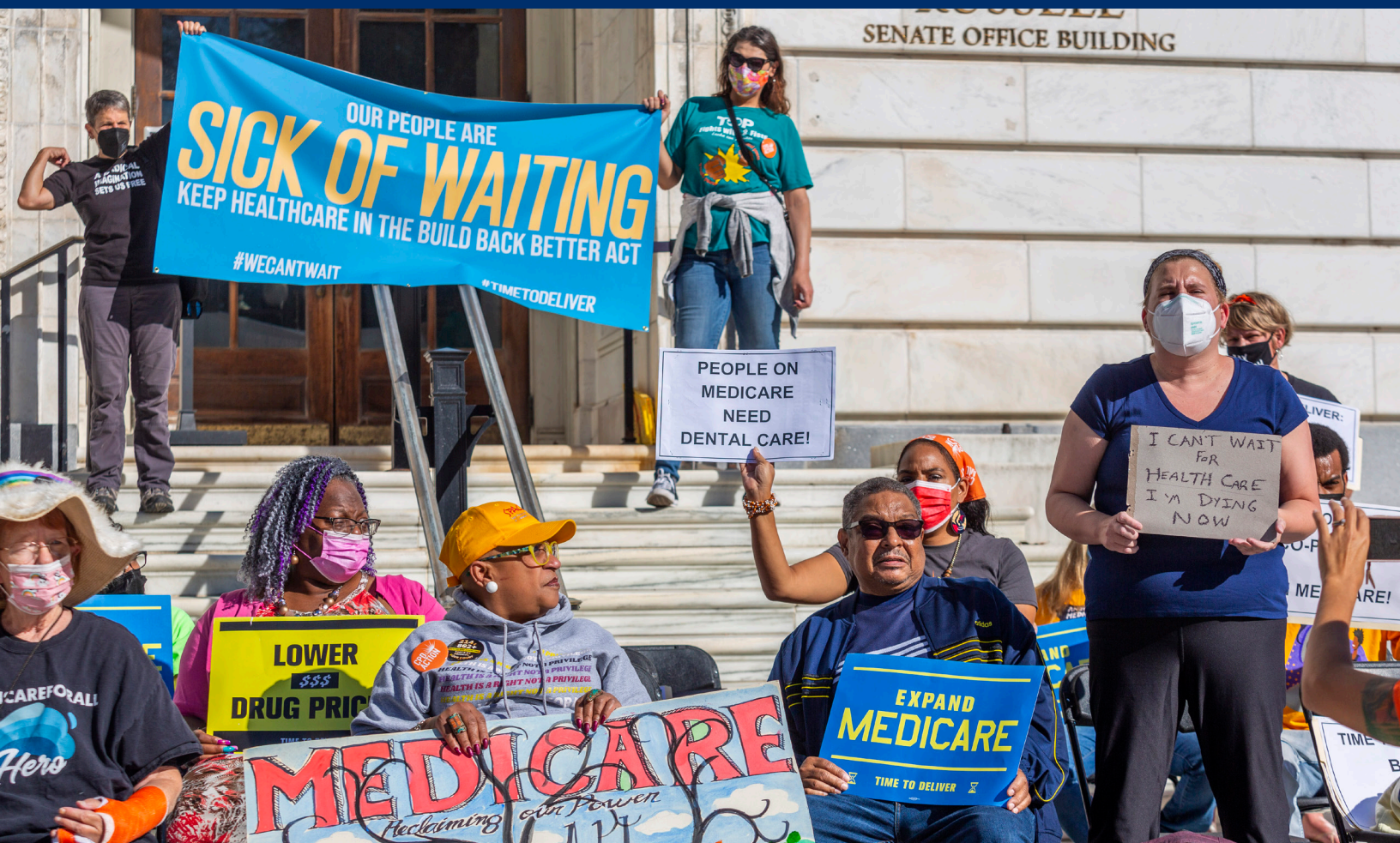


More Medicaid, Better Medicaid

Dismantling Barriers to Healthcare in the United States



July 2022



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Acknowledgements

This brief was written by Eli Vitulli in partnership with Columbia graduate students Ben Elkind, Brett Slaughenhaupt, Shahir Shukor, and Sophia Kroesche. The Columbia faculty advisor was Kristina Eberbach. The brief was edited by Jennifer Flynn Walker, Michele Kilpatrick, Sean Kornegay, and Julio López Varona (Center for Popular Democracy) and staff members from Alaskans Take a Stand, Arkansas Community Organizations, Opportunity Knocks Delaware, Rights and Democracy, Texas Organizing Project, Our Future West Virginia, and SPACEs in Action.



The Center for Popular Democracy is a nonprofit organization that promotes equity, opportunity, and a dynamic democracy in partnership with innovative base-building organizations, organizing networks and alliances, and progressive unions across the country. www.populardemocracy.org

Medicaid is an essential government program that provides health insurance to more Americans than any other single program,¹ providing coverage at low or no cost to over 87 million people,² or roughly 20% of all Americans. For these beneficiaries, Medicaid ensures access to a fundamental human right. Research has shown that improving access to healthcare for people working low-income jobs improves recipients' health outcomes and financial stability and saves lives.³ It is a crucial component of the US healthcare system, providing an important source of comprehensive children's healthcare, long-term care – including nursing home care and community-based long-term services, care for pregnant people, and primary care through community health centers.⁴ Medicaid has also helped reduce economic and racial disparities in health insurance and healthcare access.⁵ Especially during the COVID-19 pandemic, Medicaid has been critical in ensuring healthcare access, especially for those who have lost their jobs.⁶

While Medicaid has improved access to health care and health outcomes for recipients, many are not having all their needs met. Research has shown that Medicaid recipients experience many barriers to accessing quality healthcare.⁷

Understanding the barriers that Medicaid recipients in their communities experience is a prerequisite to their elimination. The Center for Popular Democracy, Alaskans Take a Stand, Arkansas Community Organizations, Opportunity Knocks Delaware, Rights and Democracy New Hampshire, Texas Organizing Project, Our Future West Virginia, SPACES in Action, and researchers at Columbia University created and administered a survey asking Medicaid recipients about their experiences accessing healthcare services with Medicaid coverage. In March and April 2022, they administered surveys via phone and text banking, social media, and outreach to community members and partner organizations. Respondents either independently filled out the survey online or had an organizer fill it out for them over the phone.

The following brief describes the experiences of 132 Medicaid recipients from 16 states and territories, who responded to the survey, and identifies the primary barriers they are facing alongside policy solutions to eliminate them. Their stories reveal two significant patterns: the critical need for expanded healthcare access and for vastly improved service delivery and quality of care across the US.

Over half of the respondents reported that they need more Medicaid, including additional coverage of necessary services (such as dental and vision), reduced costs to receive care (cheaper medicines and co-pays), and the expansion of the network of providers who accept Medicaid.

Nearly half responded that they need better Medicaid, including improving the process of receiving care, ending stigma (providers and their staff treating recipients poorly because they use Medicaid rather than private insurance), improving service quality, and eliminating administrative barriers that delay or deny needed care.

All people should have access to high-quality, affordable, easily accessible, and stigma-free healthcare that covers their needs. Medicaid has already helped us get closer to that goal but needs improvement.

“Medicaid in DC is better than I hoped for—I even get dental and no copays! I do have to wait longer for some appointments, but when I needed a neurologist, I saw a very good one. I know it’s my tax dollars, but I’m so grateful. Especially without copays; I can’t afford healthcare right now. If I had to pay for my anti-seizure medication, I don’t know if I could afford it.”


“I’m grateful that my child has Medicaid otherwise I don’t know if I could take him to the doctor. I’m happy that now the attention is so much better, in the clinic that I take my child the staff actually care for their patients.”

“... just because a person is [on] Medicaid doesn’t mean [they] should receive less than top quality care.

“Do better for [the people] depending on your services.”



Highlighted Findings



71% of survey respondents reported experiencing some challenge(s) while trying to use their Medicaid coverage.

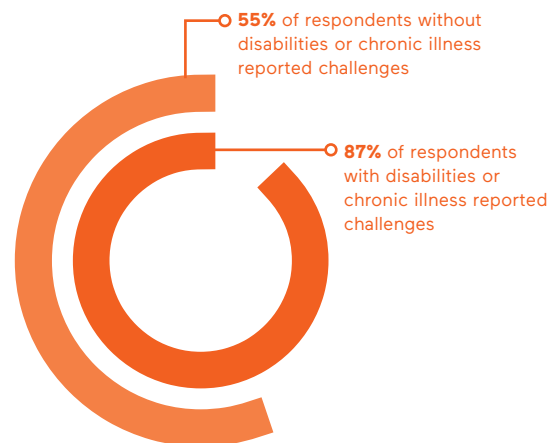
All Native American respondents reported experiencing challenges, and Latine respondents were more likely than Black and white respondents to report challenges.

All trans and nonbinary respondents reported challenges.

The three most common challenges respondents faced were

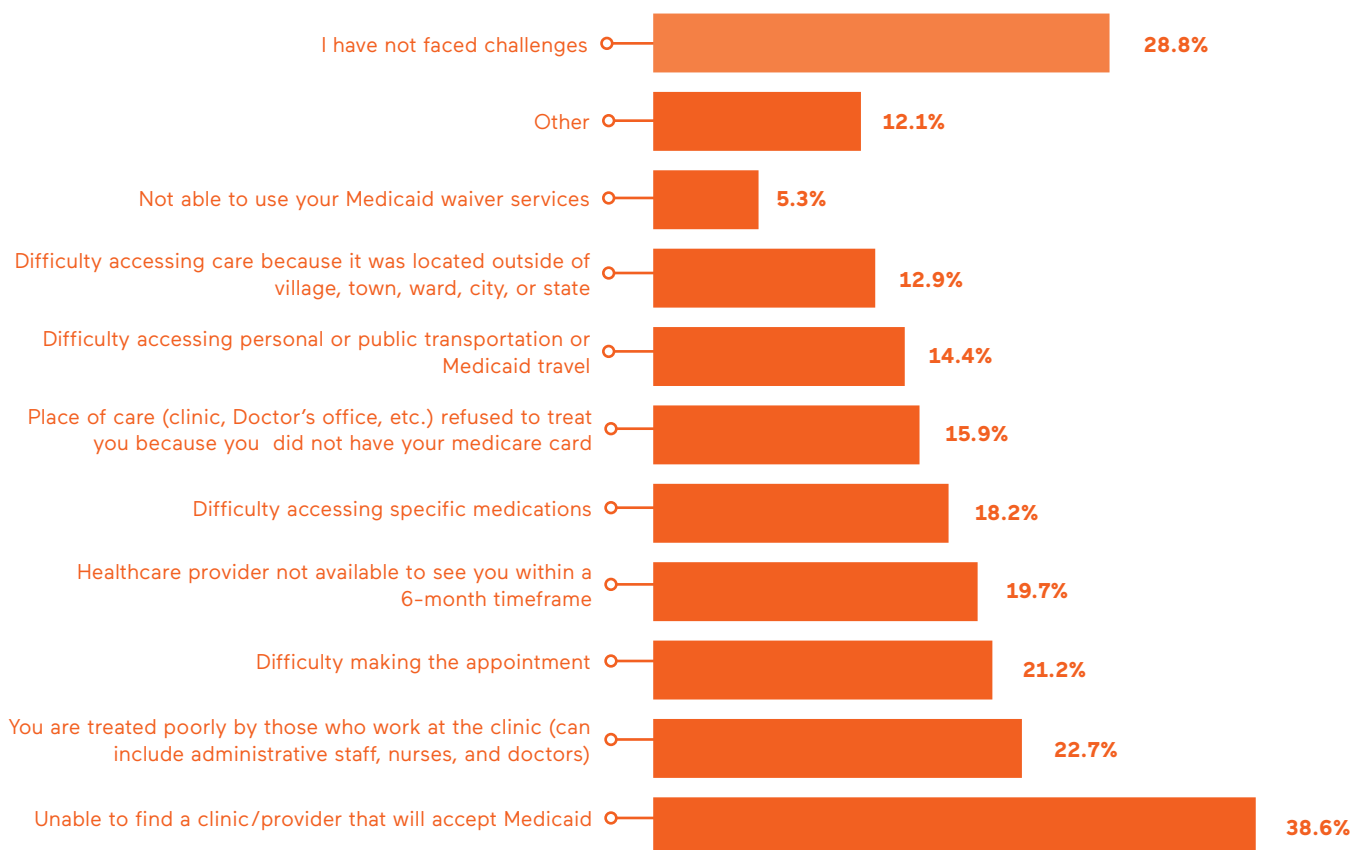
- the inability to find Medicaid providers (39%),
- poor treatment (23%), and
- difficulties making appointments (21%).

Respondents with disabilities or chronic illness were also significantly more likely to report challenges than respondents without disabilities or chronic illnesses (87% vs. 55%).

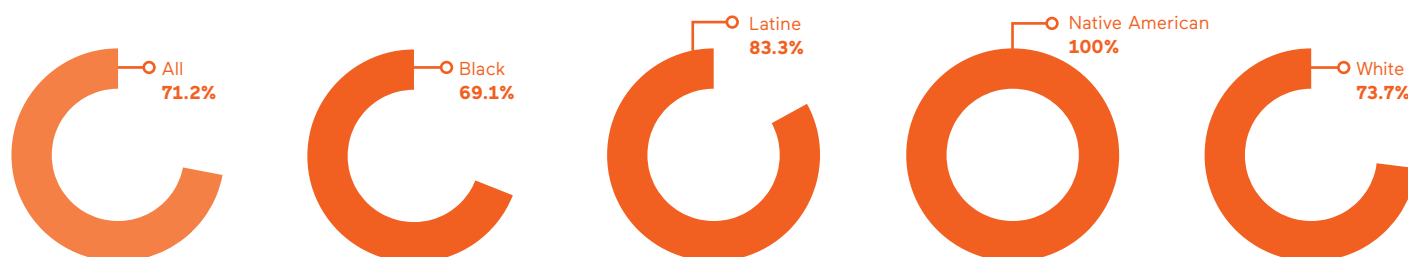


In fact, across almost every challenge cited, people with disabilities or chronic illnesses are at least 50% more likely to experience them than individuals without disabilities or long-term chronic illnesses.

What challenges have you (your child/dependent) faced trying to access healthcare services that are covered by Medicaid? Check all that apply.



Percentage of Respondents Facing any Challenge by Race*



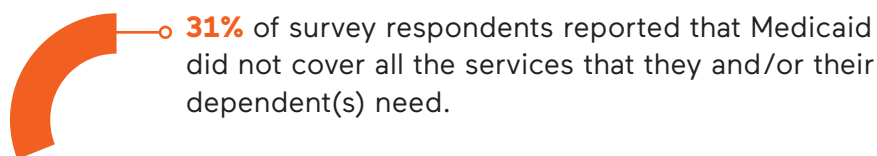
* Because the sample size of respondents who identified as Asian, Pacific Islander, Native Hawaiian, Middle Eastern, and/or North African (and not the above racial categories) was very small, we did not include their responses in this chart.

I Need More Medicaid

Respondents stressed the crucial role healthcare plays in their life, but many experienced gaps in access. Lack of coverage, unaffordability, and inadequate availability of doctors were barriers for over half of the respondents.

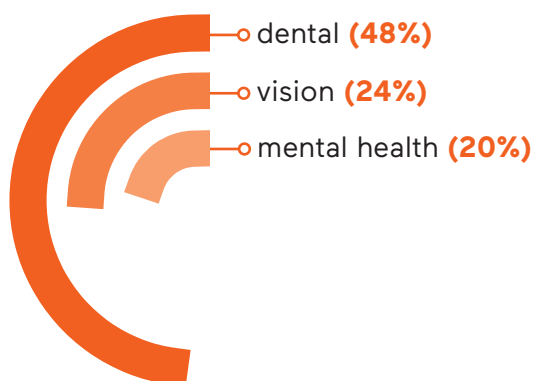
“It seems as though we receive the bare minimums and are limited to where we can actually seek services.”

Lack of or Inadequate Coverage



“DENTAL AND MENTAL HEALTHCARE ARE ESSENTIAL. They are not nice ‘add-ons.’”

Of those who experience gaps in care, the most cited gaps in coverage were:



“[...] I need a dental check, but there’s no coverage, it’s been over a decade.”

“It’s a blessing that he has some insurance, but it’s like you have a flashlight in your house, it’s a blessing that you have some light, but it’s not all you need.”

Being denied access to specific healthcare services was one of the main reasons respondents stated that they did not see a healthcare provider even though they needed to visit one. In at least one instance, a respondent's doctor recommended running tests, but Medicaid did not cover them. Others identified the lack of access to mental healthcare providers as a major issue.

“The [doctor] on call at the ER said he needed [an echocardiogram]... and the cardiologist agreed, but the insurance denied the test.”

“It seems Medicaid isn't set up to provide funds for mental health development problems.”

Provide comprehensive dental, vision, mental health, and physical therapy coverage.

Good oral, vision, and mental health, as well as physical therapy support, are all key to a person's overall health. While federal law requires states to cover at least some dental, vision, and mental health services for children,⁸ these services and physical therapy are optional for adults. Many states choose to either not cover them, only cover emergencies, or severely limit coverage in other ways.⁹ States must comprehensively support Medicaid recipients' dental, vision, mental, and physical therapy health care needs without co-payments.

For example, Massachusetts' Medicaid program (MassHealth) provides comprehensive dental, vision, mental health, and substance use disorder benefits to all recipients.¹⁰ Studies of the Massachusetts Medicaid expansion have shown that it contributed to improvements in recipients' mental health¹¹ and increased access to and use of dental care among poor adults living in the state.¹²

Policy Solution

Unaffordability

Even while on Medicaid, the price of healthcare—especially additional costs for prescriptions or specialist services—can potentially have devastating financial consequences. Several respondents identified high costs as the reason they could not receive necessary care.

“I’m worried about the additional cost of tests and procedures.”

“It’s hard when you can’t afford your meds. This assistance I’m on at the moment, it’s not as bad as not having healthcare, but it doesn’t allow me everything I need.”

“They said I had a hairline fracture, and they wanted to send me to a specialist, but I would have had to pay \$200 up front co-pay, and I didn’t have that, so I didn’t go. And now it’s gotten worse, but I can’t pay that copay. I tried to deal with it.”

Respondents also described having to cover surprise out-of-pocket costs because Medicaid coverage was confusing or not transparent enough.

Eliminate premiums and cost-sharing (such as copayments and deductibles) for all recipients.

While federal guidelines allow states to impose premiums, copayments, and cost-sharing (with caps by income level and recipient types, such as children, pregnant people, and other adults), research has shown that even small amounts of cost-sharing can result in worse access to health care, increased financial burden, and lead to worse health outcomes. Moreover, states save little by imposing cost-sharing because lower-cost recipients tend to drop out, leaving a smaller, higher-cost population of recipients.¹³

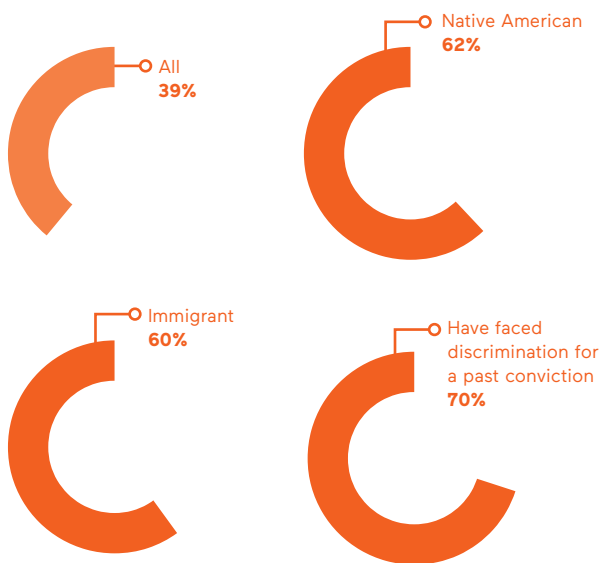


Availability of Physicians and Travel Time

Finding available doctors who practiced nearby was a constant challenge for many respondents.

Nearly two-fifths of respondents **(39%)** reported not being able to find a clinic/provider that accepts Medicaid, with Native American **(62%)** and immigrant **(60%)** respondents as well as respondents who said they faced discrimination for a past conviction **(70%)** being significantly more likely to report not being able to find a provider.

Respondents who struggle to find available physicians



“Having to travel over an hour one way for simple appointments. I have to take a large chunk of time off work if not a whole day off.”

Policy Solution

Increase the number of providers that accept patients with Medicaid.

Encourage more providers to accept Medicaid recipients by increasing provider payments, simplifying administrative paperwork, and streamlining enrollment for providers.¹⁴ Research shows that low reimbursement rates for Medicaid are a major reason why not enough doctors accept patients with Medicaid.¹⁵

Create network adequacy standards that ensure timely access to care (such as time between a request for an appointment and the appointment itself) and travel time/distance. The network will need to have enough providers to meet these standards for all recipients. If recipients cannot find a provider that meets these standards, they should have the option to get an out-of-network provider covered. There should also be oversight and monitoring of the network to ensure compliance with these standards.

California’s Medicaid and CHIP Managed Care has strong network adequacy standards that establish travel time and distance benchmarks alongside timely access to non-urgent appointments. For example, the standards require that recipients be able to get an appointment with a primary care physician that is within 10 miles or 30 minutes from their residence and that the appointment must be within ten business days from making it.¹⁶

Policy Solution

Cover multiple options for non-emergency transportation at no cost to recipients.

Federal regulation requires state Medicaid programs to provide necessary transportation for recipients to travel to and from their providers. However, several states have sought waivers from providing this service, and others have limited its availability. Research has shown that access to transportation is vital to improving people's health and that providing transportation is cost-effective for Medicaid programs.¹⁷

The Centers for Medicare and Medicaid Services should refuse a state's application for a waiver of the transportation requirement unless the state can show that it has accounted for recipients' transportation needs in other ways (for example, through a comprehensive mass transit system). States' obligation to cover Medicaid recipients' transportation needs should include expanding coverage to reimburse gas mileage for recipients with access to cars but for whom covering the cost of gas would be burdensome and covering rideshares/car services.



I Need Better Medicaid

Better healthcare does not only mean being able to see a healthcare provider. It also means accessing needed services readily and without discrimination and stigma. Better access to healthcare is not just a question of convenience but vitally important to living a healthy life and thriving.

While most respondents (69%) were satisfied with the care they received through Medicaid, many spoke of negative experiences while interacting with the healthcare system, including medical personnel treating them as inferior because they were Medicaid recipients, providing limited or inadequate treatment options, and other administrative barriers, such as long waiting times at the clinic or doctor's office.

Limited or Inadequate Treatment

“ [...] I've been going through a lot ... and I've been to a doctor for it, but so far they've only given me [medicine for the pain], which doesn't help at all. ...Now I'm afraid that they could find something that's been left too long, and I'm continuing to have worse issues.”

“ [...] for urgent care I feel like we've been on many occasions set aside or not receive the care needed because of our demographics.”

“ Doctors dismiss children that have Medicaid and don't fully investigate options.”

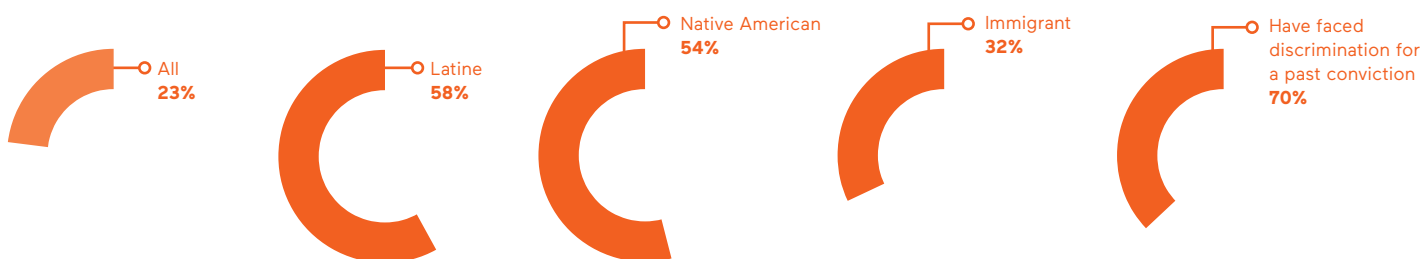
“ Just [feels] like [the Medicaid] system is against us receiving quality healthcare.”

Stigma

Doctor and administrator perceptions of Medicaid, including negative stereotypes of Medicaid recipients, were a primary concern for respondents. Many shared stories of experiencing stigma, being “treated like cattle,” leading them to wonder if doctors “truly want to help you,” and ultimately thinking “the rich get the best care.”

Nearly a quarter of respondents (23%) have felt unfairly treated when navigating the healthcare system through Medicaid. Latine (58%), Native American (54%), and immigrant (32%) respondents, as well as respondents that reported experiencing discrimination based on a past conviction (37%), were more likely to report feeling mistreated.

“I was treated unfairly when navigating the healthcare system”



“Most of the dental offices were unkind when I was making inquiries about them taking Medicaid.”

“Just treat everybody fairly; people aren’t treated fairly now. Because you have people in pain, and you have Black people in pain, but White people get way better service.”



Others found discrepancies in how medical professionals treated them, saying they were “scolded and judged by a doctor [who] treated another individual with better care” or made to feel like they were “a society burden” because they used Medicaid. Respondents had to deal with assumptions and stereotypes, such as staff talking down to them and making them feel as if their concerns were not being listened to or respected.

“ [I was] treated like less of a person because I had state insurance as opposed to private.”

“ We are mistreated in hospitals and not treated fairly”

“ If I hadn’t had experience with being a carrier of [private insurance] I’d say it was good... It varies from office and dr to dr. But in general they are more willing to reject your complaint and dismiss your pain [as a Medicaid recipient].”

Policy Solution

Provide training for Medicaid staff, medical providers, and medical office staff aimed at reducing stigma and mistreatment of Medicaid recipients.

Quality health care is stigma-free. Experiencing mistreatment and stigma by providers and their staff creates barriers for Medicaid recipients, resulting in people possibly missing needed treatment and worse health outcomes.¹⁸ Anti-stigma and cultural competency training can help reduce and eliminate stigma. For example, studies of trainings for providers addressing mental health stigma showed that they can improve provider knowledge and communication, patient-perceived empathy, and quality of care for patients with mental health disorders.¹⁹

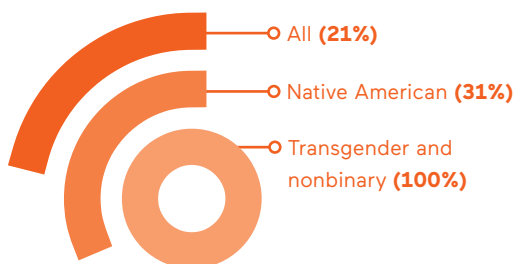
Administrative Barriers

Administrative processes like making appointments and obtaining referrals are essential to accessing healthcare. Many of our respondents identified administrative barriers, including referral processes, long wait times before appointments, and providers limiting the number of Medicaid patients they are willing to see.

Over one fifth (**21%**) of respondents, including **all** transgender and nonbinary respondents and **31%** of Native American respondents, reported difficulty making appointments because of administrative burdens.

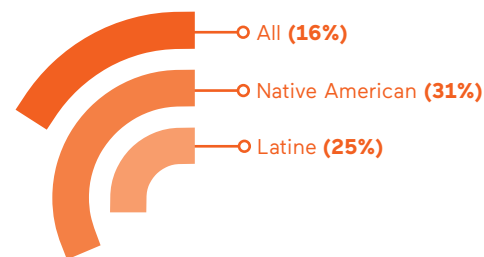
One respondent notes, while Medicaid provides coverage for primary care, it “*limit[s] choices and [it is] difficult to get services from specialists. The whole referral process is a hassle.*”

“I struggled to make an appointment because of administrative burdens”



Sixteen percent of respondents—including **31%** of Native American and **25%** of Latine respondents—reported experiencing providers refusing to provide treatment because they did not have their Medicaid cards.

“I was refused treatment because I did not have my Medicaid card”



Moreover, renewing coverage can be a complex and confusing process. **Thirty-four percent** of respondents reported losing Medicaid coverage for various reasons, including the inability to navigate the burdensome re-application process and errors from the Medicaid office. In one instance, a respondent shared that the Medicaid office lost their application paperwork, which led to them losing coverage during chemotherapy: “*I had been on the program for a year... [I] had rounds of chemotherapy delayed because of the error.*”

Another respondent’s experience navigating the Medicaid system was so cumbersome and dispiriting, it led them to think “*the [Medicaid] system is designed to fail.*”

Policy Solution

Simplify enrollment and renewal processes.

Reducing paperwork and using existing data as much as possible will reduce the administrative burdens on recipients. Most of the information required for Medicaid enrollment or renewal is already in the hands of federal, state, and local government data sources, such as Internal Revenue Service, Social Security Administration, and state labor department data,²⁰ and many Medicaid recipients are also enrolled in other state or federal assistance programs, such as SNAP.²¹

States can simplify enrollment and renewal processes by 1) using a single form for all state-administered programs; and 2) creating automatic renewal systems (or “*ex parte*” renewals), using available federal and state data sources to determine continued eligibility without requiring recipients to provide information, unless necessary.

In addition, adopt a continuous eligibility policy, which keeps recipients enrolled for 12 months, regardless of fluctuations in income. This policy can be implemented for adults through an 1115 waiver and children through a state plan amendment.²² Continuous eligibility is important for low-income families whose income fluctuates throughout the year, such as people who are self- or seasonally employed, have unpredictable schedules, are tipped workers, or work overtime. Low-income families and families of color disproportionately experience income volatility.²³



Policy Solution

Create communication systems that use multiple options for contacting recipients to meet the needs of the state's Medicaid populations.

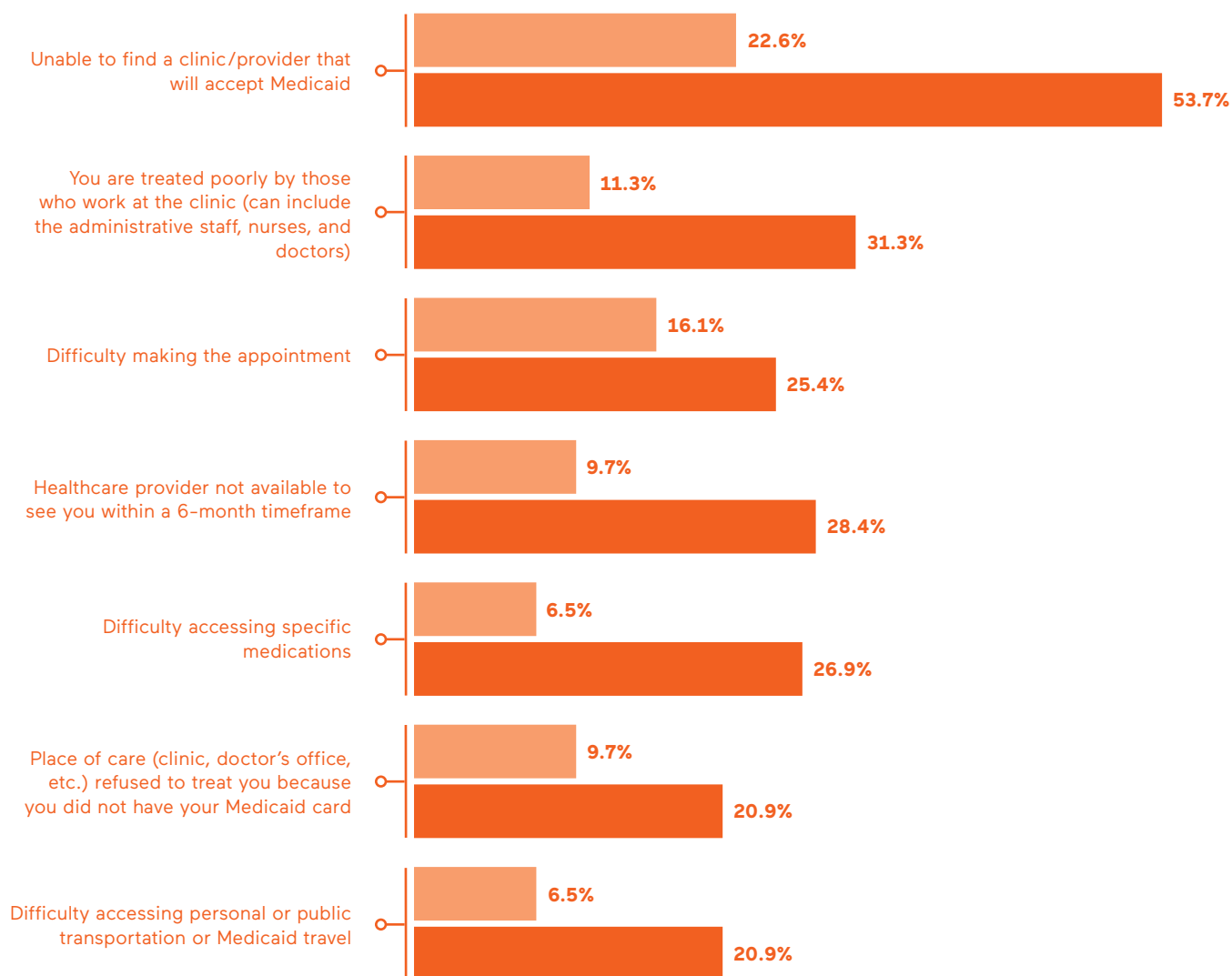
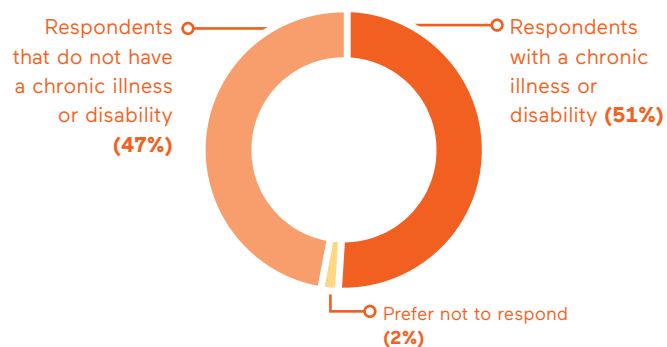
Clear communication is vitally important during the enrollment and renewal processes and for recipients trying to access healthcare using Medicaid coverage so they can understand guidelines, limitations, costs, and other requirements. Because Medicaid recipients are low-income, many will have communication limitations. For example, sending letters to people with unstable housing and emails to rural populations with limited internet access are ineffective, yet this is often how Medicaid programs communicate with recipients. Poor communication by a Medicaid program can cause recipients to lose coverage, incur unnecessary costs, and miss opportunities, which can lead to devastating health and financial consequences.

We recommend that states do a needs assessment of recipients' communication needs and challenges, as well as why people are dropped temporarily from coverage (i.e., was there a communication challenge involved?), to identify and fix problems.

We also recommend creating navigator or assister programs. Specifically, fund trusted community-based organizations to implement these programs so their staff and community members become trained to assist community members. Navigators should have the tools and access required to help community members officially submit applications during the enrollment and renewal processes and other paperwork needed to access healthcare. Some community-based organizations already provide navigator-type services; they deserve funding for this vital work.



People with disabilities and long-term chronic illnesses face greater challenges at a higher frequency compared to those without disabilities and chronic illnesses across all challenges.



Many respondents with disabilities or long-term chronic illnesses highlighted how physical access, availability of providers, and administrative barriers to Medicaid were a concern:

“It takes a lot of planning to find home health nurses [who] can help us access care outside of the home.”

“I had to wait three years for a mental health therapist because there are so few.”

“[Healthcare] needs to be more easily accessible to people with physical challenges.”

“Because of my cerebral palsy, people treat me like I’m not able to think or have feelings.”

“Stigma and poor treatment also continues to be a problem, with respondents saying that doctors and staff treat them like they are “not able to think or have feelings” due to their disability and, in general, “they are more willing to reject your complaint and dismiss your pain.”



Consequences of Barriers

For many respondents, poor coverage, administrative barriers, stigmas, mistreatment by providers and their staff, and poor quality of care made it more difficult to access necessary healthcare services.

Numerous other studies have found that Medicaid recipients are much more likely than people with private health insurance to experience these barriers to accessing quality healthcare.²⁴ Many who experienced barriers had their care delayed or not met, prolonging their pain and worsening their health and quality of life.

Some respondents delayed seeking care until their concerns were considered an emergency because of barriers to accessing healthcare.

“[I] did not see [a] doctor for over 1-2 years.”

“Not going whenever I should have, letting my concern get worse so they might deem my needs valid.”

“They’re affecting his quality of life. If they would actually treat him [and meet his needs]... He would have a better quality of life.”

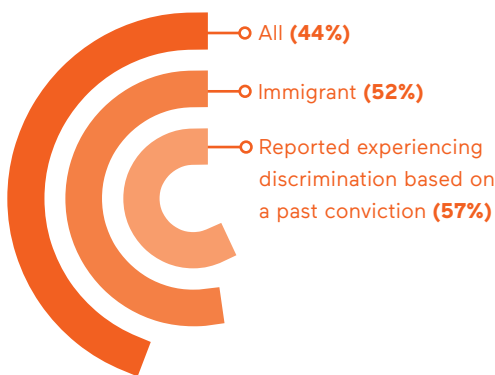
“I feel like I’m not human.”



Nearly half **(44%)** of respondents said they did not receive care when care was needed at least once in the last year.

Immigrant respondents **(52%)** and respondents who reported experiencing discrimination based on a past conviction **(57%)** were most likely to say they did not receive care when they needed it at least once in the last year.

“I did not receive care when I needed it at least once in the last year.”



“I only seek [care] if it’s under emergency situations.”

“A lot [of] time in places like the DHS or Medicaid offices, [because of] the way people get treated and denied ... they wait till the last minute with their health [problems].”



In addition, being dropped from coverage can have significant health implications. Some respondents spoke of not being able to go to the doctor to receive care or take their medicines during no-coverage periods, which ranged from “a month or two” to “about 1-2 years.”

When Medicaid recipients do not receive adequate and prompt treatment, they are at greater risk for poor health, worsened health conditions, longer hospital stays, and unmet needs.²⁵ The failure to provide care at an earlier stage also strains the healthcare system, requiring more advanced and costlier care.²⁶ For the sake of patients and the entire system, barriers to preventative and early-stage care must be eliminated.

“It was scary, how am I going to get help, get enough money to pay for what’s going on with me. It was serious.”

A Stronger Medicaid Program

Respondents identified Medicaid as an important, lifesaving program that needs much improvement to meet recipients' needs. Medicaid requirements need simplification, provider networks must be expanded, quality of care must be improved, and out-of-pocket costs must be reduced or eliminated.

Many also argued that the government should expand the program so that everyone in the US can access affordable health insurance.

Medicaid should be strengthened, improved, and expanded to provide truly comprehensive, high-quality, affordable health care without stigmas that is easily accessible to all people with low incomes.

“[Medicaid] services, access, treatment all need to be fixed and expanded to ensure millions of people are getting quality healthcare.”

“Trust the judgment of doctors. If a drug is prescribed, cover it. If chemotherapy is ordered, cover it. Stop making doctors and patients fight to get the needed care.”

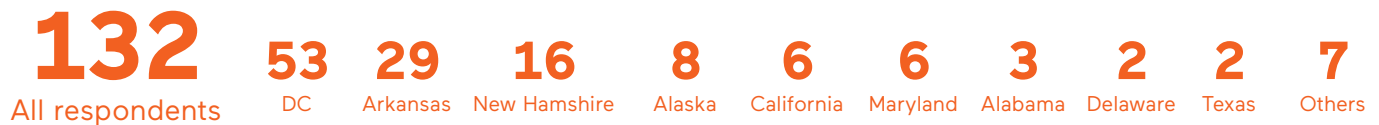
“Make it better, make it for everyone, make it more widely accepted.”

“I want [policy-makers and Medicaid administrators] to keep in mind the policies they make. If they were in our shoes, how would it feel for them. When policies [are] agreed upon, they see it as black and white and on paper. Not in reality. I would want them to imagine how it would be for them if they were treated the way I have.”

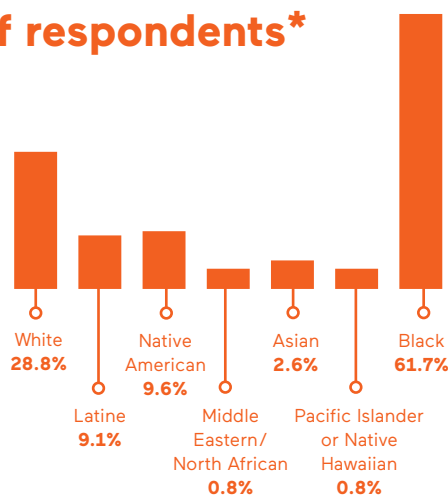
“I would like to tell them that everybody's medical needs should be met regardless of their demographic info, or where they live, or their poverty level. When they go into the dr office, it should feel like a safe haven”

About

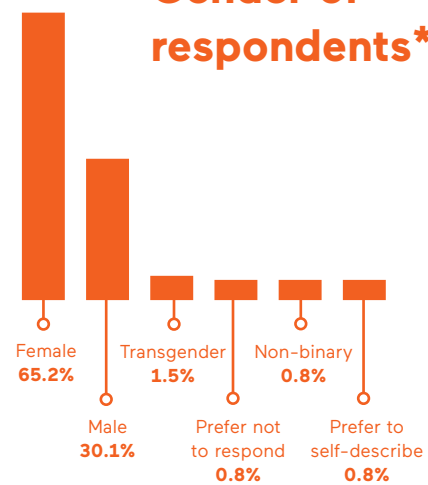
Respondents in each state



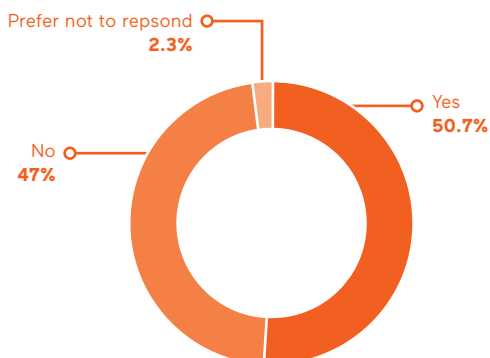
Race/ethnicity of respondents*



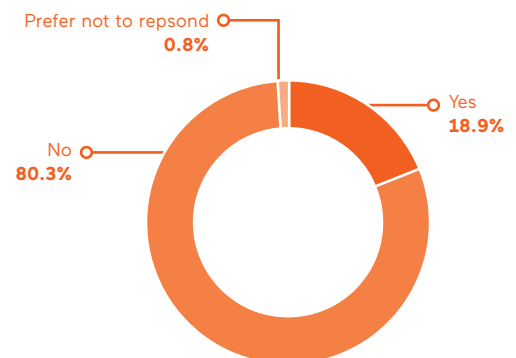
Gender of respondents*



Do you have a chronic illness or disability?



Are you an immigrant?



* Percentages add to more than 100% because respondents could check all answers that applied

Endnotes

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