commonly experienced social need among MEEs. 62% surveyed say they, or their families, have been concerned about being lonely and away from friends at some point. The largest share of these respondents (40%) says that, "connection with a social worker, counselor, or mental health provider" would be helpful to them if they are experiencing loneliness. This is a service that 67% of MEEs would like to see Medicaid provide. Additionally, there is interest in online support groups or group therapy (36%), home visits and wellness checks (35%), and a referral to online or in-person therapists or psychiatrists (34%).

#### **Additional Findings of Interest**

Communities of color are interested in Medicaid programs assisting with access to healthy, nutritious food. There is a strong desire among MEEs of color for greater Medicaid access to healthy, nutritious foods (53%).

# **Additional Findings**

Among the Hispanic MEEs surveyed, 53% of unacculturated Hispanics and 64% of acculturated Hispanics have gone through the Medicaid renewal process. Additionally, 42% of unacculturated Hispanic MEEs and 47% of acculturated Hispanic MEEs have submitting a Medicaid application online. Among Hispanics enrolled in the Medicaid program, unacculturated Hispanics (46%) and acculturated Hispanics (61%) report clinical staff described as 'helpful' during care delivery.

When examining preferred methods of housing assistance, 45% of unacculturated Hispanic MEEs and 39% of acculturated Hispanic MEEs report they would be "very interested" in a Medicaid program assisting with stable, safe housing.

**56% of Black or African American MEEs surveyed report concerns about being lonely, away from family or friends.** Among this audience, there is an interest in the idea that the Medicaid program might help with issues beyond health with 40% of Black or African American MEEs recommending home visits and wellness checks as the best way for the program to help with feelings of loneliness.

When going through the Medicaid application journey, Black or African American MEEs rely on trusted information sources to learn about the program. 29% of Black or African American MEEs surveyed report speaking to a family member and 27% visit a Medicaid or social services office in-person to learn more about the Medicaid program. Alternatively, Black or African American MEEs report lower reliance general online searches, such as Google or Bing, to learn about Medicaid, with 19% using this method to find program information.

In our questionnaire survey, Native Hawaiian/Pacific Islander (NHPI) MEEs do not have high self-reported usage of telehealth (18%) but share high levels of interest in exploring telehealth (94%). NHPI MEEs in our qualitative research suggest introductory telehealth consultations as a helpful option for familiarizing this audience to the telemedicine and e-appointment system.

Additionally, NHPI MEEs surveyed report concerns about lack of housing and not having enough food. 80% report they and/or their family has been concerned about not having housing or a safe place to stay and 76% report concerns about not having enough food.

Asian Medicaid enrollees report positive experience navigating the Medicaid system once they started to use its services, describing the overall process of applying for Medicaid as 'very' or 'somewhat' easy (71%) and the process of finding providers who accept Medicaid insurance as positive (87%). Nonetheless, Asian enrollees surveyed in our research also report discriminatory experiences of classism (43%) and racism (42%) from clinical staff while receiving care.

**MEEs with disabilities have a strong desire for housing support.** When queried on the Medicaid program helping in the form of direct placement in affordable housing, 51% of MEEs with disabilities and 39% of non-disabled MEEs shared an interest in housing support.

On the question of interest in the Medicaid program aiding in the form of vouchers (e.g., coupon) to help cover the cost of housing, 55% of MEEs with disabilities and 44% of MEEs without disabilities are in support of this form of support. Medicaid eligible and enrolled individuals with disabilities shared a desire for program assistance in the form of utility bill payments, with 65% desiring cash payments to help with utility bill payments compared to 57% of non- disabled enrollees.

MEEs who identify as LGBTQ+ have an interest in Telehealth and those enrolled in Medicaid are likely to renew program coverage. However, enrollees report negative experiences of classism during the delivery of care. LGBTQ+ Medicaid eligible and enrolled persons share an interest in Telehealth, with 52% using Telehealth services during COVID-19. LGBTQ+ respondents currently enrolled in the Medicaid program report high rates of renewal (68%), but also share instances of classism during delivery of care from administrative (37%) and clinical staff (34%).

LGBTQ+ Medicaid-enrollee Experiences of Discrimination in Care (Yes)			
	Administrative Staff	Clinical Staff	
Experiences of Racism in Care (Yes)	26%	26%	
Experiences of Classism in Care (Yes)	37%	34%	
Experiences of Sexism in Care (Yes)	27%	24%	

LGBTQ+ Medicaid Experiences		
Have you been through the Medicaid renewal process? (Yes)		
LGBTQ+ MEEs using telehealth during COVID-19? (Yes)	52%	

Because the sample size for gender non-conforming individuals is too small to make any significant observations, it is worth noting that there is an argument for conducting a more robust study on the experience of Medicaid among the LGBTQ+ community.

# 4. Appendix

#### Methodology

The Robert Wood Johnson Foundation partnered with Sensis, a cross cultural integrated marketing and advertising agency to conduct a series of focus groups and in-depth interviews from 11 unique populations - people of color, people with disabilities, and LGBTQ+ - across 23 states among Medicaid enrolled and eligible (MEE) individuals. To explore the sensitive topics of health and socioeconomic status with hard-to-reach audiences, we employed a mixed-method research approach. This approach enabled us to deeply probe and understand people's experiences and perspectives via qualitative focus groups and in-depth phone interviews with 80 total participants in 10 focus groups and 42 in-depth interviews (IDI). We launched an additional survey to better understand the experiences of 3,003 Medicaid eligible or enrolled participants from all 50 states with special emphasis on multicultural populations to understand their health care needs.

Finding Support	The ways and methods of learning about eligibility requirements and how Medicaid enrolled and eligible populations "get started" with the program.
Preparation & Enrollment	The experiences of Medicaid enrolled and eligible as they prepare and submit required documents to attain Medicaid benefits.
Renewal	The experiences of Medicaid enrolled and eligible as they receive renewal notifications and prepare renewal documentation.
Utilization of Care	The experiences of Medicaid enrolled and eligible as they utilize healthcare services to understand major pain points, frustrations, and opportunities.
Social Determinants of Health	The impact of food insecurity, housing insecurity and social isolation on perceptions and decisions as they relate to overall health of Medicaid eligible and enrolled, and on the delivery, effectiveness, and outcomes of the Medicaid program.

#### **Recruitment Methodology**

The panelists recruited for our focus groups, in-depth interviews and questionnaire were recruited through email campaigns, social media, and advertisements. Panelists were vetted through a process in which our panel providers implementing a double opt-in process at the time of registration requiring respondents to register for a panel and fill out a brief profiler, followed by validation of their membership via acknowledging a link provided via email.

Potential participants were targeted through our online panels based on the qualifying criteria and key audiences of interest, targeting to individuals with at least one child under 18 and HHI of \$29,000 or below, single adults with a HHI or \$17,000 or below, as well as the selected ethnicities. For this research project, the sample was intended to be nationally representative based on our desire to oversample, and thus amplify, minority segments of the population. As this population is often unheard, weighting the survey data had the potential to introduce bias and diminishing the voices the research was intended to amplify. Additionally, national data for the minority audiences in some of the categories studied is not readily available, making it difficult to establish accurate weighting targets for the minority audiences examined in this research project.

As a result, our Research Science team elected to test an overall sample that is not necessarily representative of the Medicaid-eligible population, as some groups, such as American Indian/Alaska Natives and Native Hawaiian/Pacific Islanders, are over-represented in order to get a readable sample size for analysis purposes. Nonetheless, loose fielding quotas were implemented to ensure a relatively balanced sample, particularly in terms of gender.

#### **Analytical Approach**

To ensure the voices of Medicaid eligible and enrolled audiences of color, people with disabilities, and LGBTQ+ were well represented, we gathered the opinions and perspectives of nearly 3,080 people in five languages via focus groups, indepth interviews (IDI), and a national online survey. Our sample included 11 unique audiences from all 50 states who represented a diverse set of genders, ages, education levels, and geography.

#### **Audience Criteria**

The diverse audiences selected for this study represent many of the groups overlooked by other Medicaid studies because of their hard-to-reach nature. As the table below shows, the recruitment criteria for each audience of interest may have differed slightly between qualitative and quantitative testing to ensure the people included were the best fit.

	Multicultural Recruitment Criteria	
Audience	Survey	Focus Groups/In-Depth Interviews
American Indian/Alaska Native	Self-identifies as American Indian, Native American, or Alaska Native	
Acculturated Asian	Self-identifies as Asian	Self-identifies as Asian and is "confident" or "very confident" in English-speaking ability
Unacculturated Asian (Chinese-, Korean-, Vietnamese- speaking)	Not applicable (1)	Self-identifies as Chinese, Korean, or Vietnamese, speaks Mandarin, Korean, or Vietnamese "confidently", is less than "very confident" in English-speaking ability, and consumes media in Mandarin, Korean, or Vietnamese
Acculturated Hispanic	Self-identifies as of Latino or Hispanic origin (any race) and speaks English only	Self-identifies as of Latino or Hispanic origin (any race) and is "confident" or "very confident" in English-speaking ability

Unacculturated Hispanic (Spanish- speaking or Spanish preferred)	Self-identifies as ethnically Hispanic (any race), speaks Spanish only or English and Spanish, is less than "very confident" in their English speaking ability, is at least "confident" in Spanish-speaking abilities and consumes at least some media in Spanish	
Individuals with Disabilities	Self-identifies as a person with a disability	Self-identifies as a person with a disability that does not prevent them from using the internet or communicating directly with others
LGBTQ+	Self-identifies as a member of the Lesbian, Gay, Bisexual, Transgender, and/or Queer/Questioning community	
Native Hawaiian/ Pacific Islander	Self-identifies as a Native Hawaiian or Pacific Islander	Self-identifies as a Native Hawaiian or Pacific Islander and is "confident" or "very confident" in English speaking ability
Multiracial (of 2 or more races)	Self-identifies as not ethnically Hispanic and at least two of the following races: White, Black or African American, Asian, American Indian/ Alaska Native, Native Hawaiian/Pacific Islander, Other race	Not applicable

Note: (1) Although the survey was offered in Chinese, Korean, and Vietnamese, Unacculturated Asian was not prioritized as a key survey audience due to low population incidence. Six survey participants completed the survey in one of these languages and these responses are analyzed as part of the "Acculturated Asian" audience.

**Medicaid eligible and enrolled.** Medicaid is jointly funded by the federal government and individual states and administered at the state level with specific eligibility requirements. This makes it difficult to screen each respondent for the exact requirements of their reported state. Instead, we developed a common set of eligibility criteria based on federal guidelines for the Medicaid program. A person was determined to be Medicaid eligible if they met any of the following requirements:

- Aged 65+
- Have a disability
- Are pregnant
- Have an annual household income of less than \$19,000¹
- Reported a combined annual household income and household size that put them at or below the 2020 federal poverty level<sup>2</sup>

**Non-Hispanic White participants.** Although Medicaid eligible and enrolled (MEE) people from multicultural or minority communities (i.e., people who are not part of the White, heterosexual, able-bodied majority) are the focus of this study, White participants made up 51% of the online survey sample (still lower than the national incidence rate of 60%). Many in this group have other characteristics that qualify them as part of a multicultural audience of interest – 57% live with a disability and 13% identify as LGBTQ+. Nearly all (97%) were enrolled in Medicaid, and the other 3% were eligible for the program and not enrolled. Non-Hispanic White participants, while not necessarily multicultural based on race, make up an important part of the Medicaid community. They help to inform our understanding of how to improve the program for communities of color by serving as a comparison group, and also as an important group of Medicaid users with valuable experiences.

#### Qualitative

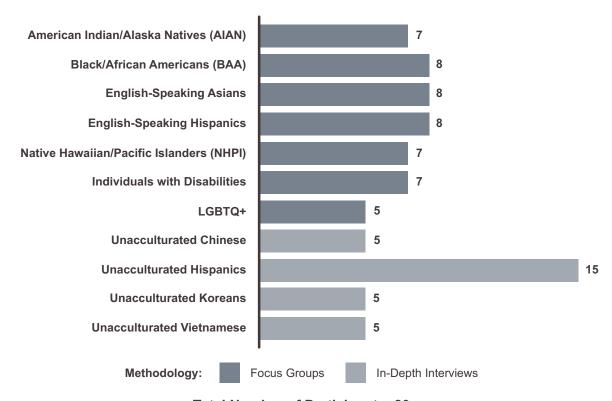
In the first phase of the project, we conducted online focus groups in tandem with in-depth phone interviews (from October 26-November 16, 2020). These groups were made up of seven to eight people in each of the English-speaking audiences: American Indian/Alaska Native (AIAN), Black/African American (BAA), Asian, Hispanic, and Native Hawaiian/Pacific Islander (NHPI). We used online focus groups instead of in-person groups to mitigate risks and adapt to the constraints imposed by the COVID-19 pandemic. These online groups offered the same advantages of in-person groups – the ability to capture rich data, such as nonverbal cues and changes in tone – while giving us the advantage of speaking with people from all over the country in each group. These groups also had the added benefit of allowing participants to talk about sensitive topics from the comfort of their homes.

<sup>&</sup>lt;sup>1</sup> In the survey, eligibility was slightly more difficult. Participants who were 65+, had a disability, were pregnant, or had two or more children living in the house also had to have an income of \$19,000 to qualify. This prevented higher income people who might otherwise possess those characteristics from being included in the sample.

<sup>&</sup>lt;sup>2</sup> https://www.healthcare.gov/glossary/federal-poverty-level-FPL

We connected with the hardest to reach non-English speaking audiences through phone IDIs and spoke to them one-on-one in their native languages (Chinese, Hispanic, Korean, and Vietnamese). We also conducted IDIs with the LGBTQ+ audience and people with disabilities. The one-on-one format of the IDI allowed for open and candid conversations, and we conducted IDIs with these groups to increase the likelihood that participants would provide frank and detailed responses to potentially sensitive questions about health and other challenges they may not be comfortable discussing in a group setting.

Online focus groups, in tandem with in-depth phone interviews, enabled us to develop a comprehensive understanding of the issues surrounding Medicaid delivery and health outcomes among MEEs. Through online video focus groups, we captured rich data, such as non-verbal cues and changes in tone, as participants responded to topics raised during discussions from the comfort of their homes. We connected with the hardest to reach people through phone IDIs and spoke to them one-on-one in their native language. These formats allowed for open and candid conversations about sensitive topics with audiences that are often difficult to reach.

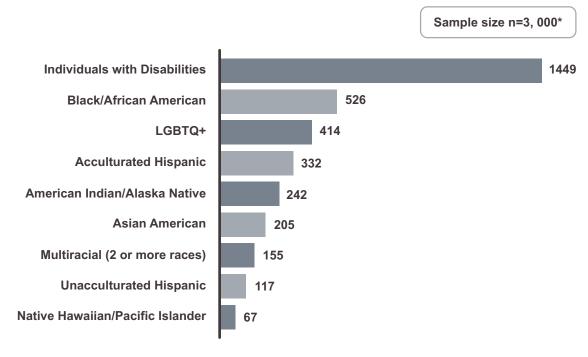


**Total Number of Participants: 80** 

#### Quantitative

We used insights and lessons learned from the qualitative phase of the study to optimize the quantitative survey fielded in the second phase of the project (December 28, 2020 to January 20, 2021). Like the focus groups and IDIs, the survey focused on issues surrounding Medicaid delivery, three social determinants of health—food insecurity, housing, and social isolation, - and health outcomes but allowed us to examine variation in experiences and opinions among a large number of Medicaid-enrolled and eligible audiences across the United States.

To ensure the experiences of these audiences were adequately represented in the survey, we aimed to survey at least 100 people from each of our target audiences of interest as part of our 3,000-person sample. The final sample also included a mix of genders, urban/rural respondents, and age groups of 18-26, 27-44, and 45-64.



<sup>\*</sup> Participants in our questionnaire survey may fall into more than one audience. Example: An Asian American who self identifies as LGBTQ+ and an individual with Disabilities would be counted across each of the three audience categories.

#### **Analytical Approach**

This report synthesized results from the two phases of research to develop a holistic assessment of the consumer Medicaid journey – from finding information and support during the application process to utilization and renewal - and how the Medicaid program can engage with people on key social determinants of health to improve overall wellbeing. Insights shared in the Research Brief and Key Findings outlined in this report highlighted overarching takeaways and how observations may vary across people from communities of color, individuals with disabilities and LGBTQ+.

We categorized participants by ethnicity, LGBTQ+, and disability status separately. Our audiences based on ethnicity were all exclusive – for example, people were only coded into "Black/African American" if that was the only race/ethnicity they selected; otherwise, they were placed in the "Multiracial (people of 2 or more races)" category.

People who identified as LGBTQ+ or as having a disability could be of any race and we determined that it made the most sense methodologically and sociologically to code these respondents in both categories. Because these individuals navigate the world through the lens of both identities, and because it's impossible to separate their identities in the real world, we believe it was valuable to capture that in our research. For example, someone who is both African-American and LGBTQ+ has a unique experience navigating Medicaid and it's not possible to separate out which part of that experience is because they are African-American and which is because they are LGBTQ+ – both identities compound one another. As a result, we took an intersectional approach and incorporated their responses into both categories to get a holistic picture of the Medicaid experience for each audience category. The alternative was to have a non-LGBTQ+ African-American only sample, which would have presented serious issues in terms of making normative assumptions about those audiences.

Analysis of qualitative data. All focus groups and in-depth interviews were recorded, transcribed, and translated into English (where necessary). The project team supplemented focus group transcripts with notes taken during the live focus groups that included information on important unspoken communications including changes in tone, body language, facial expressions, and overall group dynamics. The project team synthesized the information in transcripts and notes from all focus groups or in-depth interviews for each audience into a single audience-specific summary. The summary analysis for each audience detailed the audience's experiences, challenges, and opportunities as they related to the five key research topics (i.e., finding support, preparation and enrollment, renewal, utilization of care, and social determinants of health) and a summarization of key takeaways. The research team used these analysis documents to inform the audience-specific key insights and aggregated findings outlined in this report.

Analysis of quantitative data. Survey responses from the online and phone modes were combined into a single dataset and all univariate or bivariate relationships reported in this report are based on this final dataset. Bivariate tabulations compared dependent variables of interest across key independent variables, or our key audiences of interest. Hypothesis tests were performed pairwise on all combinations of pairs within a given independent variable using an alpha level of 0.05. Differences in attitudes or opinions between audiences denoted throughout the report are statistically significant unless noted otherwise.

Additionally, quotations attributed to online survey respondents are based on responses to the open-ended question at the end of the survey, "Reflecting on your experience with Medicaid, please share 1-2 suggestions of what the Medicaid healthcare program can do better for you and your family." Respondent reflections did not cover every topic for every audience, so there are fewer of these quotes throughout the report than from the focus groups or in-depth interviews – which asked participants to comment directly on each of the topics.

#### **Methodological Materials**

- Quantitative Survey Instrument
- Qualitative Discussion Guide

Three online and phone survey partners struggled to reach the number of eligible Native Hawaiian/Pacific Islanders they had projected. After discussing this with other researchers doing similar work, we hypothesize that this happened due to the Covid-19 pandemic's disproportionate impact on this audience, making them more difficult to reach.