How Medicaid Members Can Shape Its Future

Five Findings from a Medicaid Equity Initiative

August 2025

Health Leads

Executive Summary

A wealth of research [i] demonstrates that Medicaid beneficiaries experience far greater access to healthcare [ii] than uninsured individuals. This vital support ensures that low-income individuals are much less likely to delay or forgo essential medical care simply because they cannot afford it. By providing this safety net, Medicaid plays a crucial role in promoting health equity and ensuring that everyone can receive the care they need when they need it. During the Covid-19 pandemic, Medicaid enrollment increased by 32% between February 2020 [iii] and April 2023, when it reached a record high of 94 million. However, since then, millions of people have been disenrolled from Medicaid as states resume eligibility redeterminations [iv]. This means that this same population that can't afford health insurance will experience gaps in their insurance coverage [v]. Medicaid resourcing was further cut by the H.R. 1 budget reconciliation bill, signed into law on July 4, 2025, which reduced gross federal Medicaid and CHIP spending [vi] by $990 billion over 10 years, and added restrictions on how states can finance Medicaid through provider taxes.

With Medicaid funding over 50 percent of births in the United States and providing essential health care to more than 83 million adults and children [vii], the program is uniquely positioned to tackle the health disparities experienced by its diverse enrollees. Medicaid [viii] is the largest health insurer for low-income populations in the United States, and it has a higher proportion of members of color compared to White members.

The low-income status of people of color largely stems from systemic laws [ix] that have disproportionately impacted communities of color throughout the history of this country. These laws [x]have significantly affected the health status of these communities. Studies have shown that Medicaid managed care enrollees who belong to racial and ethnic minority groups have historically reported worse care experiences than White enrollees [x]. Additionally, procedural hurdles are a major obstacle; Black and Hispanic Americans were twice as likely as white Americans [xi] to lose Medicaid last year because of an inability to complete renewal forms during a vast trimming of the program's rolls. By unearthing causes of inequities and increasing understanding of members' experience of Medicaid, policymakers and health care organizations have an opportunity to close critical and potentially harmful gaps in care.

To that end, on December 19, 2023 [xii], the State Health Access Data Assistance Center (SHADAC) began its partnership with Health Leads for the second phase of the Medicaid Equity Monitoring Tool (MET) project [xiii]. Supported by the Robert Wood Johnson Foundation, the project aims to hold state Medicaid programs accountable for improving population health by advancing health equity. Health Leads facilitated a process to collect input from community stakeholders who utilize Medicaid services to understand their thoughts on Medicaid policies and critical health services.

This project was intended to fill a critical research gap around the experience of Medicaid members. While a wealth of research around Medicaid exists, the majority of it does not center on the experiences of populations most impacted by systemic racism - for example, pregnant and birthing people, individuals with mental illness, individuals who identify as LGBTQ+, justice-involved individuals, individuals living with disabilities, etc. The input collected in this report informed the facilitation of discussions with Medicaid subject matter experts, and at the end of this phase, recommendations were made about the feasibility of moving forward with designing and developing a Medicaid equity monitoring tool that will enable ongoing review and improvement of this vital benefit.

While the full impact of H.R. 1 remains to be seen, the reduction of Medicaid funding will further strain a vital service and widen both health care gaps and health inequities in the U.S. For the local, state, and federal organizations left to fill these gaps, and any entity aiming to improve health services and reduce inequities in the face of reduced resources, the input and recommendations in the report below reinforce the importance of designing not for, but with, the intended communities. The community-centered approach taken in this project can be applied by any federal or local service to ensure all have the potential to achieve their desired impact.

5 Asks from Medicaid Members on How to Improve Medicaid Experience

The MET Interest Form gathered preliminary information from **128 respondents** who were Medicaid recipients or caretakers of people who use/used Medicaid services. The Interest Form sought to better understand their Medicaid experience. The respondent population consisted of **54% African American** individuals from **28 states**.

The highest number of respondents were from New York (32 responses) and Texas (22 responses). From there, we designed regional community stakeholder groups in three states. Community stakeholders provided more in-depth information about how they define *health equity* as users of the Medicaid program, and further insights on how or if they would utilize a Medicaid Equity Tool. The Interest Form asked community members, *"What is one thing you would change about your Medicaid experience*?" These responses generally fell into five categories:

1. Improve Experience with DSS Offices and Streamline Processes
2. Increase Expansion & Eligibility, Simplify Renewal
3. Stabilize the Medical Workforce and Diversify Service Options
4. Increase Service Provider Access, Variety, & Expertise, and
5. Create Avenues for Education & Equity.

Below are synthesized suggestions, experiences, and quotes from anonymous respondents to the Interest Form from groups of people who are not frequently reflected in current literature in a broad way about their Medicaid experience. As we begin to imagine a healthier future for all, we have to ensure we center on those most impacted.

Improve Experience with DSS Offices and Streamline Processes

The Department of Social Services is often the first place where Medicaid applicants gain a view of the program. When the experience is poor, it can create poor relationships with applicants, resulting in barriers to accessing healthcare for some of the lowest-income individuals in the U.S.

Interest Form respondents in several states recommended that extending office hours to meet customers' needs is essential, particularly by offering later hours. For example, one person suggested that *"it would be beneficial to have one day a week when the phone line is open in the evening to cater to those who cannot contact the office during regular work hours*."

Another respondent stated that, "*The initial application phone interview process, as well as client support in general, is criminally inaccessible. It's literally impossible to get a hold of anyone at my state's job and family services dept. They said I have to call between 8-10 am Monday through Friday (when everyone's working!), and then you could be on hold for over an hour*."

Respondents expressed the need for clearer communication within the state department to improve efficiency. They also recommended establishing a safe and confidential method for customers to file concerns. Additionally, they suggested that there should be a way to communicate via email for convenience and documentation purposes.

Community members also stated that the application process is burdensome, and the approval wait times are very long. One Texas respondent stated, "*I would also like for the Medicaid application review process to be made more timely for those in need, as most people are in an urgent need when applying. I've experienced months of wait times to be* *approved or denied*." In addition to this comment, others suggested that applicants should be allowed to reschedule interviews online. Lastly, they recommended prioritizing the streamlining of the eligibility and enrollment process.

Increase Expansion & Eligibility, Simplify Renewal

In addition, many states in both *expanded* and *non-expanded* states have moved to an *active enrollment process* from a continuous enrollment process [xiv], which requires participants to re-certify or renew every year for their Medicaid coverage. The main difference between *active* Medicaid enrollment and *continuous* Medicaid enrollment is that *continuous* enrollment allows individuals to remain enrolled for a specified period of time, even if their income changes. There are many variables in state Medicaid policies, around how approval processes are handled, and they are held to federal regulations around how to implement enrollment efforts within their states. Essentially, feedback from the MET Interest Form highlights some of the ways that Medicaid's federal and state regulations impact access to healthcare.

Some respondents in southern states expressed interest in Medicaid Expansion [xv] for their state. The Affordable Care Act (ACA) [xvi] permits states to expand Medicaid coverage to adults with incomes up to 138 percent of the poverty level (about $20,780 annually for an individual or $35,630 for a family of three).

Participants from Washington, New York, and Pennsylvania specifically spoke on their state's renewal process, indicating that the renewal process is burdensome. Interest Form respondents generally stated that the renewal process is long and impacts their ability to receive medical services when needed. Having to re-enroll is a huge cultural shift for this population, and sometimes is much more difficult for people who will *always* need Medicaid services, such as people with Supplemental Security Income (SSI) or other disabilities.

For example, one New York respondent stated, "*My daughter recently transitioned from SSI to SSDI, so she now has to recertify for Medicaid every year. She is permanently disabled and will always need Medicaid, so annual recertification is an unnecessary burden, on top of all the other burdens of being disabled*."

Respondents from North Carolina and Texas stated that "*there needs to be a higher income eligibility bracket for working families.*" Medicaid eligibility [xvii] for adults in states that haven't *expanded* their Medicaid program is very limited. For parents in these states, the income limit is only 38% of the federal poverty level, which means a family of three can earn only $9,812 a year (about $817 a month) in 2024 to qualify. Most childless adults remain ineligible for Medicaid, regardless of their income, except in Wisconsin.

In Texas, the state with the lowest income threshold, parents cannot qualify if they earn more than $4,131 a year (around $344 a month). As a result, 79% of those who are unable to get coverage are childless adults. Data reports such as *Asset Limited, Income Constrained, Employed* (ALICE [xviii]), highlight the gap between low-paying jobs and the cost of living. ALICE represents the growing number of families who are unable to afford the basics of housing, healthcare, food, transportation, childcare, and technology. These workers often struggle to keep their households from financial ruin while keeping our local communities running.

As work requirements for Medicaid programs continue to spread across states, one might assume that the population of people who are considered ALICE will continue to grow, and this may be why respondents in non-expanded Medicaid states specifically are advocating for Medicaid expansion.

Stabilize the Medical Workforce and Diversify Service Options

Social determinants of health (SDOH) [xix] are non-medical factors that affect health outcomes. They include the conditions in which people are born, grow, work, live, and age. SDOH also includes the broader forces and systems that shape everyday life conditions.

> *“Stipulations should be implemented on home health agencies to ensure that a greater percentage of the reimbursement is applied toward worker compensation.”*
>
> – Respondent, North Carolina

Even in certain states where efforts have been made to make additional services related to SDOH more efficient, the Interest Form respondents indicated that there are still a few barriers to healthcare access. For example, respondents in Massachusetts, Tennessee, and Oregon specifically spoke about services provided directly related to SDOH, such as the need for better transportation services offered with their program. They expressed a desire for healthcare providers to offer more remote healthcare services. This would be beneficial for those with disabilities or lack of access to transportation.

One respondent from Tennessee stated that “*there are long waitlists for services like transportation, especially in rural areas*. “ In both expanded and non-expanded states, there was a suggestion to focus on services like food insecurity and housing assistance services, as well as mail-order pharmacies for those who can't easily access a pharmacy. Lastly, members often experience problems with requests for medical equipment being denied, despite some Medicaid services covering them.

Respondents from North Carolina not only advocated for themselves but also advocated for the medical workforce, stating that there should be higher reimbursement rates for healthcare workers. They also suggested that "*stipulations be implemented on home health agencies* [xx] *to ensure that a greater percentage of the reimbursement is applied toward worker compensation.*"

Increase Service Provider Access, Variety & Expertise

Medicaid is the nation's public health insurance program for people with low income. The Medicaid program covers more than 1 in 5 Americans [xxi], including many with complex and costly needs for care [xxii]. The program is the principal source of long-term care [xxiii] coverage for people in the United States. A considerable amount of research [xxv] shows how Medicaid evolved [xxiv] to better address the needs of those with developmental disabilities in some states. There has also been additional research [xxv] that highlights gaps in access to specialty providers, highlighting the need for reforms and innovative care models to increase this type of access. Medicaid beneficiaries have substantially better access to care than people who are uninsured (who are also primarily low-income) and are less likely to postpone or go without needed care due to cost.

The Interest Form results showed persistent alignment with the research surrounding access to specialty providers within the program. A multitude of comments mentioned the availability of providers available to Medicaid recipients on their Medicaid plans, inferring that there were not enough providers who accepted the program. For example, one respondent even listed that "*every provider should accept Medicaid.*" Others highlight that even the available providers often had low ratings or were not "quality". Respondents indicated that choosing a provider was challenging, and scheduling appointments was burdensome. A more streamlined appointment scheduling process should be implemented. In states like Texas, in particular, the provider list was often outdated and needed to be updated more often. This would help recipients locate available providers more efficiently.

In addition to provider access, multiple comments centered on the variety of providers and specialists offered through the program. Respondents listed the types of providers they would like more access to. These included dentists, optometrists, physical therapists, and psychiatrists. Often, states' Medicaid programs may cover some of these specialty services [xxvi] for a short length of time, but the recipients can't afford to continue to pay for them on their own after the coverage has ended.

One California Medicaid recipient stated, "*I wish I could see a therapist regularly without having to worry about whether it's covered or not. It would make a huge difference in my overall well-being and ability to care for my family.*"

Create Avenues for Education & Equity

People seeking Medicaid often want to know more about Medicaid service coverage and its qualifications. They wanted more ways to educate themselves and listed solutions such as making websites more user-friendly and having more educational outreach programs that focused on information about benefits and rights as a recipient of Medicaid. One respondent stated that if they could change one thing about their Medicaid experience, it would be *"A more seamless process…that markets services to those in need better. Many parents/individuals that have a need don't know what is available to them*."

Finally, respondents suggested that states should modify the way applicants access information about the program, making it culturally appropriate and available in multiple languages.

There were comments about how Medicaid recipients wished to be treated with dignity and respect, "*the same as people with private insurance*". This suggests that there is provider bias [xxvii] when a person is labeled "Medicaid." They offered that to combat provider bias, the program should have more physicians who represent different cultural and racial backgrounds that are more connected to the clientele. For example, one person from North Carolina stated, "I *would change the amount of resources available and the amount of African American doctors who don't accept Medicaid/Medicare. I truly believe representation matters*."

Opportunities & Next Steps

To effectively address these pressing issues, the Medicaid Equity Tool Project underscores the vital importance of amplifying the voices and experiences of those facing inequities in our health systems. As we strive to promote health equity across state Medicaid programs, for now, we are pivoting away from the development of a data tool toward a more proactive approach focused on safeguarding these essential programs for the communities they serve, even amid uncertainty.

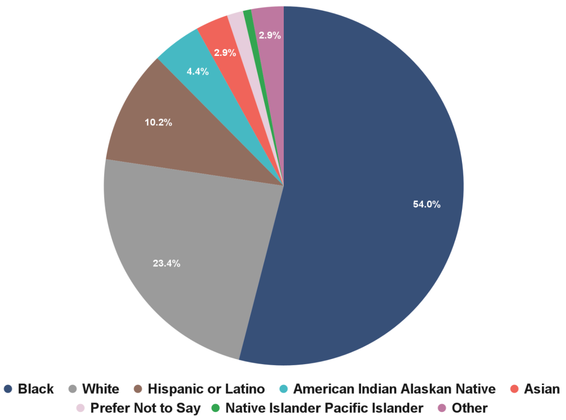
Community stakeholders shared invaluable perspectives on their definitions of health equity, helping us envision the potential of Medicaid equity program integration that genuinely serves those in need. Health Leads leveraged insights gathered from the Medicaid Equity Interest Form to kickstart community member stakeholder groups in Texas, New York, and California. The lessons learned from these engagements will inform the design of future initiatives, ensuring that they resonate deeply with the communities they aim to uplift. The knowledge gained thus far has provided us with crucial insights and resources, fueling our partners' dedication to dismantling barriers to achieving equitable health outcomes.

The uncertainty about the impact of future Medicaid funding and resourcing makes this vision more imperative than ever before. When forced to imagine new possibilities for the role of Medicaid, centering and designing around those most impacted is even more crucial if we are going to increase access, improve experiences, and shift the narrative around what people need to achieve health, well-being, and dignity.

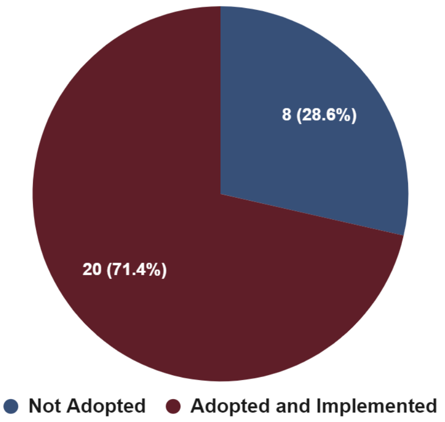
About the Respondents

Demographics

The respondent population consisted of 54% African American individuals from 28 states. The highest number of respondents were from New York (32 responses) and Texas (22 responses). This is advantageous as we aimed to recruit individuals from states that have adopted and have not adopted Medicaid expansion and represented diverse populations where current data about their experience is limited.



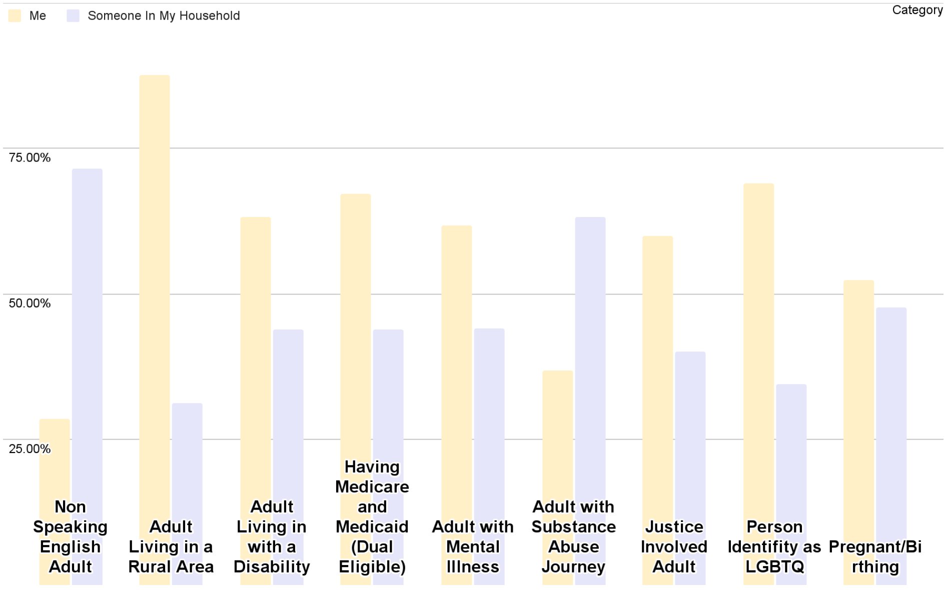
[Data Chart 1]



[Data Chart 2}

Community MakeUp

Respondents indicated that the following communities represented them or someone in their household. Again, these are communities where current data about their Medicaid experience is limited. We used this data to help narrow participant types in the stakeholder groups to ensure group diversity.



[Data Chart 3]

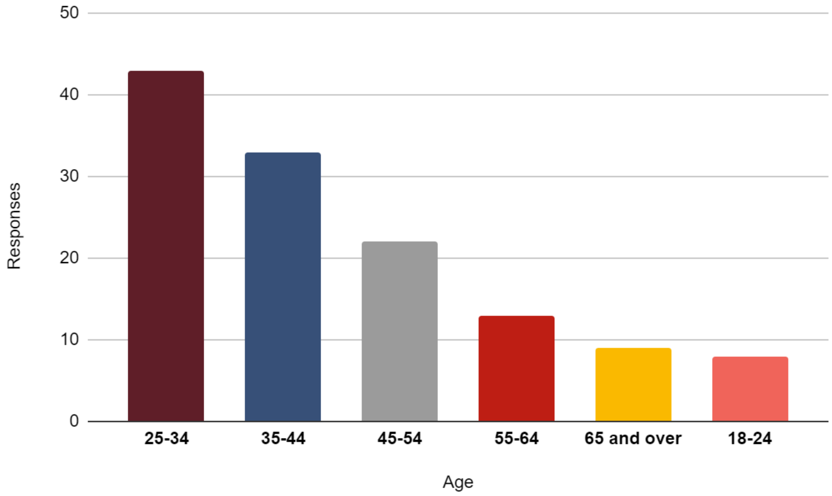
Age and Gender

The age of respondents ranged from 25 to 65 and over, with the majority of them ranging from 25 to 34. In addition, the majority of respondents identified themselves as women.

- ★ Women 79.8%
- ★ Men 18.2%
- ★ Nonbinary or Gender Non-Conforming 1.6%
- ★ Two-Spirit .8%

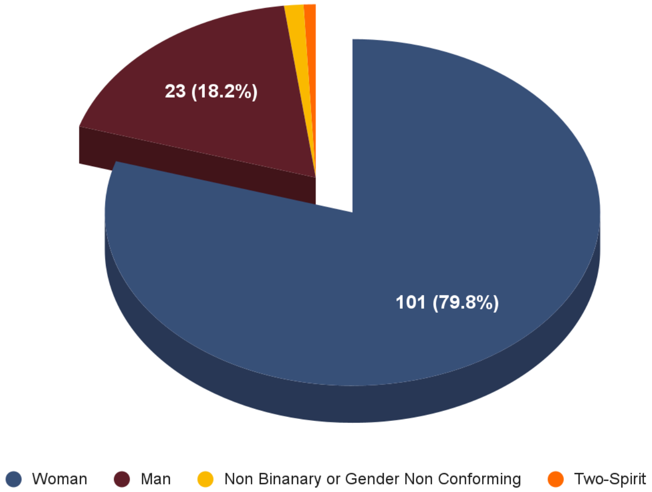
Age

[Data Chart 4]



Gender

[Data Chart 5]

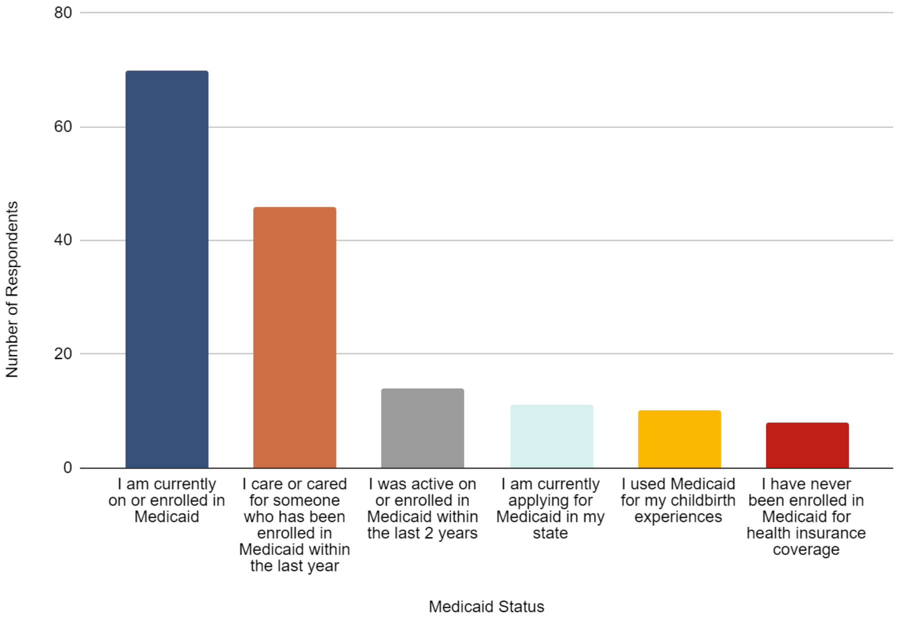


Medicaid Status and Years of Service

Respondents (118) provided their current status along with their years of receiving Medicaid service (119). We intended to capture not only participants of the Medicaid program but also participants who were caretakers of family members who use the Medicaid program as well. The voices of both audiences were used in the selection process for the community stakeholder group.

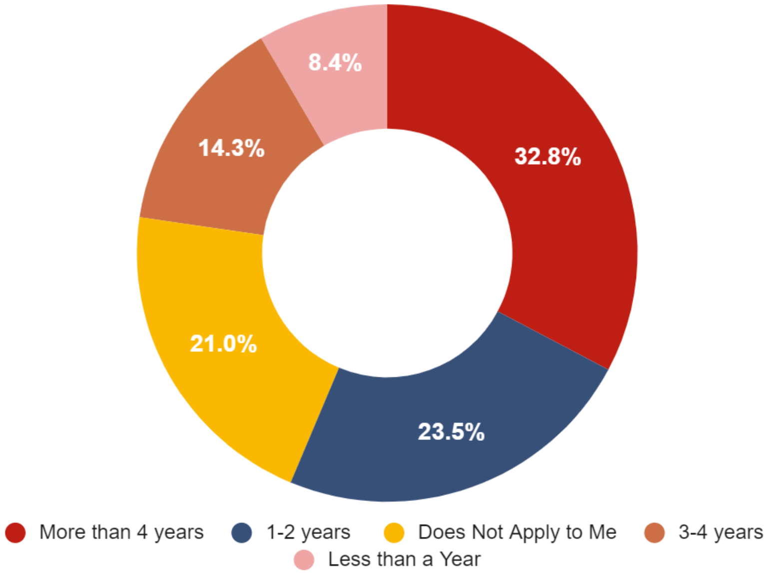
Medicaid Status

[Data Chart 6]



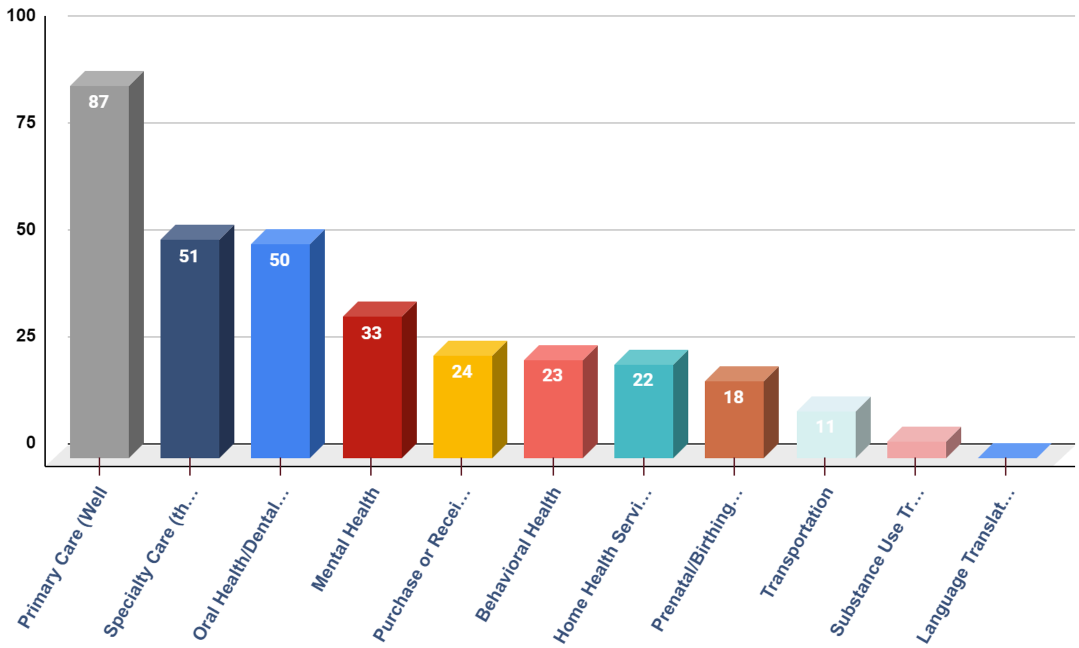
Years of Medicaid Service

[Data Chart 7]



Top Services Used and Medicaid Access Ratings

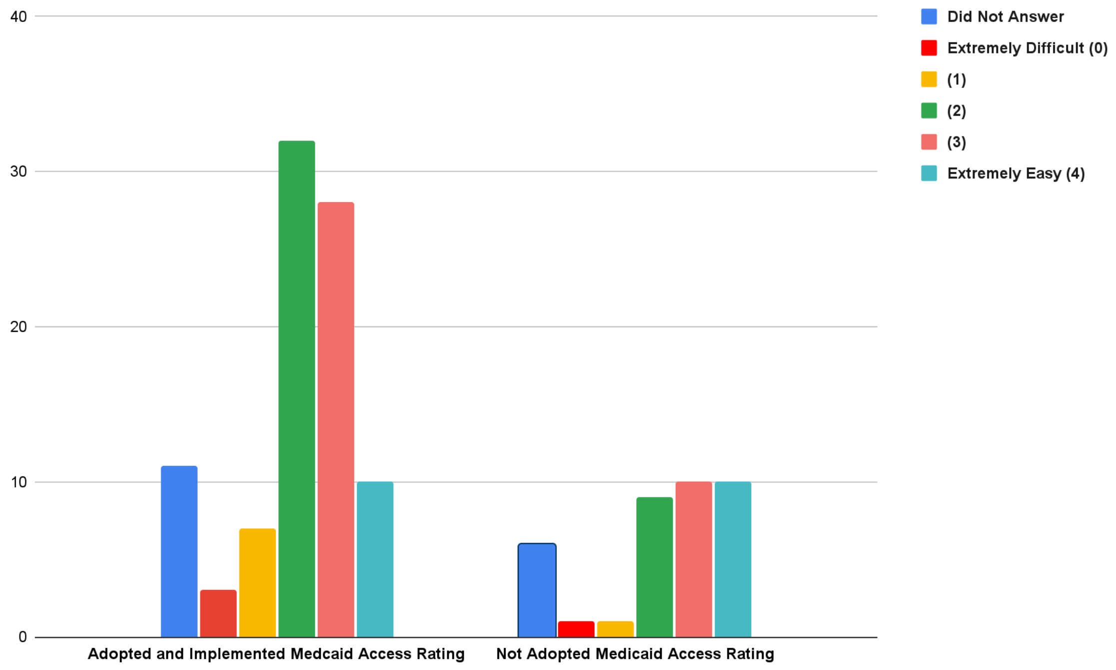
The top 4 services utilized among interest form respondents encompass primary care and oral health. Respondents also scored how well they can access services in their states from *0 Extremely Difficult* to *4 Extremely Easy.* Medicaid is an important program and provides a majority of services to those who would otherwise not be able to afford healthcare.



[Data Chart 8] Above [Data Chart 9 below]

Medicaid Access Rating: Adopted Expansion States v. Non-Adopted Expansion States

(How easily can you access your Medicaid coverage? Rating 0-4)



About Health Leads

With a vision of “health, well-being, and dignity, for every person, in every community,” Health Leads works collaboratively with local and national partners to unearth and address the root causes of some of the most pressing and complex health equity challenges of today. From maternal health and vaccine access, to housing and food security, Health Leads applies its proven approach and nearly 30 years of experience to removing barriers to health and building a future where communities lead the design of the essential resources they need to thrive.

About State Health Access Data Assistance Center (SHADAC)

SHADAC is a multidisciplinary health policy research center using data to inform state policy and foster health equity. Through research, evaluation, and technical support on a range of topics, including health care coverage, cost, and access, SHADAC serves as a leading source of trusted state health policy data and information.

About the Robert Wood Johnson Foundation

RWJF is a leading national philanthropy dedicated to taking bold leaps to transform health in our lifetime. Through funding, convening, advocacy, and evidence-building, RWJF works side-by-side with communities, practitioners, and institutions to achieve health equity faster and pave the way, together, to a future where health is no longer a privilege, but a right.

About the author

LeAndra A. Padgett, MSW, is a skilled professional with over 10 years of experience in project management, technical assistance design, data analysis, and negotiation. She has extensive experience in addressing food insecurity, school-based health policies, state Medicaid policies, and community-driven health insurance enrollment efforts. Currently, LeAndra is serving as the Health Leads’ Senior Director of Program and Learning. Her main objectives are to expand sector and shared learning initiatives for community members, healthcare companies, and staff through a lens of equity and justice. LeAndra holds a Master of Social Work (MSW) from Florida Agricultural and Mechanical University.

Credits

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